Cognitive influences on self-care decision making in persons with heart failure

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Background Despite advances in management, heart failure is associated with high rates of hospitalization, poor quality of life, and early death. Education intended to improve patients' abilities to care for themselves is an integral component of disease management programs. True self-care requires that patients make decisions about symptoms, but the cognitive deficits documented in 30% to 50% of the heart failure population may make daily decision making challenging. After describing heart failure self-care as a naturalistic decision making process, we explore cognitive deficits known to exist in persons with heart failure. Problems in heart failure self-care are analyzed in relation to neural alterations associated with heart failure. As a neural process, decision making has been traced to regions of the prefrontal cortex, the same areas that are affected by ischemia, infarction, and hypoxemia in heart failure. Resulting deficits in memory, attention, and executive function may impair the perception and interpretation of early symptoms and reasoning and, thereby, delay early treatment implementation.

Conclusions There is compelling evidence that the neural processes critical to decision making are located in the same structures that are affected by heart failure. Because self-care requires the cognitive ability to learn, perceive, interpret, and respond, research is needed to discern how neural deficits affects these abilities, decision-making, and self-care behaviors. (Am Heart J 2007;154:424-31.)

Heart failure affects an estimated 5 million Americans with more than 550,000 new cases diagnosed every year.[1] Outcomes of heart failure are dismal, with poor quality of life and a high rate of hospitalization and death. Readmission rates average 33% to 40% within 3 months[2] and 40% to 50% 6 months after discharge.[3] In the decade between 1994 and 2004, the mortality rate from heart failure rose 28%.[1] Although advances in pharmacologic, surgical, and medical management have decreased readmission rates, other heart failure outcomes have improved little in the past decade.[4]

Self-care is acknowledged by most as the cornerstone of management for persons with heart failure and a key component of patient education and disease management programs.[5] Self-care is defined as a naturalistic decision-making process engaged in to maintain health and manage illness when it occurs.[6] As such, self-care is an active, cognitive decision-making process.[7] Yet, 30%[8] to 50%[9] of persons with heart failure have some impairment in cognition, which may make it difficult for them to engage in self-care. In middle-aged patients with heart failure, cognitive impairment is more common than what is expected as part of normal aging.[10] In this article, we provide evidence that self-care is poor in persons with heart failure and propose that neural alterations known to be associated with the syndrome may contribute to poor self-care by impairing decision making.

Self-care in heart failure as a decision making process

Self-care is an active process intended to maintain health through treatment adherence, symptom monitoring, recognition, and treatment and an evaluative process whereby learning occurs in response to prior self-care. Managing an illness such as heart failure requires that symptoms are recognized early and treated quickly.[6] Yet, numerous studies have demonstrated that dietary indiscretion, medication nonadherence, and failure to detect and act upon early symptoms of fluid retention are primary contributors to acute hospitalization in persons with heart failure.[11] Disease management interventions that teach self-care to patients with heart failure have been shown, on meta-analysis, to decrease the relative risk of a heart failure hospitalization by 34% (relative risk, .66 [CI, 0.52-0.83]).[12]

In heart failure, self-care decisions are made daily—when to take medicine, what foods to eat, or how to interpret nonspecific symptoms such as fatigue. Yet, as many as one third of patients with heart failure admit to skipping medication doses,[13] and this may be an

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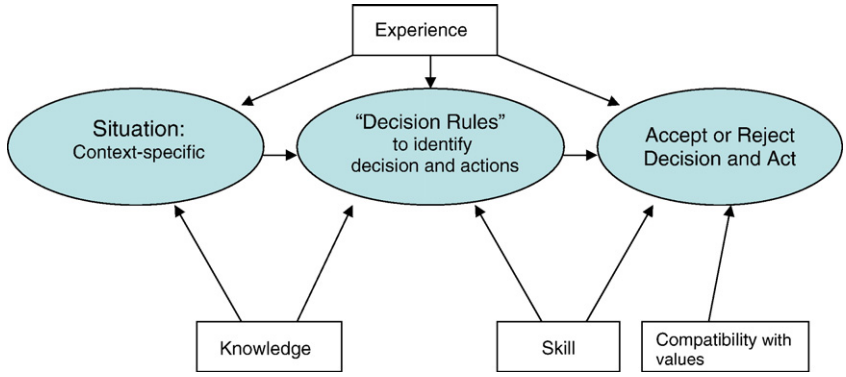
Figure 1



