Editorial

Heart Failure and Low Health Literacy: Mitigating This Lethal Combination

Nearly 6 million Americans are afflicted with heart failure (HF), with 825,000 new HF cases diagnosed annually, incurring direct costs of care that exceed $21 billion. Current estimates of this burden project that by 2030, nearly 8 million Americans will be diagnosed with HF and direct costs will escalate to over $53 billion. Heart failure ranks high among the most frequent causes of adult hospital admissions; representing the greatest cause of hospital readmission among both medical and surgical patients, and, for the Medicare patient population, the single most common reason for hospitalization. After hospital discharge, more than 30% of HF patients are readmitted to the hospital or die within 90 days. Because those who are hospitalized for acute HF have a 3 times greater risk of death compared to those who can be managed in an outpatient setting, considerable research and reimbursement incentives have been generated to reduce preventable readmissions.

Many of the efforts to reduce the toll of HF have examined approaches for reducing rehospitalization by targeting its known risk factors. Although some of these risks (advanced age, medical history of diabetes mellitus, pulmonary or renal disease, sleep apnea, myocardial infarction, coronary artery disease, cardiac valvular disease, cardiomyopathy, and myocarditis) are not amenable to modification, targeting other risk factors such as diet, exercise, obesity, hypertension, and medication adherence has not produced resounding success tales. One of the reasons for this limited success may relate to the complexity of this clinical disorder as well as to the number and range of therapies employed. Another reason relates to the capacity of these patients to provide the self-care that this condition demands. At a minimum, even patients with stable, chronic HF need to be able to manage their salt, fluid, and calorie intake; measure and document their weight; exercise regularly; take prescribed medications; and recognize when to notify their health care provider. Several studies show that low patient health literacy is a significant contributor to the high mortality in patients with acute HF.

Definition of Health Literacy

Many definitions of health literacy exist. Ratzan and Parker’s definition of health literacy, widely used and adopted by the Institute of Medicine (IOM), defines this term as “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions.” The IOM website presents important facts about the relevance of health literacy:

- Nearly half of all American adults (90 million people) have difficulty understanding and using health information.
- There is a higher rate of hospitalization and use of emergency services among patients with limited health literacy.
- Limited health literacy may lead to billions of dollars in avoidable health care costs.

Health literacy requires more than just reading comprehension; it includes a wide repertoire of multidimensional skills necessary to secure and respond to relevant information. These skills include facility with printed

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information (accessing, reading, writing, interpreting, and acting upon written text), with numeric information (understanding, calculating, acting upon quantitative facts), and verbal literacy (listening and speaking effectively). Without these skills, patients with chronic and acute HF are disadvantaged to provide the self-care they need and, for many, a lack of health literacy leaves them more likely to die from this disorder. In order for critical care nurses to provide evidence-based care for patients with HF, we need to examine research that supports these concerns.

Effects of Low Health Literacy on HF Patients

A substantial number of studies across multiple settings and geographic locations in the United States have reported inadequate levels of health literacy in adult patients with chronic and acute HF. In addition to broad, theoretical concerns of the problems that low health literacy might pose to HF patients, an expanding body of evidence of these detrimental effects already exists:

- **Low health literacy is associated with diminished HF-related knowledge attainment.** Newly referred HF patients with inadequate health literacy had less HF knowledge after educational intervention than those with adequate health literacy. Low health literacy may create a barrier to the acquisition of knowledge related to HF and performance of self-care behaviors.

- **Low health literacy is associated with lower HF-related knowledge, self-efficacy, self-care behaviors, and quality of life.** Low health literacy was found in 37% of more than 600 HF patients in southern California. Patients with adequate health literacy had higher general HF knowledge than those with low literacy, higher self-efficacy, higher prevalence of key self-care behaviors, and higher quality-of-life scores compared to those with low literacy.

