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Assessing Health Literacy in Heart Failure Patients?

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Abstract

Background—Health literacy has important implications for health interventions and clinical outcomes. The Shortened-Test of Functional Health Literacy in Adults (S-TOFHLA) is a timed test used to assess health literacy in many clinical populations. However, its usefulness in heart failure (HF) patients, many of whom are elderly with compromised cognitive function, is unknown. We investigated the relationship between the S-TOFHLA total score at the recommended 7 minutes limit and with no time limit (NTL).

Methods and Results—We enrolled 612 rural-dwelling adults with HF (mean age 66.0 ± 13.0 years, 58.8% male). Characteristics affecting health literacy were identified by multiple regression. Percent correct scores improved from 71% to 86% (mean percent change = 15.1 ± 18.1) between the 7-minute and NTL scores. Twenty-seven percent of patients improved at least one literacy level with NTL scores ($p < .001$). Demographic variables explained 24.2% and 11.1% of the variance in % correct scores in the 7-minute and the NTL scores respectively. Female gender, younger age, higher education, and higher income were related to higher scores.

Conclusion—Patients with HF may be inaccurately categorized as having low or marginal health literacy when the S-TOFHLA time limits are enforced. New ways to assess health literacy in older adults are needed.

Keywords

health literacy; heart failure; rural population; elderly

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Introduction

Heart failure management requires a high level of patient involvement and self-care. Adequate health literacy is critical for interpreting treatment information and following recommended treatment plans. It also influences communication with health care providers and navigation of the health care system. As defined by the US Health and Human Services, health literacy is the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.¹ Prior investigators have linked low health literacy to older age, limited education, lower income, chronic disease, having English as a second language, and poor mental health status.²⁻¹¹ Findings from a recent study on the association between age and health literacy among elderly persons suggest the need for more studies to examine whether functional literacy declines with age and whether it is explained by a decline in cognitive function¹²

Assessment of patient health literacy is critical to tailor educational programs appropriately and provide special assistance to patients with limited ability to manage complex medical conditions such as heart failure. HF patients have specific issues related to their physical and cognitive functioning and HF is more common in people over the age of 65 years.¹³ Clinicians face a unique challenge in determining the educational needs of their HF patients. About 28% to 58% of patients with chronic heart failure have impairment in one or more domains of cognitive function.¹⁴ Although this level of impairment does not meet diagnostic criteria for dementia, it can interfere with a patient's ability to process and remember information.¹⁵ Many health care providers may overestimate patients' understanding of health information, and consequently, not employ appropriate educational strategies.¹⁶ Conversely, low health literacy scores are often interpreted as the failure to carry out the reading and numerical tasks required to deal with complex health regimens, and clinicians may recommend educational interventions that do not address underlying cognitive impairment.

The S-TOFHLA, a 7-minute timed test, is widely used to identify patients, including HF patients, who have poor health literacy and require more intensive educational, counseling, and caregiver interventions. The complex challenges that HF patients face when trying to make sense of actionable health information in a fast-paced health information system¹⁷ may not be related to their capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. Rather, HF patients may need more time to obtain, process, and understand basic health information and services, and their S-TOFHLA literacy scores may underestimate their true literacy level. This reality has implications for practice when patients' health literacy is judged low and patients' informal caregivers become the target for education. Heart failure patients' ability to understand health information without time constraints is often overlooked in the assessment of health literacy. There is a paucity of research examining whether the scoring of functional health literacy levels would change without the constraints of a timed-test in the adult chronic HF population. Therefore, we explored the relationship between the S-TOFHLA literacy levels between the standard 7-minute timed test and with no time limit (NTL), as well as the relationship of patient characteristics to health literacy, in a group of community-dwelling patients with HF.

Methods

Study Design and Sample

This study was part of an ongoing randomized clinical trial, titled Rural Education to iMprove OuTcomEs in Heart Failure (REMOTE-HF) that is designed to test an education and counseling intervention to improve self-care in patients with HF. Institutional Review Board approval was obtained and all patients gave informed written consent to participate. Patients with HF living in rural areas were recruited from California, Kentucky, and Nevada. Criteria for recruitment in the parent study and for this substudy included the following: age ≥ 18 years old with stable HF, hospitalized for HF within the last 12 months, able to read and write English, and living independently with primary decision-making ability (i.e., not institutionalized). Patients were excluded if they had a complicating serious co-morbidity (disease or illness predicted to cause death within the next 12 months), a psychiatric illness or untreated malignancy, a neurological disorder that impaired cognition, or concurrent participation in a HF disease management program. Patients who met the inclusion criteria were screened using the Mini-Cog, which is a global measure of mental status.¹⁸ Patients with a word recall score of < 3 or a clock drawing score of 'abnormal' were excluded. In this study, 12 patients did not pass the Mini-Cog test.