Naturalistic decision making is a sequential process wherein decision rules are used to match a context-specific decision with an action. To make a decision in a particular situation or context, the naturalistic decision maker needs to have experience with and knowledge about the situation and the decision, skill to act on the decision, and the decision or action must be compatible with values.

underestimation.[14] Few patients carefully follow a low sodium diet.[15] Nonspecific or vague symptoms are often ignored.[16] Early symptoms of heart failure decompensation are typically well tolerated, may not be considered serious, and often fail to evoke patient concern. Symptoms may be considered unimportant vague sensations with multiple unknown causes.[17] These descriptions illustrate why decision making is so challenging for persons with heart failure.

Overview of patient decision making

Most of patient decision making research has focused on studies of patient choices about specific treatment options, informed consent, advanced directives, or general treatment preferences. When choosing between limited options, the problem-solving task is discrete, and the decision is made based on static choices. That is, patients weigh the specific options and make one decision, for example, choosing surgery over radiation therapy as cancer treatment. Although researchers have attempted to frame patient self-care decision making within this rational, fixed context, such an application assumes that once patients decide to practice self-care, they will continue to do so in a consistent manner. Current literature refutes that assumption.[18]

A variety of classic decision theories[19] have been used to explain patient decision making, but we use a naturalistic decision making framework to explain heart failure self-care because a naturalistic model integrates the experiential, environmental, and situational factors found to influence heart failure self-care.[20] Naturalistic decision making differs from models based on classical decision theory in 2 important ways. First, classical decision making models focus on the decision event—the choice between specific but fixed alternatives. Naturalistic decision making is performed in real world settings in response to unpredictable decision tasks. Second, classical decision making is a discrete process that can be planned, scheduled, and taught, whereas naturalistic decisions are often embedded in larger dynamic tasks.

According to the naturalistic decision making framework (Figure 1), in real-world settings, people make decisions that are meaningful and familiar to them.[19] Real-life decisions are influenced by the interaction between the individual, the problem, and the current setting or environment. A sequential process is typically used, wherein decision rules are used to match a context-specific decision with an action. Experience and empirical information available at the time are used to make the decision.[20] These real-world decisions must be made at unscheduled and perhaps inopportune times, and they require knowledge and skill acquired at least partially through hands-on experience. A similar situation may well generate a different decision if the setting and information available to the decision maker are different. Inputs must often be integrated under conditions of uncertainty, time constraints, and varied situational contexts.[21,22] This description of naturalistic decision making captures the process that occurs when persons with heart failure make decisions about self-care.

According to naturalistic decision making theory, in order to make a decision in a particular situation or context, 3 criteria are needed. The naturalistic decision maker needs to have experience with and knowledge about the situation and the decision and skill to act on

Table I. Characteristics of naturalistic decision making situations[20]

Characteristics	
Ill-structured problems	• Real-life decisions rarely present in model form. • A hypothesis must be generated about what is happening based on knowledge and experience from a previous same or similar situation.
Uncertain dynamic environments	• Decisions are made with incomplete or imperfect information or data that are ambiguous. • Decision rules are used to match a context-specific decision with an appropriate action. • Naturalistic decision makers rely on experience and information that is available to them at the time in matching the decision rules.
Shifting ill-defined or competing goals	• More than one purpose drives the decision. • Decisions may be embedded in broader tasks or driven by larger goals.
Action/feedback loops	• Action and outcome are linked. • Decisions are either made more difficult or easier when there is an opportunity to change course or deal with complications later.
Time stress	• Decisions are made under the pressure of time, resulting in high personal stress, potential for fatigue, and loss of vigilance. • As a result, thinking may shift in the direction of less complicated reasoning strategies.
High stakes	• The risks, either personal or property, may be life-threatening and generally beyond what is observed in laboratory settings.
Multiple players	• Others may be involved directly or indirectly in naturalistic decision making. • Those with a vested interest, either through commonality of goals or competing priorities, influence the decision made.
Organizational goals and norms.	• Decisions made within an organization or group, such as the family unit, influential values, and goals include the group's as well as the individual's values and goals.