- **Low health literacy is associated with diminished adherence to prescribed HF drug therapy.** For 314 HF patients, 29% had inadequate health literacy. Patients with adequate health literacy demonstrated significantly greater HF-related drug adherence (69.4%) compared to those with inadequate (54.2%) health literacy. Of greatest concern, of course, is the continuing weight of evidence from studies that confirm high rates of mortality associated with diminished health literacy in HF patients:

- **Low health literacy is associated with higher mortality in outpatients with chronic HF.** One study of 1494 HF outpatients reported that although low health literacy was found in only 17.5%, that finding was independently associated with higher mortality. In another study, 37% of ambulatory patients with symptomatic HF had low literacy. Patients with low literacy had higher rates of all-cause hospitalization or death as well as HF-related hospitalization.

- **Low health literacy is also associated with higher mortality following hospitalization for acute heart failure.** In a study designed to examine that relationship, researchers found that after adjusting for age, gender, race, insurance, education, hospital length of stay, and comorbid conditions, the risk of death for patients with low health literacy was 32% higher than for patients with higher literacy scores. The lethal outcomes associated with low health literacy held true not just at the lowest health literacy level, but remained significant for an increased risk of death at each higher level approaching adequate literacy. These findings suggest that any health literacy level less than adequate contributes to higher mortality in patients with acute HF. An inverse and step-wise relationship was demonstrated between health literacy level and mortality risk: each lower level of health literacy was associated with an increased risk of death. Finally, low health literacy was associated with a shorter median time to death than for those with higher health literacy scores.

- **In individuals with HF, low health literacy can predict morbidity and mortality.** In one study, adults hospitalized for HF were followed for at least 2 years. Those with inadequate or marginal health literacy were 1.94 times more likely to experience HF readmission and 1.91 times more likely to die from any cause. Even after adjustment for covariates, health literacy remained a predictor of those outcomes, so both inadequate and marginal health literacy are risk factors for HF-related rehospitalization and for mortality from any cause.

Despite numerous attempts at reducing rehospitalizations and mortality from HF, little substantive progress has been made. Sperry et al, who recently completed “a novel analysis” of this “longstanding problem,” observed that although a few interventions have demonstrated some reduction in HF readmissions, the measures usually target only a single aspect of care. They recommend...
integrating promising strategies into a comprehensive, patient-centered model that includes 6 categories: early reassessment, neuropsychological status, functional status, medical management, financial means, and health literacy. If health care providers could screen for deficiencies in each of those categories, then resources could be targeted to interventions known to reduce readmissions and improve survival outcomes in HF.

How Critical Care Nurses Can Contribute to Improved Health Literacy in HF Patients

Although critical care and progressive care nurses provide care that supports patients with HF along the full spectrum of their needs, we do not know to what extent health literacy is included in that care. In order for critical care nurses to contribute toward improving health literacy for HF patients, the following series of actions may be helpful:

Step 1: Familiarize yourself and your colleagues with the concept of “health literacy” and its important implications for a person’s health

Health care professionals may not be conversant with the term, health literacy, or may view it as something more relevant to a patient’s self-care, primary care, or home care rather than to progressive or critical care. As a result, providers may not fully appreciate its direct and indirect impact on virtually every patient we encounter and along the entire health wellness-illness continuum. Becoming acquainted with what health literacy is represents a necessary first step in recognizing its essential role in a person’s health. Some good sources of information on health literacy include the following: United States Department of Health and Human Services, Health Resources and Services Administration25 and Office of Disease Prevention and Health Promotion26 websites, the Agency for Health Care Quality and Research’s Health Literacy Universal Precautions Toolkit,27 the Medical Library Association’s Consumer and Patient Health Information Section,28 and a book on the topic from experts at the Harvard School of Public Health.29

Step 2: Get acquainted with research evidence that describes the effects of health literacy on patients with HF

Even from the brief review of the literature in this area presented here, there is clear evidence of a direct relationship between health literacy and desired HF outcomes. Not every study supports those findings for chronic and acute HF patients, but a substantial number confirms those findings. Before we can develop evidence-based approaches to reverse negative effects of low health literacy, we need to be well informed on what the evidence shows.

