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Rural Patients' Knowledge about Heart Failure

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Abstract

Background—Heart failure (HF) is a potentially disabling condition requiring significant patient knowledge to manage the requirements of self-care. The need for self-care is important for all patients, but particularly for those living in rural areas that are geographically remote from health care services.

Objective—To identify the level of knowledge of rural patients with HF and the clinical and demographic characteristics associated with low levels of HF knowledge

Methods—Baseline data from 612 patients with HF enrolled in the REMOTE-HF trial were analyzed using the Heart Failure Knowledge Scale, the Short Test of Functional Health literacy in

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Adults, and the anxiety subscale of the Brief Symptom Inventory. Multiple linear regression was used to explore the contribution of sociodemographic and clinical variables to levels of HF knowledge.

Results—Mean age was 66±13 years; 59% were male, and 50.5% had an ejection fraction (EF) <40%. Mean percent correct on the HF Knowledge Scale was 69.5±13 (range 25 to 100) percent, with the most frequent incorrect items related to symptoms of HF and the need for daily weights. Males and older patients scored significantly lower in HF knowledge than females and younger patients ($p = 0.002$ and 0.011 respectively). Patients with preserved systolic function also scored significantly lower than those with systolic HF ($p=0.030$).

Conclusion—Patients can be identified who are at risk for poor self-care because of low levels of HF knowledge. Older patients, males and patients with HF with preserved systolic function may require special educational strategies to gain the knowledge required for effective self-care.

Keywords

rural; heart failure; patient education

Patients with heart failure (HF) face many challenges to maintaining health and avoiding frequent hospitalizations. They must follow complex medical regimens, incorporate stringent modifications in their diet, monitor their condition and avoid complications by noting changes in symptoms and daily weight, and learn how and when to communicate with their physicians. Therefore, patient education about aspects of HF self-care is consistently listed as a high priority in clinical guidelines;^{1,2} however, little is known about what patients with chronic HF know about their condition.

Physicians and other members of the health care team spend a significant amount of time in each clinical encounter educating patients and their family members about the requirements of self-care to prevent HF exacerbations and re-hospitalizations. Although insufficient for assuring appropriate adherence,^{3,4} knowledge is a minimum requirement for the behavior changes and self-care strategies required to avoid the high mortality and frequent re-hospitalizations for worsening heart failure documented in this patient population.^{5,6}

Patients living in rural areas have particular challenges when diagnosed with HF. They often have limited economic resources,^{7,8} lower levels of education and health literacy,^{9,10} and limited access to specialists and multidisciplinary disease management programs¹¹ compared to those who live in metropolitan areas. When hospitalized for HF, they are less likely to have early physician follow-up (within 7 days of hospital discharge).¹¹ These factors underscore the importance of assessing the knowledge of rural HF patients about their condition, the symptoms that signify deterioration, and the appropriate time to seek medical care in order to prevent unnecessary re-hospitalizations. It is likewise important that physicians and other health care practitioners know the areas of most common misunderstanding in this population. To date, the knowledge level of this population of HF patients has not been studied. Therefore, we conducted a study to assess the level of HF knowledge in patients living in rural areas and to identify demographic and clinical characteristics associated with low levels of HF knowledge.

Methods

Study Design and Sample

This study was part of a randomized clinical trial, Rural Education to iMprove OuTcomEs in Heart Failure (REMOTE-HF), that was designed to test an education and counseling intervention to improve self-care in patients with HF who live in rural areas. Six hundred and twelve patients with HF living in California, Kentucky or Nevada were recruited and the data reported here were collected at baseline prior to randomization. Institutional Review Board approval was obtained at each site and all patients gave informed written consent to participate. Rural areas were defined as towns of <2,500, living in open country or a metropolitan center of <50,000.¹² The methods used in the parent study have been described elsewhere.¹³ Briefly, inclusion criteria were age ≥ 18 years old with stable HF, hospitalized for HF within the last 6 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), required dialysis, had 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 eligibility criteria were screened using the Mini-Cog, which is a global measure of mental status.¹⁴ Patients with a word recall score of zero or a word recall of 2 with an abnormal clock drawing were excluded from participation.