the decision, and the decision or action must be compatible with values.[19] Self-care decision making by persons with heart failure has been shown to be influenced by attitudes, self-efficacy,[17] and social factors,[23] but the effects of these influences appear to vary depending upon individual and physiologic factors,[24] including cognition.[8] Eight factors typical of naturalistic decision-making situations illustrate the complexity of real-world decisions (Table I). Not all characteristics are evident in each decision-making situation, but frequently, one or more of these factors complicate the decision task.[20]

Cognitive impairment in heart failure

Cognitive function refers to the information-processing abilities of attention, learning and memory, executive function (eg, cognitive flexibility and abstract reasoning), visual-spatial and visual-construction skills, psychomotor abilities, perceptual skills and language—functions critical to self-care. Cognitive deficits have been demonstrated in persons with heart failure using general cognitive measures such as the Mini-Mental Status Examination[8] and neuropsychological testing. Two leading hypotheses regarding the etiology of cognitive impairment in heart failure are the following: (1) chronic or intermittent hypoperfusion leads to cerebral ischemia,[8] and (2) microemboli originating in the heart cause cerebral infarction.[25] Other potential mechanisms include hypoxemia, as might result from sleep apnea[26] and abnormalities in blood viscosity in dehydrated patients.[27] The degree of cognitive impairment is related to the severity of heart failure.[28] Persons with more severe heart failure, for example, New York Heart Association class III to IV, generally have more cognitive impairment than those with less severe illness.

Two specific cognitive deficits found in persons with heart failure are impaired memory and attention,[9,28] and these deficits may be associated with frontal and temporal lobe deficits.[29] Brain imaging has confirmed the presence of white matter[25] and gray matter[30] lesions in brain regions associated with cognitive function. For example, Woo et al[30] found that patients with heart failure had substantial gray matter loss in brain regions critical to cognition function and cardiovascular regulation including the prefrontal cortex areas critical to decision making. Alves et al[31] demonstrated significant reductions in posterior cortical cerebral blood flow in patients with heart failure, compared with a control group using functional imaging. The reduction in cerebral blood flow was directly correlated to cognitive deficits measured by neuropsychological testing ($P < .001$). In another study using magnetic resonance imaging, investigators found that patients with idiopathic dilated cardiomyopathy had significantly higher rates of cerebral infarcts ($P < .05$), cortical atrophy ($P < .01$), and poorer cognitive performance on neuropsychological testing than age-matched controls.[32] Together, these studies illustrate significant localization of gray matter loss in cortical structures associated with cognition, memory, and symptom perception; the insular cortex that receives viscerosensory input; and the cingulate cortex important to symptom perception.

Table II. Neural basis of symptom perception[36,38,39]

Neurologic mechanism	Functions relevant to decision making	Implications for decision making
1. Sensory fiber accommodation	With sustained stimuli, over time, sensory fibers adapt either partially or completely.	Altered symptom perception leads to lack of symptom recognition. • For example, may not recognize shortness of breath or sensation of ankle swelling
a. Mechanoreceptors	Information from mechanoreceptors is used to assess activity of the ventilatory muscles and provide primary sensory information to the brain via the vagus nerve. This information leads to a perception of respiratory discomfort or dyspnea.	Over time, adaptation of pulmonary receptors may blunt the perception of dyspnea in heart failure patients.
b. Rapidly adapting receptors	In heart failure, rapidly adapting fibers act as mechanoreceptors and respond to the effects of increased acute pulmonary congestion. Stimulation of these rapidly adapting fibers leads to rapid shallow breathing and perception of breathlessness or dyspnea.	
c. Slowly adapting receptors	Slowly adapting fibers are stimulated in heart failure and result in shortened expiration time and increase in breathing frequency that may be perceived as dyspnea.	
2. Loss of central visceral sensing capability	The insula is the structure responsible for conscious perception of visceral states.	Gray matter loss in the insula, particularly the right insula, may blunt conscious perception of pulmonary congestion or other signs of heart failure decompensation.

