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What Do We Know About Adherence and Self-care?

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Abstract

Despite advances in healthcare, heart failure patients continue to experience complications that could have been prevented or treated. This occurs because the only way that a therapeutic or preventive regimen can be effective, assuming that the patient's condition has been accurately diagnosed and appropriately treated, is if the patient implements self-care behaviors and adheres to the treatment regimen. However, it is widely accepted that this does not occur in many or even most instances. This article provides an overview of the current evidence related to adherence and self-care behaviors among heart failure patients and describes the state of the science on interventions developed and tested to enhance self-care maintenance in this population. Our review of literature shows that effective interventions integrate strategies that motivate, empower, and encourage patients to make informed decisions and assume responsibility for self-care. Gaps in current evidence support the need for additional research on ways to improve adherence and self-care for patients who are at an increased risk of poor adherence, including those with cognitive and functional impairments and low health literacy.

Keywords

adherence; self-care; self-management

With so many advances in treatments and medical options for patients with heart failure (HF), managing this condition has become increasingly complex for both patient and provider. For the 5.2 million Americans who reportedly have HF and almost 550,000 new patients diagnosed each year,¹ the challenge lies in their ability to care for themselves, recognize and manage their symptoms, adhere to a very complex treatment regimen, and adjust existing behaviors or implement new behaviors to improve health or prevent exacerbation.² Unfortunately, the nature and severity of the symptoms associated with the illness and the very complex treatment protocols demand much from the HF patient in terms of knowledge, cooperation, and active participation. As a consequence, treatment goals are often difficult to achieve, and recurrent episodes of HF exacerbation requiring hospitalizations for treatment characterize the illness trajectory of many of these patients.^{3–5}

The successful treatment regimen for HF is largely dependent on a patient's ability and willingness to carry out a series of complex and multifaceted self-care activities. However, patients are often faced with the dreadful reality that many of these changes are difficult, if not daunting, to make. Changes in dietary habits and exercise patterns are challenging for most.

Learning how to take multiple medications and recognizing symptoms may be difficult, if not impossible, for some patients (eg, elderly persons and those with low health literacy).⁶ Motivation to change established routines can be the first barrier to overcome. In addition, the changes need to be sustained to keep the HF patient symptom-free and to decrease hospital readmissions. A patient's adherence is clear when symptoms such as shortness of breath are decreased or eliminated. This cannot be accomplished by medication alone. Thus, adherence to medication taking and other self-care activities is vital to living successfully with HF.

Nurses, who are present in virtually every healthcare setting, can seize the opportunity to help HF patients and families cope with the symptoms and complications of their condition, follow their treatment regimens, and achieve better outcomes. Therefore, it is imperative that nurses become familiar with the latest evidence to support best practice as they strive toward the goal of enhancing adherence and promoting adequate self-care behaviors among HF patients. This includes helping HF patients and families recognize the factors that contribute to preventable hospital readmissions and poor health outcomes, such as inadequate patient and family education, failure to seek medical attention and manage symptoms when they reoccur, and lack of social support systems, among others.⁷ Nurses who have a better grasp of the magnitude of the problem of nonadherence among HF patients are better prepared to guide and support them as they face the many challenges associated with performing self-care behaviors. Thus, the purposes of this article were to (1) provide an overview of the most recent evidence related to adherence rates of HF patients in the performance of self-care behaviors specific to them, (2) describe the state of the science on interventions for helping people with HF manage their care, and (3) identify gaps in the science and barriers to implementing interventions for promoting adherence to treatment plans in HF patients at risk for inadequate self-care maintenance.

Methods

This overview is not exhaustive but does represent most of the studies conducted related to adherence and self-care behaviors since our first manuscript examining the compliance (adherence) behaviors of HF patients published nearly a decade ago.⁸ We searched the literature in MEDLINE and CINAHL databases from January 2000 until December 2007. The term (*congestive*) *heart failure* was used, combined with the terms (*patient*) *adherence*, (*non*) *compliance*, and *self-care behaviors* (*management*). All descriptive studies on adult HF patients that reported levels of performance of self-care behaviors in accordance with current guidelines (eg, monitor daily weights, exercise regularly, alter dietary patterns, and take prescribed medications) were included and summarized to reflect the average adherence rates or degree of compliance to prescribed regimens. Randomized trials that incorporated an HF disease management program that was delivered primarily by a nurse and measured effects on adherence with self-care behaviors were selected and carefully reviewed to provide a summary of the state of the science on interventions to promote adherence to or performance of self-care activities in HF patients. A total of 22 articles were included for this review.