Our prior experience with administering the S-TOFHLA has been that patients were often upset when asked to stop at the 7-minute time period and requested that they be able to complete the S-TOFHLA questionnaire after the allotted 7-minute time limit. To maintain the integrity of the standard S-TOFHLA and to accommodate patient requests, patient instructions were developed at the initiation of the study to include a 7-minute time limit and to provide the option of completing the test with no time limit (NTL). Patients were instructed that the research nurse would time and note the last question completed at 7-minutes and that they had the option to continue and complete the S-TOFHLA questionnaire. Out of 612 patients in the study, three patients did not attempt the S-TOFHLA (neither the 7-minute version nor the NTL). All 609 patients who took the S-TOFHLA with the standard 7-minutes, also continued with NTL. Since the S-TOFHLA was administered as one continuous test with a short interruption to note the question last attempted at the 7-minute limit, any bias with administering the timed test was minimized.

Procedures

The research nurses at each site completed appropriate training related to the study protocol, patient interview, intervention administration, and administration and scoring of all study instruments. Demographic information (i.e. age, gender, race/ethnicity, education, and income) was collected through a simple self-administered form. Information pertaining to medical history was collected by chart review. Co-morbidities were assessed using the Charlson Co-morbidity Index (CCI)¹⁹ Knowledge and self-care behaviors were evaluated by a Heart Failure Knowledge (HFK) questionnaire developed by the investigators and the European Heart Failure Self-Care Behavior Scale²⁰ respectively. Anxiety and depression were measured using the Basic Symptom Inventory (BSI).²¹

The S-TOFHLA is a 36-item, 7-minute timed test of reading comprehension. It measures the ability to read and understand actual health-related passages with readability levels of 4.3 and 10.4 grade levels. Reading comprehension is evaluated using a section on x-ray preparation and Medicaid application. The S-TOFHLA employs the Cloze procedure, in which a word in a sentence is omitted and must be chosen from a multiple choice list. Results are categorized into inadequate (0–16 correct answers), marginal (17–22 correct answers), and adequate health literacy (23–36 correct answers). The S-TOFHLA has good internal consistency (Cronbach's $\alpha = 0.98$ for all items combined) and demonstrated

concurrent validity compared to the long version, the TOFHLA ($r = 0.91$) and is widely used in research studies.²²

Self-care behaviors were measured using the European Heart Failure Self-Care Behavior Scale (EHFScBS),²⁰ a 12-item, self-administered yes/no questionnaire that covers items concerning self-care behavior of patients with heart failure including 7 items (on a 0-5 scale) that directly measure behaviors associated with fluid weight management (for example, daily weighing, fluid restriction, or contacting a health care provider). The EHFScBS is a valid and reliable scale to measure self-reported behaviors of heart failure patients. Face and content validity were tested using pooled data of 442 patients from 6 centers in Europe. An internal reliability of .081 was established using Cronbach's alpha.²⁰ A lower score implies better self-care behavior.

Knowledge about heart failure, symptoms and barriers to seeking care was assessed with a questionnaire developed and tested during two pilot studies. In brief, the questionnaire contains 6 questions with sub-questions that are multiple choice and yes/no or true/false questions. For each item, patients can choose from three options, with one of the options being the correct answer. The questions on HF disease knowledge were adapted for the HF population from the Rapid Early Action for Coronary Treatment (REACT) study in the AMI population.²³ Content validity of the modified instrument was established by a review of five physicians and nurses with expertise in heart failure care. The instrument has acceptable internal consistency of 0.83 using Cronbach's alpha. Higher scores indicate better knowledge with a maximum score of 100 percent.