Cognition and decision making in heart failure self-care

Cognitive impairment may contribute to failed self-care in 2 ways. Deficits in memory and attention may impair treatment adherence, one aspect of self-care, because of forgetfulness and poor learning ability. In a study testing the effect of standardized one-on-one instruction and written information about the treatment regimen on medication adherence, more than 50% of patients with clinically stable heart failure were unable to name their medications or dosages, and 75% failed to remember to take their medications 30 days after the intervention.[33] In another study, Bennett et al[34] asked focus groups of patients with heart failure about symptoms and how symptoms were managed in order to describe the strategies used in self-care. A significant number of patients reported problems with forgetfulness, decreased attention, and diminished concentration that made adhering to a complex medication regimen difficult and led to decreased independence.

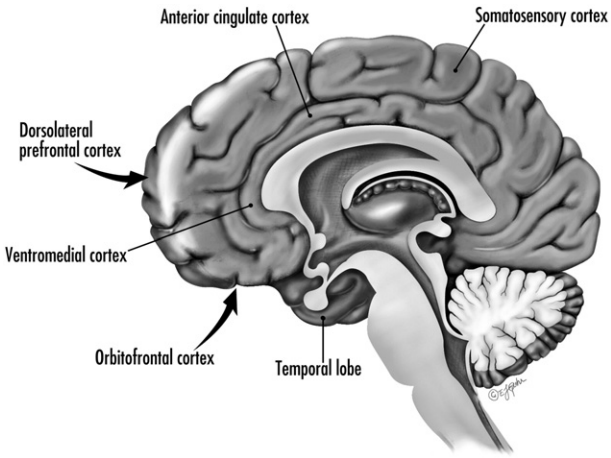
Another way that cognitive impairment may contribute to failed self-care is through problems with decision making in complex situations, such as early recognition and interpretation of symptoms. Manifestations of the deficits in executive function known to occur in persons with heart failure include problems with information processing. A systematic review and pooled analysis of 5 case-control studies found significantly poorer scores on attention, memory, and executive function in persons with heart failure.[35] Studies investigating predictors of heart failure rehospitalization have identified cognitive impairment as a likely contributor.[2] The link between cognition and self-care may be explained by examining how decisions are made within the nervous system.

Neural processing and the effect on self-care decision making

Self-care decision making requires that symptoms are perceived and interpreted. A timely response to symptoms requires the ability to reason, make associations, and foresee consequences of actions. The ability to learn, thereby improving self-care decision making in the future, assumes memory.

Treatment seeking delay in response to early symptoms could reflect neural processing problems manifested in increased deliberation time. Impaired symptom perception has been identified as a mechanism underlying treatment delay in asthma patients.[36] A similar process may occur in patients with heart failure who may have difficulty recognizing symptoms relayed from mechanoreceptors, such as those associated with peripheral edema or dyspnea, due to a deficit in the cerebral cortex that interferes with perception.[37,38] As a result, slowly progressing symptoms such as peripheral edema or dyspnea may not be recognized in time to avoid acute decompensation. It is plausible that for those with a mild, subthreshold cognitive deficit, cognition is further compromised in the early stages of fluid overload and physiologic decompensation. Consequently, the ability to

Figure 2



As a neural process, decision making has been traced to several regions of the prefrontal cortex—dorsolateral prefrontal cortex and the orbitofrontal or ventromedial cortex and the anterior cingulate cortex. The temporal lobe and the somatosensory cortex also have important functions related to memory and sensory perception.

make decisions based on subtle symptoms may be compromised, and averting a heart failure exacerbation may be even more difficult (Table II).

