

Role of Self-Care in the Patient with Heart Failure

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Abstract

Optimal outcomes and quality of life for patients with heart failure depend on engagement in effective self-care activities. Self-care is a complex set of activities and most clinicians are not adequately prepared to assist their patients engage in effective self-care. In this paper, we provide an overview of self-care that includes definitions, the importance of self-care to outcomes, the physiologic basis for better outcomes with good self-care, cultural perspectives of self-care and recommendations for the improvement of self-care. Promotion of effective self-care by all clinicians could substantially reduce the economic and personal burden of repeated rehospitalizations among patients with heart failure.

Introduction

Promotion of effective self-care among individuals with heart failure (HF) is vitally important to patient outcomes, yet is one of the most difficult tasks facing clinicians today. Most of the cost associated with the care of patients with HF is the result of rehospitalization for exacerbations of HF [1-4], many of which can be traced to failed self-care [5-7]. There are multiple modifiable factors known to precipitate hospitalization for HF exacerbation, but the two most common are non-adherence to prescribed medications and diet, and failure to seek timely medical care for escalating symptoms [6, 8-14]. Both of these are prime examples of poor self-care.

Patient nonadherence to recommended self-care activities is common [8, 13, 15, 16]. Patients recently discharged from a hospitalization for an exacerbation of HF where they presumably received appropriate self-care education demonstrate high rates of diet and medication nonadherence and very low rates of daily weighing and symptom monitoring [17]. Patients' ability to recognize symptoms and take appropriate steps in a timely manner is another area where self-care commonly fails. The most common symptom prompting emergency department visits among HF patients is dyspnea [11, 18]. Delay time in seeking care can range from more than week with dyspnea to almost two weeks with edema [14].

Self-care is fundamental to the maintenance of physiologic stability and quality of life among individuals with HF. Most care activities associated with HF are done in the home by patients and their families or other informal caregivers. Thus, it is essential that HF patients engage in self-care, yet most clinicians do not have the training to prepare their patients to engage in effective self-care. The purpose of this paper is to provide clinicians with an understanding of HF self-care so that they can better assist their patients adopt appropriate self-care activities.

What is Heart Failure Self-Care?

We have defined self-care as a naturalistic decision making process of maintaining health through positive health practices (self-care maintenance) and managing illness and disease (self-care management) [19]. The positive health practices of self-care maintenance include all those behaviors traditionally considered under the rubric of treatment adherence. For adults with HF, those behaviors include limiting dietary sodium, taking medications as prescribed, and monitoring for early indicators of fluid retention with daily weighing [20, 21]. As challenging as this is, the process of self-care management is even more complex for patients because it involves decision-making. Successful self-care management requires that patients first recognize their signs and symptoms, judge the importance of such changes, do something about the changes, and then judge the efficacy of the remedy initiated. As discussed below, symptom recognition is quite challenging, and this may be the place where the whole process of self-care management falls apart.

We view the process used by patients in the performance of self-care as a naturalistic decision making process. This theory of decision-making focuses on real world decisions, which typically involve dynamically evolving conditions, uncertainty, ambiguity, missing information, time stress, and high stakes. These decisions may have ill-defined, shifting or competing goals. Sometimes multiple individuals are involved in the decision making process. The key to effective naturalistic decision-making is experience. Adept naturalistic decision-makers use prior experience to quickly identify patterns in situations. Once the situation is categorized, prior experience is synthesized to guide decision-making about the issue at hand. Experience provides a repertoire of patterns that provide relevant cues, suggest expected outcomes associated with specific responses, and point to reasonable goals and actions in specific types of situations [22].

Why is Heart Failure Self-Care Important for Clinicians to Understand?

The emphasis in medical education is on pharmacologic over behavioral therapies. As a consequence, many clinicians have not appreciated the impact of behavioral therapies on patient outcomes. When clinicians better understand the role that self-care plays in HF outcomes, promotion of self-care may become a priority in their practices.

Effective HF self-care is associated with a number of positive outcomes, the strength of which can be equivalent to or greater than that seen with drug therapy [23-27]. Data from randomized, controlled trials of HF disease management programs that include promotion of self-care as part of their services demonstrate that rehospitalization rates and mortality are reduced [24, 27-30]. These outcomes can persist for months to years, particularly when education and other strategies to promote self-care are included [31, 32]. Some trials have not demonstrated an effect of disease management on mortality or rehospitalization compared to usual care. This may be, in part, due to failure to include self-care strategies, ineffective use of self-care strategies or to intervention times too short to sustain an effect.