Emotional distress was measured by the anxiety subscale of the Brief Symptom Inventory (BSI), with 6 questions that measured anxiety symptoms and their intensity at a specific point in time on a 0-4 scale. Designed to be brief and easy to administer, the BSI assessment is designed to provide an overview of a patient's symptoms and their intensity at a specific point in time. Internal validity has been established by Cronbach's alpha at 0.87.²¹ A lower score implies lower anxiety.

The Charlson Co-morbidity Index (CCI) predicts one-year mortality. The index was tested for its ability to predict risk of death from comorbid disease. With each increased level of the comorbidity index, there were stepwise increases in the cumulative mortality attributable to comorbid disease (log rank $\chi^2 = 165$; $p < 0.0001$).¹⁹ The Index is weighted for severity of co-morbidity and is computed as a total score. Higher scores imply higher co-morbidity.

Statistical Analysis

Data were analyzed using the SPSS® for Windows (version 18.0, SPSS, Inc., Chicago, IL). Descriptive statistics were used to characterize the sample. Out of a 36-item test questionnaire, we calculated how many items each patient answered correctly. To interpret differences between the two forms of the S-TOFHLA, we turned the raw correct scores to % correct scores and categorized them into one of three categories: Inadequate scores 0-16 correct (<45% correct); Marginal scores 17-22 correct ($\geq 45\%$ to <63% correct); Adequate scores; 23-36 correct ($\geq 63\%$ correct).²² Differences between the S-TOFHLA % correct scores at 7-minutes and with NTL were analyzed using paired t-tests. The relationship of demographic and patient characteristics to literacy scores with and without a time limit was assessed using multiple regression and Pearson product moment correlation coefficients.

Results

Of the 612 patients enrolled in the study, 609 had complete S-TOFHLA data. On average the patients were 66 (± 13.0) years old and the majority (58.8%) were male. The

demographic characteristic of patients is characterized in Table 1. Knowledge about HF, self-care behaviors, and level of emotional distress (anxiety and depression) at baseline are summarized in Table 2. In our sample, the mean score for self-care behavior was 20 (lower than the midpoint of 27); the mean and median scores for HF knowledge were 69.5 and 70.0 percent respectively; the mean score for anxiety was low (0.83) compared to a possible maximum score of 4.0, and on average, the level of co-morbidity was on the lower end of severity.

The average number of items attempted in 7-minutes and with NTL were 27 ± 9.7 and 33 ± 8.7 respectively. On average six more items were attempted with NTL. The mean difference in the percent correct score was $15 \pm 18\%$ with a mean score of $70.9 \pm 24.6\%$ and $86.0 \pm 18.9\%$ between the 7-minute and the NTL score respectively. The correlation between the percent scores for both time frames was 0.68, which implies that not every patient improved to the same degree. Cronbach's α for subjects who attempted all 36 items was 0.76. Overall 27% of patients improved at least one literacy level when 7-minute scores were compared to NTL scores, and the change was statistically significant ($p < .001$). Seventeen percent of patients went from "Inadequate" to "marginal" levels of literacy and 10% went from "Inadequate" to "adequate" levels of literacy.

The demographic variables were entered into a multiple regression and explained 24.2% and 11.1% of the variance in percent correct scores in the 7-minute and the NTL score analysis respectively (see Table 3). There was no significant relationship between health literacy scores (7-minutes and NTL) and HF knowledge, self-care behaviors, and emotional distress. The one exception was with HF knowledge and health literacy with NTL ($r = .104$, $p = 0.012$) (see Table 4).

Discussion

This prospective study was conducted to investigate the difference in literacy levels and the relationship of specific patient characteristics to both the 7-minute and NTL health literacy scores. During the 36-item test, patients in our study answered, on average, an additional 6 items with NTL compared to the standard 7 minutes. Similarly, there was a 15 percent correct score improvement when patients had no time limit. Finally, over one-quarter of patients improved at least one literacy level with NTL scores.

We speculate that some of the patients in the sample had mild cognitive impairment that caused them to process the material more slowly than healthy individuals, and that with additional time they were able to answer the items correctly. Heart failure can lead to cognitive impairment. For example, data from a case controlled study with 50 HF patients that used neuropsychological tests to assess cognitive outcomes in orientation, attention, memory, executive function, motor speed, and reaction times, linked heart failure with cognitive impairment; investigators found that patients with HF incurred a more than 4-fold risk for cognitive impairment compared with matched community controls.²⁴ Although we only included patients who achieved an appropriate score on the Mini-Cog test, a limitation of the current study was that we did not use formal neuropsychological assessments to test patients' cognitive processes. Specific neuropsychological testing may be needed to understand the relationship between different levels of cognition and the results of health literacy testing.