Impaired visceral sensory function also could contribute to delay in response to symptoms. Sensory information from thoracic viscera (including the heart and lungs) is relayed by the vagus nerve through the brainstem and thalamus to the insula, the cortical region associated with conscious perception of visceral states.[39] Interpretation of sensory information is processed in areas of the prefrontal cortex and the cingulate cortex.[40] Damage to the insula, prefrontal and/or cingulate cortex—all vulnerable to the cerebral damage found in heart failure[30]—may account for the difficulty that persons with heart failure have with self-care skills of symptom perception and recognition.

On the other hand, the difficulty recognizing altered internal states could reflect a peripheral neurologic deficit or impaired interoception. For example, dyspnea, the sensation of difficulty breathing commonly experienced by patients with heart failure, originates from several different mechanisms. Afferent signals from pulmonary receptors in the lungs and airways include slowly adapting fibers, rapidly adapting fibers,[41,42] and mechanoreceptors in the chest wall.[43] In heart failure, rapidly adapting fibers, acting as mechanoreceptors, respond to acute increases in pulmonary congestion.[41,42] Stimulation of the rapidly adapting fibers in the lungs and airways leads to rapid shallow breathing. Slowly adapting fibers also are stimulated in heart failure, although the effect is less dramatic than that associated with the rapidly adapting fibers. The result of slowly adapting fiber stimulation is shortened expiration time and increased breathing frequency.[37] Consequently, rapid shallow breathing is commonly observed in patients with heart failure. Over time, adaptation of pulmonary mechanoreceptors may blunt the perception of dyspnea.

Interpretation and response to symptoms can be traced to regions of the prefrontal cortex, including the insula,[44] (the same areas that are affected by ischemia, infarction, and hypoxemia in heart failure[30] (Figure 2 and Table III). The orbitofrontal region and ventromedial regions of the prefrontal cortex are used in decision making that requires a rapid response to the environment or an emotional response.[45] Deficits in regions of the prefrontal cortex result in difficulty foreseeing future long-term consequences, failure to act despite knowledge of correct actions, and increased deliberation time.[45] Individuals with impairment of the prefrontal cortex structures take longer to learn appropriate responses to specific stimuli, make more processing errors, and have difficulty in creating associations. In addition, value-laden decisions may be affected in patients with deficits in the ventromedial prefrontal cortex.[46] Recent neuroimaging data suggest that decisions requiring access to values elicits varying degrees of activity in the prefrontal cortex. Therefore, it is plausible that decisions involving one's values may be altered in patients with a deficit in this prefrontal region.

Decisions about symptoms must be made in a timely fashion to avoid decompensation and acute hospitalization. When the orbitofrontal and ventromedial cortex regions are impaired, decisions made under time pressure may be delayed. Changes in symptoms that require vigilant monitoring, such as fluctuating dyspnea, may be overlooked when there is a deficit in either the central processing of sensory information or in sensory fiber adaptation mechanisms. Several studies investigating treatment seeking behaviors in heart failure have found that slowly progressing symptoms, such as dyspnea and edema, are associated with delays in seeking care.[47]

Once symptoms are perceived and interpreted, reasoning and the ability to foresee the consequences of action or inaction are essential. The dorsolateral region of the prefrontal cortex is responsible for maintaining and manipulating information in working memory and for responding to environmental stimuli.[45] Individuals with a deficit in the dorsolateral region of the prefrontal cortex may exhibit problems with reasoning and decision making under uncertain or novel circumstances. Many of the rule-based self-care recommendations, such as taking an extra diuretic in response to a weight gain of 2 or more pounds in 1 day, may be problematic for patients with a deficit in the dorsolateral region of the prefrontal cortex.