Examination of specific self-care activities (not imbedded within the context of disease management) further reveals the positive impact of engagement in appropriate self-care activities. Objectively measured medication adherence, an important self-care activity, predicts event-free survival in patients with HF [33, 34]. A self-care intervention designed to improve medication adherence in patients with HF resulted in enhancement of self-care abilities and better event-free survival compared to usual care [35]. Non-adherence to self-care behaviors related to symptom monitoring and exercise was associated with increased risk of HF readmission and mortality [36]. Patients who report engagement in more appropriate and effective self-care have lower mortality and rehospitalization rates than those who report poor engagement in self-care [37]. In addition, better quality of life, functional status and lower symptom burden or distress are associated with better self-care abilities or confidence in self-care abilities [38-40].

By What Mechanisms is Heart Failure Self-Care Effective?

Generally, it is assumed that effective self-care is an essential and adjunctive strategy to evidence-based medical treatments in delaying the progression of HF [41]. Several hypothetical and thus far unexplained mechanisms by which HF self-care influences health outcomes have been proposed [42]. In concert with the dominant pathogenic theories explaining the progressive nature of HF,[43, 44] emphasis is placed on the potential influence of effective self-care behaviors on neurohormonal activation and systemic inflammation and the downstream consequences thereof in this paper (Figure 1).

Self-Care Maintenance Behaviors

Certain general health and HF specific self-care maintenance behaviors are associated independently with partial neurohormonal deactivation and/or partial mitigation of systemic inflammation. For example, routine exercise training is associated with partial neurohormonal deactivation and a significant reduction in biomarkers of systemic inflammation in adults with HF [45-48]. Vaccinations, presumably by limiting infection, are associated with reductions in the risk of hospitalization and death among adults with HF [49]. Several classes of HF medications target neurohormonal activation. Hence, taking prescribed HF medications is associated with reductions in biomarkers of neurohormonal activation and systemic inflammation [50-53]. Although there are some notable exceptions,[54] medication non-adherence in HF is generally associated with increased risk of clinical outcomes like mortality and hospitalization [55]. Despite our limited ability to provide evidence-based recommendations for dietary restrictions as part of routine self-care,[56] it is a commonly held view that adherence with dietary sodium restrictions is associated with reductions in neurohormonal activation. Further, when considered collectively, better HF self-care maintenance behaviors are

associated with a decreased likelihood and frequency of episodes of congestion[57] – the consequence of neurohormonal activation and predominant reason for HF hospitalization [58, 59].

Self-Care Management Behaviors

The greatest efficacy of HF medications occurs in the absence of clinical congestion [60]. As such, it is likely that patients who recognize and respond to episodes of congestion more effectively have optimal benefit from HF medications. Patients who are able to detect and manage subtle symptoms also may be less likely to require high-dose diuretics that cause increases in neurohormonal activation [61]. The greatest risk for bacterial translocation in HF also occurs during episodes of congestion [62]. Thus, recognizing and treating symptoms of clinical congestion early may limit the risk of infection from gut bacteria. Moreover, there is direct evidence that patients who recognize and respond to HF symptoms more quickly and effectively are less likely to have levels of neurohormonal activation and systemic inflammation that are associated with poor clinical outcomes such as urgent advanced therapies and early death [63].

Importantly, the direct mediating effect of neurohormonal deactivation/blockade and systemic inflammation between HF self-care behaviors and health outcomes has yet to be supported empirically; this has been highlighted as an important future research priority in the study of HF self-care [41, 42].

What Heart Failure Self-Care Activities are Important?

Self-care recommendations largely represent opinion from expert consensus groups because non-pharmacological therapy has not been a major focus for researchers. Only during the last decade has self-care been increasingly recognized as an important component of heart failure care.

Nonetheless, a number of self-care activities appear important to good outcomes in HF and these include the following: 1) becoming knowledgeable about the condition; 2) adhering to medications and diet recommendations; 3) actively engaging in signs and symptom surveillance, recognition and taking

appropriate action; 4) getting exercise; 5) taking preventative actions such as stopping smoking, limiting alcohol intake, receiving immunizations; 6) managing comorbidities; and 7) navigating the healthcare system [41]. Reducing the needed activities to a list tends to obscure the complexity involved for patients attempting to engage in self-care. To provide a better picture of what we are asking patients to do when we ask them to perform these self-care activities, refer to Table 1.

