Health Literacy and Heart Failure Management in Patient-Caregiver Dyads

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ABSTRACT

Background: Older adults with heart failure (HF) often need caregivers to assist with care, yet little is known about the health literacy of both patients and their caregivers. The objective of this study was to assess health literacy and the relationship between health literacy and HF self-care in HF patient-caregiver dyads.

Methods and Results: Seventeen patient-caregiver dyads were recruited. Dyads completed a measure of HF self-care and 2 measures of health literacy: 3 validated questions and a nutrition label reading task. Patients were older than caregivers and the majority of both patients and caregivers were female. Caregivers had higher health literacy by both the health literacy questions ($P = .001$) and label-reading measure ($P = .001$). All caregivers had adequate health literacy as assessed by the 3 questions, but 29% had inadequate health literacy according to the label-reading task. Caregivers and patients scored adequately in HF maintenance but inadequately in management and confidence domains.

Conclusions: Caregivers had better health literacy than patients; however, the task-oriented label-reading measure revealed poorer health literacy than the self-report measure. Measures of health literacy that reflect day to day tasks may be more illuminating than the 3 questions. (*J Cardiac Fail 2014;20:755−761*)

Key Words: Self-care, label reading task.

Poor health literacy has important implications for health outcomes such as increased hospitalizations and higher mortality.[1−3] It is estimated that 27%−54% of patients with HF have low health literacy.[2,4−6] As such, the Heart Failure Society of America (HFSA) recently formed a working group to identify and assess the current state of health literacy research and clinical implications of inadequate health literacy in patients with heart failure (HF).[4] Overall, the health literacy literature specific to HF is relatively sparse and there is a great need for research in this area.[4] Those studies that have been conducted with HF patients support the findings that low health literacy is associated with poorer health outcomes.[2,3] The HFSA consensus statement emphasizes that to be able to successfully participate in illness management, it is vital that a person understand health information rather than simply be able to read written material, underscoring the complexity of health literacy.[4]

Given that the management of HF requires a multitude of routine self-management tasks, including maintaining a low-salt diet, taking daily weights, a complex medication regimen, and monitoring HF symptoms on a daily basis,

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adequate health literacy is a necessary condition for successful HF management. Furthermore, given that older patients with HF are often dependent on a caregiver for at least some self-care needs, adequate health literacy in caregivers is also a necessary condition for HF management of the patient. Therefore, the study of the patient-caregiver dyad has become an area of increased interest as it relates to HF self-care management.[7]

Health literacy measurement is also an important consideration and may vary depending on the setting and clinical population.[8] Given the busy nature of HF clinics, a quick and practical validated method to measure health literacy is the most useful.[3] Furthermore, it is vital to supplement any measure of health literacy with an assessment of ability to carry out a self-management task accurately.[9] The present study set out to examine 2 measures of health literacy: 3 health literacy questions compared with performance on a practical health literacy task (food label reading).

Patients were recruited from an HF program that has intense HF care and teaching. It was predicted that the caregivers would have better health literacy than the patients and that better health literacy in caregivers would be associated with better HF self-care in patients.

Methods

Subjects and Recruitment

Patients over the age of 65 years, without documented dementia, in New York Heart Association (NYHA) functional class II–IV, and receiving treatment in an academic HF management program were recruited. The data were collected from October 2012 to February 2013. During this period, all consecutive patients meeting inclusion criteria were informed about the study by 1 of 2 HF doctors. Eligible patients were then recruited by a research assistant by phone. To qualify for the study, each patient had to identify 1 primary caregiver and score ≤7 on the Instrumental Activities of Daily Living Scale (IADL),[10] indicating dependence in ≥1 IADL. The HF program included documented nurse-driven education modules, written materials for patients and caregivers, and patient-specific coaching on self-care needs. All patients were treated by physicians specializing in HF care. The study was approved by the University Hospitals Case Medical Center Institutional Review Board. Both the caregiver and the patient gave informed consent. Forty-five patients were screened, and 29 did not meet inclusion criteria (2 were <65 years old, 2 were in NYHA functional class I, 1 was unable to identify a caregiver, 1 scored >7 on the IADL; 2 had known dementia; 6 refused to participate, 7 were lost to follow-up (1 died before coming to the interview), 4 were currently participating in another clinical research study, and 2 were living in a nursing facility). A total of 34 subjects made up of 17 patient-caregiver dyads composed our study cohort.

Measures

Caregivers and patients completed the 2 health literacy measures in separate rooms with the assistance of 1 of 2 research assistants or the clinical psychologist. The research assistants were trained to administer the questionnaires by the psychologist and were observed before the onset of data collection to verify the accuracy of questionnaire administration. Questions were read verbally to the subjects because of possible impairment in reading skills and/or vision. Subjects pointed to enlarged responses printed on cards which were also read to them aloud. For the label-reading task, participants were given a copy of the label and asked the questions aloud. They were also given a copy of the questions and the option of using a paper and pencil for calculations. Charts of patients were reviewed to obtain number of clinic visits, documentation of nurse teaching, and emergency department visits/hospitalizations.

IADL[10] was used as a screening tool to assess independent-living skills. The measure scores 8 domains of function, including ability to use the telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medications, and ability to handle finances. Scores range from 0 to 8, with 8 representing total independence and 0 total dependence.

Three health care literacy questions[11] were administered verbally to determine health literacy level. These screening questions have been validated as an instrument to rapidly and unobtrusively assess health literacy by clinical staff with varying levels of experience in busy clinical settings.[11–13] The questions were developed to focus on a person's ability to navigate the health care system and include:

- How often do you have problems learning about your medical condition because of difficulty understanding written information?
- How confident are you filling out medical forms by yourself?
- How often do you have someone help you read hospital materials?

These self-reported health care literacy questions have high specificity for detecting inadequate health literacy in various populations,[11–13] including in patients with HF.[3] Each screening question is graded on a 5-point Likert scale and a total summary score is obtained. The sum score was calculated on an ordinal scale (scores 1–5), and based on the literature,[3] a cutoff of 10 was used to create a dichotomous variable such that ≥10 was considered to indicate inadequate health literacy.

Newest Vital Sign[14] (NVS) is a measure of health literacy consisting of 6 questions that test the ability to read, understand, and apply information from a nutrition label. The measure takes ∼3 minutes to administer. The instrument has an internal consistency score of 0.76 and has been shown to correlate strongly with the Test of Functional Health Literacy in Adults.[13,14] One point is given for each correct answer, for a possible total score of 6 points. Those who score >4 are unlikely to have low literacy, where a score of ≤4 indicates the possibility of limited health literacy.[8,14] A score of <2 is considered to indicate a high likelihood of inadequate health literacy. The continuous total score was converted into a dichotomous variable with scores of <2 considered to indicate inadequate health literacy.

The Self-Care Heart Failure Index[15] (SCHFI) measures self-care in HF and consists of 15 items with 3 domains of self-care, including self-care maintenance (behaviors to maintain clinical stability), self-care management (decision-making process regarding symptom changes), and confidence to manage symptoms. Scores are generated for the 3 subscales. Summary scores for each domain are transformed into a subscale ranging from 0 to 100, with higher scores reflecting better self-care. Adequate care is considered to be indicated by scores >70. Internal consistency scores range from 0.55 to 0.83 on the subscales. Validity has