Table III. Neural basis of decision making[21,31,47]

Neurologic structure	Functions relevant to decision making
Prefrontal cortex	Complex cognitive functions
	Abstract reasoning
	Problem solving
	Planning
	Working memory
Orbitofrontal cortex	Contributes to motivational and affective aspects of decision making
	Supports rapid changes in behavior to accommodate environmental changes
	Links knowledge and action
	Emotional and reward processing (leads decisions based on preferences)
Ventromedial (prefrontal) cortex	Repository for recorded linkages between knowledge and responses (emotional and bioregulatory)
Dorsolateral (prefrontal) cortex	Working memory
	Similarity processing
	Manipulating decision relevant information online
	Conscious deliberation during decisions
	Reasoning
	Involved in deciding under uncertain circumstances
Anterior cingulate cortex	Involved in ability to register errors
	Used in conditions that require hypothesis to solve
	Monitor and mediator that channels information to the proper regions
	Detects need for rapid behavioral change
	Role in initiation, motivation, and goal-directed behaviors
	Involved in symptom perception of sensory stimulation transmitted from peripheral or specific organ level
Insula	Transforms sensory stimulation from peripheral or target organs into meaningful sensations
	Involved in visceral sensory perception
Temporal lobe	Short-term memory
	Sorting new information

The anterior cingulate also plays an important role in decision making, as it is involved in information processing in relation to outcomes.[45] Deficits in the anterior cingulate, found in patients with heart failure,[30] may cause problems in making decisions in ambiguous situations, such as in response to fatigue or changes in activity tolerance and in registering and learning from errors that would lead to a different decision in future similar situations (eg, altering activities in inclement weather).

The self-care regimen for heart failure is complex, and few patients master it without structured education. Although knowledge about heart failure generally increases after an educational intervention,[48] the improvement is frequently not sustained.[49] The reasons for poor long-term retention is not fully understood, but those with memory and attention deficits may have difficulty recalling verbal instructions or maintaining attention during education sessions. Thus, the knowledge attained may not be sustained over time and may not be available to the patient when a decision is needed. Even those with sufficient knowledge and the ability to describe symptoms and actions that are needed in response to symptoms (ie, skill) still may delay acting on those symptoms.[45] Sulzbach-Hoke et al[50] found that only 40% of patients weighed themselves daily, although 70% recalled instructions to do so. Of those who did weigh themselves daily, 33% did not know what to do with the information once obtained.

Self-care training focuses on helping patients to develop the skill of linking information (daily weight gain) or symptoms (ankle swelling, shortness of breath) with an interpretation (fluid retention) and a needed action (seek care or take an extra diuretic). Deficit in the prefrontal cortex regions may interfere with the ability to make these links and master these skills. Patients will not make a decision or select an action requiring a skill they do not have.[19] For example, if a patient feels unable to adjust a diuretic dose, s/he will not decide to take an extra diuretic in response to a weight gain. Skill development is promoted by role-playing, problem-solving exercises, and practice. However, persons who are cognitively impaired and experiencing difficulty with memory and attention may have difficulty engaging in such activities, which impedes learning.

Conclusion

True self-care is a decision-making process requiring the cognitive ability to learn, perceive, interpret, reason, and respond. Cerebral ischemia, infarction, and hypoxemia impair concentration, memory, and processing abilities. These deficits, which have been shown to occur in persons with heart failure, may affect naturalistic decision-making ability through their influence on

knowledge acquisition, interpretation of physical sensations, use of prior experience, and skill development. We propose that these cognitive impairments may explain many of the self-care problems seen in persons with heart failure.

Future implications

Research in this area is greatly needed. The challenge to investigators is to discern how cognition affects self-care abilities and behaviors. Studies documenting specific and even mild forms of cognitive impairment are needed so that the exact nature of the deficits can be described. Dynamic imaging with functional MRI would facilitate understanding about how specific neural regions function in the decision making abilities of persons with heart failure. Examining these variables within the context of naturalistic decision making may reveal important clues as to why some patients are not successful in self-care. In the meantime, interventions such as role playing may facilitate self-care by helping patients to think through the behaviors that are required for true self-care.

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