The self-care activities outlined are considered appropriate in patients with symptomatic heart failure. This is, however, a heterogeneous group, a fact that must be kept in mind by clinicians advising patients on self-care activities. For example, many HF patients are elderly and have a number of comorbidities (e.g., diabetes, renal failure, arthritis, or chronic obstruction lung disease). Under these circumstances, cognitive impairment, lack of social support, and multiple self-care demands from the comorbidities may limit patients' abilities to engage in effective self-care. Thus, recommendations for self-care always need to be individualized with attention to severity of heart failure and prognosis, comorbidities, cognitive ability, psychological state and social support [21, 64].

What Affects Patients' Abilities to Engage in Self-Care?

As suggested, HF patients are not a homogeneous group. Besides differences in etiology of HF, systolic or diastolic dysfunction, and functional status, patients differ in a large number of psychological, social, cognitive, and behavioral characteristics. These characteristics can have a profound effect on patients' abilities to engage in effective self-care. Clinicians need to be aware of the major characteristics affecting patients' self-care abilities, need to assess for them, and then to modify their interactions to take these characteristics into account (Table 2) [41, 64].

Major characteristics that are known to affect self-care abilities are presence of comorbidities, cognitive impairment, depression, anxiety, poor health literacy, social isolation and poor social support, low socioeconomic status, and sleep disturbances (Table 2) [41, 64]. Clinicians should have a high index

of suspicion for these characteristics among their patients as all of these are common in HF, and few patients are expert at HF self-care as a consequence [65].

An International and Cultural Perspective on Heart Failure Self-Care

The word 'self-care' is difficult to translate in some languages and in some countries the literal translation of 'self-care' does not mean the same as the definition proposed in this paper. For example, the word self-care does not exist in the Italian language and is translated as "cura di sé", which means the activities that a person does for him/herself to stay healthy. In the Dutch language the word self-care ('zelfzorg') is used, however this word includes a broader meaning than is meant by 'self-care' in our definition. For example, it is used to define which medications will not be reimbursed by insurance (e.g., certain over the counter pain relief medicines, nasal sprays). These examples illustrate the caution that has to be taken in translating a concept into another language.

When considering the content of the self-care behaviors recommended for heart failure patients, there are many similarities internationally, such as advice regarding diet, exercise and symptom monitoring [66-68]. However, due to the lack of consensus about specifics of some self-care activities, such as the amount of sodium to recommend in the diet, specific advice might differ. Thus, clinicians need to be familiar with their appropriate guidelines.

In some countries or cultures recommended self-care might be challenging due to a lack of resources, for example salt restricted or healthier foods may be difficult to purchase or weight scales may not be affordable to all patients [69]. There also might be international differences related to what is considered an appropriate response to escalating symptoms. For example, in some countries patients have access to HF clinics, in other countries patients can access a cardiologist directly and in other countries patients need to consult primary care providers before they have access to a specialist.

Culture is an important context in which to consider self-care behaviors of HF patients. While common issues related to HF self-care can be identified across cultural groups, substantial differences also exist. Lower self-care abilities are described in several different cultural groups of HF patients compared to Western, majority groups. For example, among HF patients in developing compared to developed countries, HF self-care is poorer [70]. Although heart failure disease management that includes self-care education and counseling results in improved outcomes in African-American and white indigent HF patients,[71] it appears to be ineffective in a Hispanic population [72].

Promoting self-care in HF is recognized as important in several international HF guidelines, however, this emphasis comes from a cultural perspective that reflects the value of independence and self-responsibility. In some countries and cultures self-care may be a practical necessity because there may be no one to help with daily tasks. However, these values might only be important in countries and cultures where independence is valued highly. In contrast, the emphasis in other cultures (e.g., Asian, Hispanics) is on family interdependence over independence [70]. Thus, in some countries or cultures self-care might not be an important concept. In this situation, it is of greater importance when a family member is ill, that love and concern are demonstrated through care and attention from family members and these cultural values must be incorporated into teaching about self-care. This might also be relevant in cultures where collectivist ideals influence adoption of lifestyle changes, such as in Punjabi Sikh patients.