Step 3: Exercise due diligence in selecting a means to measure health literacy

Some sources suggest that health literacy is sufficiently important to warrant its designation as one of our customary “vital signs.”30-32 Whether you agree or not, to the degree that health literacy represents a clinical marker with potentially lethal implications, it can legitimately be considered a highly relevant clinical sign.

As with any other clinical parameter, a patient’s health literacy needs to be measured as objectively as possible, rather than assumed or inferred on the basis of other attributes. One cannot assume patients are health literate based on their level of formal education or their experience in other fields or careers. Even for health care providers, although we may be competent in providing care for our patients, research shows that health care professionals may not be aware of or overestimate the health literacy capability of their patients.33-35 Making erroneous assumptions on this attribute could allow the possibility or probability that a patient with unrecognized low literacy is then transferred or discharged without the ability to understand or follow through on complex courses of therapy and polypharmacy; recall important details such as signs and symptoms to report; integrate activities, medications, and dietary demands into a coherent daily schedule; or follow explicit instructions essential to their recovery and well being. The potentially harmful sequelae of that scenario dictate the need for using an instrument known to be effective and accurate in measuring health literacy.

A wide array of devices is available to measure various aspects of health literacy (see Table) and a number of these are available in both English and Spanish. A few resources provide summaries and comparisons of relevant features of these instruments. For example, the Medscape website (www.medscape.org/viewarticle/566053_5) provides a helpful summary of the major features of many of these tools.

Because of the differing attributes of these tools to measure health literacy, it will be helpful for your unit or facility to identify the attributes most desired as selection criteria to determine which device will be used. Some
selection criteria you might consider for this decision include the following:

- Validity: types and target test results
- Reliability: types and target test results
- Usefulness: overall ease of use, ease of use in clinical setting, ease of scoring, interpretation, documentation, communication
- Benchmark variability with patients of different ages or with certain health conditions
- Administration: who must or could
- Cost: initial, subsequent
- Completion time
- Availability in languages matching patient populations

One report investigated the relationship between the total scores on the shortened version of the Test of Functional Health Literacy in Adults when measured at its recommended 7-minute time limit compared to scores obtained when no time limit is imposed. Researchers found that 27% of patients improved literacy levels when no time limit was imposed and expressed concern that these differences in literacy scores may reflect the older age and compromised cognitive function of many HF patients, rather than diminished health literacy, and suggested the need for more sensitive means of appraising health literacy in older adults.

**Step 4: Monitor health literacy as an essential parameter of care for patients with HF**

As with any other important clinical indicator, a patient’s health literacy needs to be assessed as soon as feasible following admission and at all care transitions and handoffs thereafter, and its documentation needs to be readily accessible to all staff who need to be informed of this finding. Health care staff cannot improve health literacy if no data are available to determine whether a deficiency in this area exists. Because low health literacy is known to be a potentially lethal influence on HF patient outcomes, the plan of care must provide for interventions tailored to mitigate or reverse those effects.

**Step 5: Contribute to your facility’s program(s) to promote health literacy, especially in vulnerable patient populations**

If you work within a health care organization that has already launched initiatives aimed at optimizing health literacy, you and your colleagues might see how you could design programs at the unit or critical care division level to further contribute to this dimension of patient care. You could also partner with colleagues and advanced practice nurses within your facility or from nearby academic centers to design and complete quality improvement or research projects devoted to this problem.

On an ongoing basis, sign up for alerts to monitor the literature for identification of strategies that are successful in improving HF, in reducing HF readmissions, and for improving survival/reducing mortality from chronic and acute HF.

**Closing**

Health literacy has become an increasingly more essential ingredient as our health care system has transformed from one provided almost exclusively by physicians with patients as passive recipients to one where multiple categories of providers interact with patients, whose responsibilities for self-care are often required at every level and setting of care. In this health care environment with short hospital stays and thousands of patients with newly acquired health insurance competing for care, the patient’s ability to effectively navigate a complicated system of health resources and services can be repeatedly tested. For HF patients, many of whom may be older with low functional or ongoing health literacy, limitations in this essential attribute may manifest in higher rates of rehospitalization and death. Critical care nurses can become active participants in combating and reversing those outcomes for patients with HF.

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References