Procedures

Demographic information (i.e. age, gender, race/ethnicity, education, and income) was collected through a simple self-administered form. Information pertaining to patients' medical history and physician specialty (i.e., cardiologist vs. non-cardiologist) was collected by medical chart review by trained study personnel. Co-morbidities were assessed using the Charlson Co-morbidity Index (CCI).¹⁵ Knowledge about heart failure was assessed using a 20-item scale developed by the investigators called the HF Knowledge Scale (HFKS). Content validity was established by a panel of cardiac specialists (i.e., four physicians and nurses), and predictive validity was established in a previous study.¹⁶ The 20 items consisted of 3 true-false items about the nature of HF, 3 multiple choice questions about self-management practices, and a list of 14 potential symptoms of HF (Appendix A). Anxiety was measured using the 6-item subscale of the Basic Symptom Inventory (BSI), a subscale of six items that has been used extensively in clinical populations to assess anxiety symptoms over the past two weeks.¹⁷ Cronbach's alpha in this sample was .89. Finally, health literacy was measured using the Short Test of Functional Health literacy in Adults (S-TOFHLA), which is a 36-item, 7-minute timed test of reading comprehension. It measures the ability to read and understand actual health-related passages using sections on preparing for an x-ray test and a 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. The S-TOFHLA has good internal consistency (Cronbach's alpha = 0.98) and demonstrated concurrent validity compared to the long version ($r = 0.91$).¹⁸

Statistical Analysis

Data were analyzed using SPSS® for Windows (version 18.0, SPSS, Inc., Chicago, IL). Descriptive statistics were used to characterize the sample and the individual responses to the items on the HFKS. Variables showing marginal association with HF knowledge in univariate analyses with alpha set at <0.25 or those with theoretical interest (e.g. education, marital status and anxiety) were forwarded to the regression analysis. Multiple linear regression with forced entry of all the variables in a single step was used to explore the contribution of various sociodemographic and clinical variables to levels of HF knowledge with 2-sided significance set at 0.05.

Results

The 612 HF patients who enrolled in the study were on average 66 (± 13.0) years of age, and slightly less than half were female (41.3%). Sixty-five percent had combined household incomes of less than \$40,000/year. Mean ejection fraction was 39.7 (± 15.4) percent and a large majority of patients were classified as New York Heart Association functional class II or III ($n=519$, 85.4%). The mean score on the S-TOFHLA was 70.9 ± 24.6 , with a range from 2.8 to 100. The demographic and clinical characteristics of patients are summarized in Table 1.

On average, patients scored 69.5% ($\pm 13.0\%$) correct on the HFKS, with the range of scores from 25 to 100% correct. The distribution of scores was normal, with the median score 70% correct. Of the 612 patients, all of whom had been hospitalized for HF in the past year, 45% scored less than 70% correct. An item analysis of the HFKS revealed that a significant minority of patients were confused about what symptoms to expect if their HF worsened. Some symptoms of worsening heart failure (e.g. fatigue, shortness of breath and edema of the extremities) were known by over 90 % of the patients, while other symptoms (e.g. ascites or abdominal swelling, needing extra pillows to sleep, weight gain) were not identified as symptoms by a significant percentage of patients (52%, 41%, and 22% respectively). Moreover, many symptoms that are not related to worsening HF such as neck pain or slurred speech were incorrectly identified as HF symptoms. Although 91% of patients could correctly identify why it was important to keep a daily diary of weight and symptoms, almost one-third (30%) believed that patients with HF needed to weigh themselves only once a week and an almost identical number (31%) did not identify hypervolemia (described as “too much fluid”) as the cause of increasing HF symptoms. Knowledge about HF, its symptoms, and self-care behaviors is summarized in Table 2.