The cultural meaning of HF may confound an individual's self-care ability with regard to the recognition, interpretation and response to escalating HF symptoms. Few studies have examined symptom recognition in ethnic minorities, but we recently demonstrated that the meaning of HF has cultural roots that play a significant role in how individuals recognized and interpreted symptoms [73]. Consistent with an anthropological lens that illness is culturally constructed, ethnic minority black patients perceived and labeled symptoms in terms of cultural connotations. For example, there was a

common belief that HF was inevitable among members of this ethnic group or could be attributed to "stress". Therefore, participants failed to recognize subtle day-to-day changes in fatigability or shortness of breath. Rather, recognition of worsening symptoms as related to HF was delayed until a level of acute distress prompted emergency action.

Complexities of Self-Care

Successful self-care management starts with the early recognition and accurate interpretation of symptoms. Unfortunately, patients with HF face numerous challenges in symptom recognition. The reasons for poor symptom recognition are unclear but we do know that age-related changes, comorbid conditions, and situational factors contribute in important ways to symptom recognition and interpretation.

Many HF patients are older adults and age appears to contribute to poor symptom recognition. One explanation for this difficulty is impaired interoception. Interoception is the process by which sensory nerve receptors receive and process stimuli that originate inside the body [74]. Interoceptors include physiological receptors that monitor ongoing function of visceral organs and mediate visceral reflexes. Poor interoception may result from a loss of neurons in the cortical regions of the brain (i.e., insula and anterior cingulate) [75]. When we examined differences in age-related symptom recognition in adults with HF, older adults (\geq age 73) had more difficulty detecting and interpreting shortness of breath and were half as likely as younger adults ($<$ 73) to accurately perceive their shortness of breath after exercise [76]. The older adults did not detect subtle symptoms and were more likely to attribute symptoms like fatigue or breathlessness to other conditions such as "arthritis" or "being out of shape". Others have found that HF patients who attribute their symptoms to other conditions (e.g., lung disorder, high blood pressure) or old age were less likely to recognize symptoms [77].

HF rarely occurs in isolation. On average, HF patients report 3 other concurrent conditions. Therefore, it is not surprising that HF patients experience on average nine symptoms,[78] which are often vague, insidious in onset and overlapping. We demonstrated recently that HF patients with comorbid conditions struggle to differentiate HF symptoms. When faced with multiple comorbid conditions, patients tended to attribute vague symptoms like fatigue to the condition with which they have the most experience [79]. As a result, HF self-care management is delayed or inadequate.

Safety, Legal and Ethical Aspects of Heart Failure Self-Care

Self-care may be cost-effective, making its promotion attractive to an overburdened healthcare system. However, in the era of telemonitoring and disease management programs, healthcare contacts may not always be decreased because healthcare providers receive objective data from devices or telemonitoring equipment and patients more actively monitor and report symptoms. Both of these factors may actually initiate more healthcare contacts. Although overall healthcare costs may be decreased due to reduction in hospitalizations, the demands of certain healthcare providers may increase as patient contacts shift [80].

Safety aspects must be considered when self-care is prescribed to an increasing number of individuals with HF, who are often elderly with multiple comorbidities. Comprehensive training is required for patients to be successful and in many cases, the family or other informal care givers must be included for self-care to be successful. Whether healthcare providers give the responsibility of care to patients alone or to family or other informal caregivers, they retain accountability for assessing the ability of patients and caregivers to perform self-care. Assessments and level of prescribed self-care should be documented and regularly updated.

An interesting model of self-care has been adopted in Sweden that has applicability to other countries including the United States. In Sweden, the Ministry of Health and Social Affairs of Sweden has

ruled that healthcare professionals are responsible for assessing patients' abilities and the availability of support before recommending self-care. This statute is now being implemented collaboratively between primary, secondary and community care providers. There are three steps in this process: 1) general assessment concluding whether a task is appropriate for self-care; 2) individual assessment determining whether a patient alone or with assistance from family or other informal caregivers can perform self-care; and 3) implementation including documentation of the assessment and the decision and when to conduct follow up with a new risk assessment of patient safety.