Definition of Key Terms

The terms *self-care*, *adherence*, and *self-management* are often used interchangeably in the literature. Adherence is defined as the ability to follow a healthcare professional's recommendations on treatment regimens.² Self-care refers to specific behaviors that individuals initiate and perform on their own behalf, with the intention of improving health, preventing disease, or maintaining their well-being.⁹ The nature of the illness usually determines the identifiable self-care behaviors that need to be adopted by individual patients. The current guidelines on diagnosis and treatment of chronic HF encourage patients to monitor their weight, carry out daily physical activities that do not induce symptoms, alter their dietary intake of salt, and encourage conformity with taking prescribed medications.¹⁰ Self-care

behaviors are usually prescribed by clinicians and are often described in terms of patient adherence. Some authors refer to a patient's involvement in his or her own self-care as self-management.¹¹ Self-management extends beyond the patient merely following instructions; it entails teaching the patients to monitor their symptoms, make decisions, and evaluate the impact of such decisions.¹² Self-management is viewed as cognitive decision making in response to symptoms and conceptualized as a process with stages from novice to expert.² In this review, the terms *adherence* and *self-care*, including the components of self-care maintenance and self-care management, are used.

Adherence Rates in HF Patients

Self-care and adherence are multifactorial behaviors that have gained much attention and have become the topic of intense investigation over the years. The HF literature consistently demonstrates that adherence and self-care behaviors reduced hospital readmissions^{13–15} and led to positive outcomes.¹⁶ However, many patients fail to adopt recommended self-care behaviors,⁷ and adherence to various self-care activities continues to be poor among HF patients.⁸ Specific behaviors that patients with HF should adhere to that are included in the current guidelines for managing chronic HF are as follows: monitor daily weights (20%–80%),^{17–19} exercise (9%–53%),^{17,18,20–22} follow sodium restrictions (20%–71%),^{15,18,20,21,23} and take prescribed medications (50%–96%).^{4,18,20,21,24–28}

A wide array of definitions used to describe adherence or nonadherence, coupled with innumerable approaches to measure adherence in this population, make it difficult to compare nonadherence rates across different studies and different self-care behaviors. However, the current HF literature supports the premise that nonadherence rates are high across all ages, ethnic groups, and socioeconomic status. As the population ages and patients with HF live longer, the complexity of their disease condition and treatment regimen will require more care. Consequently, adopting self-care behaviors will become more difficult and challenging, and the gap between efficacy (an effect under ideal conditions) and effectiveness (the effect in the general population) will continue to widen in the setting of chronic HF. For nurses to have a positive effect on cardiac health outcomes, more research regarding factors that influence adherence in HF patients is needed.

Instruments Used to Measure Self-care Behaviors in HF

Greater understanding and measurement of patient decision making and self-care expertise facilitate the development of effective interventions to improve patient outcomes.² Several tools have been developed to measure the type and extent of self-care behavior in patients with HF, including (1) the Self-care of Heart Failure Index, a 15-item tool that measures the multidimensional components of self-care (ie, self-care maintenance, self-care management, and self-care confidence)²⁹; (2) the European Heart Failure Self-care Behavior Scale, a 12-item tool that covers 3 aspects of health maintenance behaviors: adhering to a treatment regimen, asking for help, and adopting daily activities³⁰; and (3) the Revised Heart Failure Self-care Behavior Scale, a 29-item instrument that measures self-care maintenance and frequency of self-care management.⁷ A detailed description of each tool and a summary of similarities and differences are presented elsewhere.³¹ Although the psychometric properties have been reported for each of the 3 tools,³¹ further testing of each instrument is needed in a wide range of patients, cultures, and settings to adequately assess the usefulness of the various instruments in the assessment of various interventions intended to influence self-care and adherence.

Effective Strategies for Improving Adherence in HF

An enormous amount of research on adherence to HF treatment and management has been produced in the last few decades, illustrating its recognition as an increasingly important aspect of health-care.^{18,20,21,25-33} A review of the recent literature supports the need for strategies aimed at increasing adherence to self-care behaviors, including (1) educational interventions targeted to improve understanding about HF condition and treatment regimens; (2) behavioral interventions targeted to motivate and empower patients to adhere to self-care regimens; and (3) psychosocial interventions targeted to promote positive perceptions, beliefs, and attitudes toward the regimen. The proliferation of disease management and self-care programs and the use of several interventions in combination are currently the acceptable approach for effectively improving adherence and self-care behaviors and reducing costs and resource utilization.³⁴

Educational Interventions

Despite the existence of effective treatments, HF readmission rates of 30% to 50% are reported³⁵ and are often attributed to patients' lack of information, comprehension, or adherence to prescribed regimens.^{36,37} The goal of educational strategies is to provide information related to disease management and maximize patients' ability to comprehend and implement self-care behaviors.