The following were assessed for their potential impact on HF knowledge: age, gender, ejection fraction, education, ethnicity, marital status, anxiety, NYHA class, and medical specialty of the provider (cardiologist versus non-cardiologist). Analysis was conducted on the 602 patients with complete data on the variables of interest. The first regression model included health literacy, but is not reported here since there were 26 missing values and the model was not significantly different when health literacy was omitted. Only the first three factors were significant in the final regression model (Table 3). On average, females and younger patients had better knowledge about HF and self-care practices than males and

older patients ($p = 0.002$ and 0.011 respectively). Patients with EF $<40\%$ scored higher on the HFKS than those with EF $\geq 40\%$ ($p=0.031$).

Discussion

Although knowledge about HF does not insure adherence to the many behaviors required of patients with this challenging diagnosis,⁴ it is necessary if patients are to engage in self-care and follow the complicated medical regimen required to prevent exacerbations. Prior investigators have linked frequent re-hospitalizations for HF and increased mortality with older age, limited education, lower income, co-morbidities, English as a second language, and poor mental health status (e.g., anxiety).^{5,6,19,20} We explored the demographic and clinical characteristics identified in previous studies as predictive of HF re-hospitalization and mortality to determine if these same predictors were related to HF knowledge in a rural population. This study is one of the first to assess the accuracy of HF knowledge in patients with a recent hospitalization for HF and the first conducted in a rural population in the United States.

We found that age, gender and type of HF (systolic versus preserved systolic function) were associated with knowledge level. The latter was an unexpected finding and may reflect the lack of clear clinical guidelines for HF patients with preserved systolic function. Although the contribution of these three variables to the level of HF knowledge was relatively modest, the findings help identify those who might benefit from additional counseling time and from using strategies to reinforce learning such as repetition and teach-back techniques where patients are asked to repeat the information they were taught. The teach-back technique appears to be effective in improving patients' understanding about a chronic illness²¹ and about HF.²²

Many of the variables previously identified as associated with HF re-hospitalization such as education, income, ethnicity, health literacy, anxiety, NYHA class and specialty of care provider (cardiologist versus non-cardiologist) were not related to the HF knowledge level in the patients who participated in the current study. The lack of association between HF knowledge and many of the patient and provider characteristics that might be presumed to predict learning difficulty was an unexpected finding. In particular, health literacy has been documented to be related to learning in numerous clinical studies.¹⁹ It may be that the rural population in this study did not provide the same variability as in other studies of HF patients. For example, one-third of our sample made a combined household annual income less than \$20,000 year and two-thirds made less than \$40,000.

Our findings that patients demonstrated poor knowledge of the nature and causes of HF and its worsening trajectory are similar to those of a study conducted over a decade ago,²³ suggesting that recent attempts to increase patients' level of knowledge as a precursor to improving self-care behavior and avoiding rehospitalizations remains a significant challenge. Areas of patient education that may require special emphasis in order to increase patient knowledge about how best to avoid HF re-hospitalizations are the symptoms of worsening heart failure and the self-care behaviors related to monitoring fluid status. Our findings that one-third of patients thought that weighing themselves once a week was

sufficient to assess fluid status and that a similar number did not understand the role of increased intravascular volume as the cause of HF exacerbations point to the importance of a careful assessment of what patient's believe about self-care practices and underscores the need to review the relationship between fluid status and HF symptoms during clinical visits.

Our study may shed light on recent analyses that have identified significant geographic disparities related to HF re-hospitalization rates across the country, with significantly higher percentages seen in the lower Mississippi River Valley and the Ohio River Valley, including the Appalachian region.²⁴ The analysis was based on the claims data of Medicare beneficiaries and therefore included only individuals over the age of 65 years and did not include an analysis of rural and urban areas. However, it may be that the findings of higher re-hospitalization rates in these areas may reflect the rural nature of the communities. The investigators suggest that geographic differences can be used to tailor prevention and treatment policies and programs to the needs of communities, a recommendation that we would support based on our findings.