In the current study, younger age, female sex, higher education, and higher income accounted for increased health literacy scores in the timed version, and these four variables explained a significant amount of the variance (24%). Our findings support numerous literacy studies that have identified older age, limited education, lower income, and poor

mental health status as risk factors for low health literacy when using the standard 7-minute test.^{2-11, 25} For example, a study about cognitive abilities and health literacy in HF patients that was conducted in 314 community-dwelling adults (67% female, 48% African American) evaluated the relationship of cognitive (e.g., processing speed, working memory) and sensory measures, and the S-TOFHLA using the 7 minutes time limit. Patients who were older, less educated, male, and African American, and who had more co-morbidities or scored lower on all cognitive ability measures had significantly lower health literacy scores.²⁵ For the NTL analyses, except for the income variable, the three variables (age, gender, and education) were significantly associated with health literacy scores, although the amount of variance explained decreased to 11%. Additionally, in our sample the average co-morbidity index was on the lower end of the range (3.36) and may represent a less sick population; more studies are needed to substantiate these findings in a HF population with higher levels of co-morbidity.

In previous studies, low health literacy has been linked to decreased health knowledge, to low levels of self care behaviors (i.e., poor self-management skills, decreased use of preventive services, poor medication adherence), and to decreased physical and mental health.^{4, 9, 10, 25-34} Surprisingly we found that health literacy scores were minimally related to HF knowledge, reported self care behaviors and emotional distress in both the timed and untimed versions of the test, with the only exception being a weak relationship with HF knowledge in the NTL version of the test. The lack of association may be related to the different measurement techniques used across studies. In the current study, self-care behaviors were self-reported, which may differ from observed outcomes. Also, the majority of our subjects had HF for several years and was cared for by cardiologists. It may be that the knowledge and self-care behavior scores reflected principles of HF care that are frequently repeated by health care providers and well absorbed by patients even with low health literacy (e.g., low salt diet, common symptoms, etc.). Similarly, the instrument used to measure emotional distress, specifically anxiety and depression, also relied on self-report rather than a clinician assessment. We view reliance on self-report as a limitation of our study.

The S-TOFHLA is widely used in the assessment of functional literacy in heart failure patients including patients who require more time due to slower cognitive process. Our rationale for assessing health literacy with and without time limits was to determine if poor literacy scores masked possible cognitive impairment that does not meet diagnostic criteria for dementia, or if age-related slowing interferes with patient's ability to process information in the same time period as those with intact cognitive function. The literature and instructions on the S-TOFHLA are not clear on the criteria as it relates to administering the test for patients who may have cognitive impairment not detectable by global cognitive instruments such as the Mini-Cog. Similarly, it is not clear if the S-TOFHLA differentiates literacy scores for patients for whom English is a second language, or for those patients who may have movement disorders or other conditions that slow their test-taking abilities. We recognize that timing the S-TOFHLA allows differentiation by levels of literacy; however, our attempt was exploratory and sparked by our experience with patients who insisted that they could complete the test successfully if given enough time.

Conclusions

With cognitive decline in some HF patients, it is possible that more time may be needed to understand written information and that the 7- minute limit of the standard S-TOFHLA may underestimate true literacy levels. Although we operate in a fast-paced health information system, the time needed to provide patient education for patient populations with different needs has not been adequately assessed. This is especially true among the elderly in whom cognitive impairment may not be detectable during a routine clinic visit. Just as

accommodations are made for patients with Alzheimer's disease and their caregivers, more research is needed to develop practical and feasible approaches to address the unique needs of heart failure patients. Moreover, the difference in health literacy levels when constrained with time may have important implications for health literacy models and for educational interventions among HF patients. Our findings suggest that the time often allocated to providing health information such as medication instructions and dietary modifications may be insufficient to achieve comprehension for some patients.

Practice Implications

Patients make informed choices based on their own values and preferences, and the capacity to interpret treatment information may influence treatment decision-making. Health literacy is a critical determinant of a person's ability to navigate the health care system, fill out forms, locate providers and services, and engage in self-care and chronic disease management.