A nurse-initiated educational program conducted among patients in rural settings improved knowledge and adherence to the self-care behavior of daily weighing.³⁸ In a separate study, a similar educational intervention improved patients' knowledge of medications that they were taking; promoted symptom monitoring, recognition, and management (ie, daily weighing and blood pressure monitoring); and enhanced medication adherence.³⁹ However, improvements in self-care behaviors related to maintaining a sodium-restricted diet were not observed.⁴⁰ Another study showed that an intensive education and support intervention did not improve knowledge, judgment/decision-making skills, and self-care behaviors.⁴¹

A pharmacist-based patient education intervention that included written patient-centered instructions improved adherence to cardiovascular medications and decreased healthcare use and costs, but the effect dissipated when the intervention ceased.⁴² Patient education delivered through videotape improved HF knowledge and health status in one study⁴³ and enhanced key self-care behaviors of recognizing and managing worsening signs and symptoms of volume overload in another study.⁴⁴ Some patient education interventions including a one-time intensive educational session with monthly telephone follow-up for 1 year⁴⁵ and an interactive computer-based program⁴⁶ also increased knowledge. However, no differences in self-care behavior or quality of life were observed between patients in the intervention versus those in the control groups, which indicates the need for more extensive interventions characteristic of programs to improve self-care behaviors in these patients.⁴⁷

Participants in a group setting demonstrated an understanding and application of the self-care skills that were taught to them. They also confirmed an understanding of the connection between lifestyle and HF.⁴⁸ Although a number of perceived benefits exist in group participation, there are significant barriers to a participant's retention in group intervention studies. Factors that may limit retention include anxiety and denial about HF and logistical and emotional barriers toward attending group sessions. Factors that may promote retention include mutual support, the opportunity to engage in meaningful social activity, feeling cared for, and attention to cultural sensitivity. Factors with unclear effects on retention include remuneration, ethnicity of the group leader, and the role of religious or spiritual content in meetings.

The findings from most studies examining the potential benefits of an educational intervention in improving adherence and self-care maintenance confirm what has already been documented

in previous studies: that education alone will not have a positive impact on self-care behaviors. The use of behavioral strategies (eg, self-medication), social support (eg, from family members), and reinforcement (eg, home visits) to augment educational strategies may optimize outcomes compared with the use of educational strategies alone.

Behavioral Interventions

Behavioral interventions focus on helping patients build the skills necessary to adhere to a treatment regimen or perform self-care. For example, social-cognitive theory suggests that although knowledge related to the HF is a prerequisite to change, additional self-influences are necessary for change to occur.⁴⁹ Belief regarding personal efficacy, in particular, plays a central role in change. Thus, the primary goal of behavioral interventions is to improve knowledge, promote self-efficacy, and enhance self-care skills. Teaching the patient about the disease and how it is managed and emphasizing the importance of patient participation in management decisions and daily care allow the patient to “take charge” of his or her illness, thus fostering self-efficacy and a sense of control.³⁵

The use of a medication electronic monitor to record adherence to prescribed medications over a 3-month period showed that 71% of the patients were 85% to 100% adherent with their daily regimen of angiotensin-converting enzyme inhibitor therapy.³² This study supports the potential benefits of electronic medication monitoring in patients who are poorly adherent so that interventions to improve self-care behaviors can be targeted toward them. A pilot study conducted in 18 patients with HF examined the effects of a self-care and medication adherence device linked to a Web-based monitoring system compared with the effects of usual care alone on patients’ adherence to recommended self-care behaviors, medication taking, quality of life, and clinical outcomes. Adherence to taking prescribed medications did not change after the intervention. However, the authors reported that there were significant improvements in the quality of life of patients assigned to the intervention with a medication adherence device.⁵⁰ A third study was conducted to promote symptom monitoring through the use of a diary to record weight, vital signs, and symptoms. Diary users had improved clinical and hospital outcomes. Further investigation is needed to clarify the characteristics of a diary user and the effect of diary use on self-care and outcomes.⁵¹