The ethical aspects of self-care should be noted. Self-care now plays an essential role in many countries worldwide as it is associated with better outcomes and better quality of life. Aspects of integrity and autonomy can be fulfilled when an individual has the knowledge, skills and confidence to perform self-care. On the other hand, self-care demands may lead to guilt, frustration and burden on those individuals lacking the abilities and motivation to be involved in self-care who have not been properly prepared to assume the role. Therefore self-care advice with poor evidence of benefit should be avoided and self-care activities should be negotiated between the patient and the healthcare provider.

Self-care may not be feasible for persons with moderate to severe cognitive dysfunction. There is a risk that the concept of personal responsibility for health and self-care could lead to marginalization in these individuals instead of empowerment as intended. Self-care definitions and conceptualizations should be adapted to meet the needs of persons with developmental, mental or neuropsychological disorders.

What can Clinicians do to Improve Heart Failure Self-Care?

Promotion of HF patients' self-care abilities requires active involvement from patients' clinicians. This may require that clinicians become educated about self-care and about the best ways to promote

self-care and behavior change. An excellent strategy for busy clinicians is to collaborate with an advanced practice nurse who has expertise in self-care and behavior change and share care of HF patients; multidisciplinary care for patients with HF is highly recommended.[81]

Excellent information on the state of the science of self-care in HF can be obtained from the American Heart Association scientific statement, *State of the science: promoting self-care in persons with heart failure: a scientific statement from the American Heart Association* (available free online at <http://circ.ahajournals.org/content/120/12/1141.long>) [41]. Self-care information is also addressed in the HF guideline from the Heart Failure Society of America (HFSA) [67]. Both guidelines offer specific strategies for helping patients engage in effective self-care. The European Society of Cardiology (ESC) described the components of HF disease management that would best support HF patients at all stages including promotion of self-care [81]. The ESC also provides patients with an excellent website about HF that emphasizes self-care. Clinicians can not only learn how to teach self-care to patients by visiting this web site, they can refer patients to it: <http://www.heartfailurematters.org/EN/Pages/index.aspx>. The HFSA has a series of patient modules in which self-care is emphasized that can be found at http://www.hfsa.org/heart_failure_education_modules.asp.

The foundation of effective patient education about self-care is providing patients with the *skills* they need, and not simply the knowledge they need [82]. For example, there is abundant evidence that symptom recognition by patients with HF is complex and influenced by multiple factors, and improving recognition is not as simple as asking patients to monitor for signs and symptoms. Education must enhance understanding of the meaning of HF symptoms and include skill building tactics that improve symptom monitoring so that subtle changes in symptom can be more easily recognized (e.g., symptom diaries).[83] In addition, patients need to be taught *how* to monitor for shortness of breath, edema, weight gain, and other signs and symptoms. Steps in skill teaching for these and other self-care activities

are outlined in the American Heart Association scientific statement [41], European Society of Cardiology [68] and Heart Failure Society of America guidelines [67].

Helping patients with HF develop skill in self-care will require a shift in the education paradigm. In addition to increasing knowledge about HF and self-care, interventions should include content that supports the development of tactical skills in basic self-care content, for example, preparation of low salt meals. Situational skills that support self-care in unique situations are essential and can be modeled using role playing activities. Therefore, clinicians should incorporate hands-on strategies that enhance self-efficacy so that individuals feel confident in their ability to engage in self-care despite obstacles [82]. In addition, because family members (i.e., spouse, children, significant others) often play a role in helping patients with daily self-care activities, clinicians should include those individuals in self-care education programs whenever possible.

Because promotion of self-care requires behavior change, it is essential that clinicians understand and use those evidence-based cognitive-behavioral strategies that support behavior change. These strategies were outlined in a 2010 American Heart Association Scientific Statement and include the following: 1) counseling using motivational interviewing techniques, 2) goal-setting with specific behavioral (versus physiologic) goals and self-monitoring of goals, 3) clinician feedback and reinforcement of behaviors; 4) enhancement of self-efficacy; 5) opportunities for observing modeling of behaviors; and 6) teaching problem-solving [84].

Conclusion

Promotion of effective self-care should be a priority of all clinicians caring for patients with HF. Incorporation of self-care into practice so that it receives the same attention and status as medication prescription could substantially improve outcomes in HF. Greater strides in decreasing rehospitalization rates could be made if promotion of self-care was the standard of care for every HF patient.

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