Instruments that measure literacy like the TOFHLA, the REALM, and the Newest Vital Sign (NVS) measure reading and interpretation skills (general literacy, reasoning, and the ability to use numbers) as applied to material with health content, rather than all aspects of health literacy.^{22, 35, 36} These instruments are useful in adults without cognitive impairment. However, assessing health literacy in HF patients is especially challenging when they may have undetected cognitive impairment and declining cognition. Older HF patients face many challenges in today's complex health care environment. Accurate assessment of health literacy in older adults with HF will facilitate the identification of patients who are able to achieve self-management goals with education that is slowly paced and frequently repeated and distinguish them from those patients who may need caregiver help or more tailored health education materials.

Successful self-management in HF requires not only reading and comprehension skills of written material, but also the ability to keep a diary and communicate with health care providers. While there are no available instruments currently that differentiate reading, communication skills, and writing skills, the practicality of assessing literacy in HF patients in an ambulatory care setting may require assessments and interventions that differentiate patients with additional needs.

Our findings underscore the importance of the recent consensus statement of the Heart Failure Society of America¹⁶ that clinicians have a responsibility to recognize patients with low literacy and optimize their care by using a multidisciplinary approach and partnering with available resources to provide them with additional support to enhance self-care and optimize therapy. The authors of the consensus statement also recommend that researchers and clinicians refine tools to identify patients with heart failure who have poor health literacy. Given the central role of the S-TOFHLA in past and current research of health literacy, the issue of using the recommended time limit is a critical one¹⁶

The administration of the S-TOFHLA requires personnel to be trained and available for the length of the test. Although we did not record the amount of time needed to complete the S-TOFHLA without time limits in our study, patients were able to complete all Baseline Questionnaires within a reasonable time frame, approximately 30 minutes. However the practicality of administering the S-TOFHLA in a practice setting may not be a good option. A brief assessment of health literacy appropriate for this population is needed.

The findings of a recent meta-analysis support the principle of frequent repetition combined with remote monitoring in the care of patients with HF³⁷. Given the constraints of our current health system with busy outpatient settings, our findings suggest that shorter and

more frequent health education interventions that include family members or other caregivers who can reinforce the information may be more effective than longer, infrequent visits. Scheduling education with shorter and more frequent visits will provide for repetition of educational materials and an ongoing assessment to determine if knowledge and self-care management objectives are achieved.

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Table 1

Sociodemographic characteristics.

	N=609 Mean ($\pm$SD) or % (n)
Mean age ($\pm$ SD)	66.0 $\pm$ 13.0
Gender : Female	41.2 (251)
Race : Caucasian	88.7 (540)
Education :	
--less than high school	19.2 (117)
--high school graduate only	47.8 (291)
--beyond high school	33.0 (201)
Annual household income:	
< \$20,000	35.3 (215)
\$20,001 - \$40,000	29.6 (180)
\$40,001 - \$ \$75,000	15.4 (94)
> \$75,000	7.6 (46)
Don't know/Refused to report	12.2 (74)

Table 2

Mean HF knowledge, self-care behaviors, and emotional distress at baseline (N=609).

	Mean	SD	Range
Heart Failure Knowledge	69.5	12.95	25 - 100
Self-Care	20.07	6.99	9 - 45
Charlson Co-morbidity Index	3.36	1.79	1 - 11
Basic Symptom Inventory Score	0.83	0.93	0.00 - 4.0

Table 3

Multiple regression analysis of demographic variables and S-STOFHLA scores with and without time limit.

R²	7-minute		NTL	
	.242	<.001	.110	<.001
	beta	p	beta	p
Age	-.740	< 0.001	-.317	< 0.001
Female	7.941	< 0.001	5.237	0.001
Education in 3 groups	6.858	< 0.001	4.940	< 0.001
Income in 4 groups	4.220	<0.001	1.463	0.079

Table 4

Correlation of HF knowledge, self-care behaviors and emotional distress with health literacy scores using a 7-minute time limit and no time limit (NTL)

	7-minute		NTL	
	r	p	r	p
HF Knowledge	.060	.148	.104	.012
Self Care	-.002	.955	-.045	.276
Basic Symptom Inventory	.027	.512	.030	.471
Charlson Co-morbidity Index	-.030	.472	-.057	.167