Case management by nurses using telephone follow-up has been suggested as a convenient and effective mechanism to promote self-care among HF patients. Similarly, a patient empowerment approach to the management of chronic disease has been suggested as one that may nurture self-care in individuals with chronic illness.⁵² A telephone-delivered empowerment intervention resulted in significant improvement in patients’ adherence to the treatment plan with regard to daily weights, checks for edema, and low-salt diet in the intervention group compared with the usual care group.^{52,53}

Finally, the effectiveness of a quality improvement collaborative on adherence to daily weights and ability to recognize symptoms of worsening HF was supported in a cross-sectional survey involving 800 HF patients. Participation in a quality improvement collaborative for HF was associated with better communication, education, and knowledge and lower healthcare use. Collaborative efforts may be a useful approach for disseminating quality improvement strategies. Participants in one study of such an approach had similar quality of life when compared with patients receiving usual care but had fewer emergency department visits and hospitalizations.⁵⁴

Psychosocial Interventions

Psychosocial interventions focus on promoting adherence and self-care behaviors by providing support to HF patients to promote positive beliefs and attitudes toward the prescribed treatment

regimen. Early identification of patients' beliefs about treatment regimens seems to be an important factor in counseling and information for patients with chronic HF.⁵⁵ Psychosocial interventions also explore ways to help patients enhance feelings of self-efficacy and psychological well-being. Negative perceptions that include feelings of anxiety and depression, feelings of inadequate support, and feelings of being a serious threat to one's self are associated with lower quality of life and, consequently, poor adherence and self-care maintenance.⁵⁶ Methods that support feelings of challenge to self-consistency, self-idealism, and moral-ethical-spiritual self may enhance adherence to health regimens in individuals with HF.³³ A recent study shows that the potential benefits of a motivational intervention as an integral component of successful self-care management may be effective in improving self-care in patients with HF, but further research is needed.⁵⁷

Disease and Symptom Management Programs

The proliferation of disease management and self-care programs across the nation also occurred simultaneously to address the complex needs of HF patients. Disease management programs were designed to help patients understand their treatment regimen, enhance feelings of self-control or confidence, and maximize support systems.⁵⁸ These programs endeavor to shift some of the responsibility for managing chronic illness back to the patient. Through the educational process, patients are taught how to manage their diet, medications, physical activity, weight, and other health behaviors (eg, smoking and alcohol consumption). Specifically, patients are taught the rationale behind sodium and other dietary restrictions, the beneficial and potential adverse effects of all medications, and the value of a regular exercise program.³⁵⁻⁵⁹ Such programs reduce HF readmission by approximately 20%.³⁴⁻⁶⁰ Researchers examined the efficacy of outpatient HF management that used comprehensive strategies on quality of life, self-care knowledge, and patients' self-care adherence behaviors over time. Data showed improvements in quality of life, patients' self-care knowledge score, and self-care management (ie, daily weights). The program intervention was also accompanied by a 52% reduction in the risk of hospitalization for cardiovascular causes and a 72% reduction in emergency department visits at 6 months.⁶¹

The goal of self-care programs is to enable patients to assume a primary role in managing their condition: monitor symptoms, adjust medications, and determine when additional medical attention is necessary.³⁴ Education typically includes information about the signs and symptoms of HF, importance of daily weighing, dietary restrictions, and adherence to the medication regimen. Disease management interventions have received much attention in recent years because of the potential to reduce resource utilization while improving patient health outcomes.¹⁹⁻⁶²⁻⁶⁴ One study showed that a self-care program improved adherence and self-care management as reflected in the ability of patients to develop and implement an action plan (eg, perform daily weights, monitor symptoms, adhere to sodium and fluid restriction, exercise, and not smoke). The study also reported decreased beliefs in barriers and increased beliefs in the benefits of diet and self-monitoring.⁶² Ross and colleagues⁶³ reported a significant improvement in adherence to general medical advice and a nonsignificant trend toward improvement in self-efficacy and medication administration.

Self-care programs that are especially designed for HF patients with low health literacy have been shown to reduce hospitalizations and mortality.⁶⁵ Patients in the intervention arm received patient education on self-care emphasizing daily weight measurement, diuretic dose self-adjustment, and symptom recognition and response. Picture-based educational materials, a digital scale, and scheduled telephone follow-up were provided to reinforce adherence. Control patients received a generic HF brochure and usual care. At 12 months, more patients in the intervention group reported monitoring weights daily.¹⁹

Examining the Gaps in Adherence and Self-care Research

Despite the plethora of highly effective and relatively safe therapies for HF, patients continue to be incapacitated or debilitated by conditions for which effective treatments are available. Our understanding related to improving treatment adherence remains limited, and poor adherence to prescribed medications, diet, and exercise continues to negatively impact outcomes.³ The research to date clearly displays nonadherence in many areas of HF management but fails to identify the many challenges to adherence that patients face. Additional research is needed for us to adequately promote increased levels of adherence among HF patients.

Adherence to self-care activities demands much from the HF patient in terms of knowledge, cooperation, and active participation. One of the areas that warrant additional investigation is related to the effectiveness of patient educational approaches in HF patients with cognitive and functional impairment and low health literacy. Patients cannot be expected to fully and accurately follow through treatment recommendations unless they understand and remember instructions about the regimen. Recent research demonstrates the presence of cognitive and functional impairments associated with older age or disease and cognitive limitations associated with low health literacy among HF patients that may impact adherence to self-care behaviors.⁶⁶

The increasing age of patients with HF suggests the need for additional studies to examine how changes associated with age affect adherence and self-care behaviors.⁶⁷ Changes in cognitive and physical function as well as a decline in vision, hearing, and attention span are common with age and can impact a person's ability to comprehend and understand treatment regimens.⁶⁸ Because older HF patients are frequently taking a multitude of medications, additional goals of medication management are to simplify the regimen whenever possible, eliminate unnecessary medications, consolidate the dosing schedule, and minimize the risk of adverse drug interactions.³⁵ Efforts to simplify the treatment regimen and reduce pill burden through the use of once-daily formulations have been proven valuable in improving adherence to evidence-based therapies in older patients with HF.⁶⁹

Studies done several years ago that showed that older patients may understand what they are taught but often fail to remember the clinician's instructions⁷⁰ continue to be supported by current research.^{17,26} However, factors that impact retention in older patients remain elusive and warrant additional investigation.

Effective self-care of HF may impose heavy demands on health-related literacy or the ability to understand or act on health information, which may influence adherence and ability to engage in self-care.⁷¹ Previous studies have shown that persons with low literacy skills are more likely to have poorer health status, poor working knowledge of HF and its treatment, poorer self-care abilities (eg, medication adherence), reduced use of preventive service, and increased hospitalization and healthcare costs.^{71,72} Thus, increased efforts to identify patients with low health literacy are needed to adequately meet the special needs of this subgroup of HF patients. Low-income individuals, ethnic minorities, and persons in rural areas are disproportionately hindered by literacy barriers and also face significant adherence and self-care barriers.⁷¹ Interventions targeted to reduce the impact of low health literacy on health outcomes need to be developed and tested for this population. Alternative patient education tools need to be designed to reduce comprehension demands on general cognitive abilities and literacy skills.⁴²

The relationship between sociodemographic variables and self-care needs further exploration. It may be that these relationships differ at various stages of the self-care process and at different times after an illness event. In addition, research exploring other variables predicting self-care

is needed. Psychological variables may affect a person's drive to perform self-care and perceptions of responsibility for personal actions related to self-care. Self-confidence and perceived control may influence actions and beliefs about a person's ability to influence health outcomes. Because knowledge, attitudes, and beliefs relating to both illness and wellness are strongly influenced by culture and ethnicity, research is needed to examine culturally informed interventions targeted to promote adherence and self-care behaviors. Finally, because self-care requires the cognitive ability to learn, perceive, interpret, and respond, research is needed to discern how physiological mechanisms (ie, neural deficits) affect these abilities, decision making, and self-care behaviors.^{66,73}

Conclusion

Supporting people with HF in their efforts to manage illness requires an understanding of behavioral change and appropriate strategies. Nurses need to consider what the patient thinks about the recommended change and how involved that person wants to be in self-care. By using a patient-centered approach that fosters collaboration and empowers the patient to be involved in his or her care, nurses can help ensure that the person with HF makes informed decisions about self-care and assumes responsibility for choices to modify his or her lifestyle behaviors. Patients who are involved in their care are also more confident in their ability to manage their condition.

The ability to understand and follow the treatment plan is necessary for the self-care of patients with HF. Nurses, therefore, should translate a treatment regimen into a plan of care that a patient can follow. Nurses should also help patients and their families identify potential barriers to self-care and help them brainstorm for solutions to address these barriers. By building relationships with patients through listening, coaching, and modeling survival skills, nurses can help patients become more confident in their ability to engage in self-care behaviors. Finally, recognizing issues and obstacles faced by adults with HF, including cognitive and functional impairments and low health literacy, can influence our abilities to help patients adhere to their treatment plans. Evidence to support effective strategies for dealing with this special population is still an evolving area of research.

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