Several study limitations must be acknowledged. First, the cross-sectional nature of the design did not allow us to explore causal relationships. For example, it is not clear why patients with different types of HF (i.e., systolic HF vs. HF with preserved systolic function) would have significantly different levels of knowledge. Second, our findings can only be applied to similar populations living in rural areas. The knowledge level of patients living in urban areas and participating in multidisciplinary disease management programs may be quite different than that seen in the current study. Also, our population was predominately Caucasian and it is not clear if the findings would have been different in a more ethnically diverse population. Third, the fact that we do not have information about members of the patients' households and their knowledge of HF serves as an additional limitation. Patients' knowledge about their HF condition can be influenced by the knowledge of family members and caregivers,²² but we did not collect data from these individuals. We also do not know about the patients' experiences with discharge teaching when they were hospitalized.

Conclusion

In conclusion, educating patients with HF is a process that is important, challenging and complex. The symptoms of HF must be correctly interpreted and recognized by patients so that they can take appropriate action (e.g., increase a diuretic dose) and contact their physicians appropriately. This challenge is even more important for rural patients who live in geographic settings distant from medical services.

Our findings suggest that many patients are confused about which changes reflect worsening HF. A significant minority do not appreciate the importance of monitoring fluid status by weighing themselves each day. Helping patients, particularly older men and patients with preserved systolic function, sort out the subtleties of their symptoms requires careful attention to what they say about their past experiences and the expectations they hold for the future. Assessing a patient's knowledge about HF and self-care behaviors continues to be an important strategy to reduce re-hospitalization and improve clinical outcomes.

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Appendix A. Heart Failure Knowledge Scale

Please mark TRUE, FALSE or DON'T KNOW to the questions in the section below.			
	TRUE	FALSE	DON'T KNOW
1. Heart failure is a condition where the heart cannot pump enough blood to meet the needs of the body.	X		
2. A primary cause for symptoms of heart failure is too much fluid.	X		
3. You only need to weigh yourself once a week if you have heart failure.		X	

Below are signs and symptoms that may indicate worsening heart failure. Please mark NO if you think the item <i>is not</i> a symptom of heart failure and YES if you think the item <i>is</i> a symptom of heart failure.		
SIGNS & SYMPTOMS	NO	YES
4. Puffy legs and feet		X
5. Weight gain of 5 pounds in one week or less		X
6. Shortness of breath/difficulty breathing		X
7. Back pain	X	
8. Sharp chest pain	X	
9. Neck pain	X	
10. Dry, hacking cough		X
11. Earache or ringing in the ears	X	
12. Headache	X	
13. Heartburn/indigestion	X	
14. Needing extra pillows to sleep		X
15. Slurred speech	X	
16. Swelling in the abdomen		X
17. Fatigue		X

Below are multiple choice questions. Please circle the most appropriate answer.

18. It is important to seek care as soon as possible when symptoms of heart failure appear because:

- a. Medicare covers the cost.
- b. it prevents a worsening of your condition and may avoid a trip to the hospital.
- c. your doctor will enjoy a visit from you.
- d. socialization during illness helps the healing process.

19. Keeping a daily diary of your weight and symptoms when you have heart failure:

- a. tells you when you need to diet.
- b. enables your doctor to decide when to do blood work.
- c. can help you detect fluid overload and other early warning signs of worsening heart failure.

Below are multiple choice questions. Please circle the most appropriate answer.

d. reduces your health insurance premiums.

20. If you have signs and symptoms of worsening heart failure you should:

a. call a family member or friend.

b. call the local blood laboratory.

c. call your cardiologists or primary care physician promptly.

d. wait a few days to see if things get better.

(correct answers: 17-b, 18-c, 19-c)

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What's New

- Patients with heart failure are primarily confused about the specific signs and symptoms that reflect worsening HF.
- A significant minority do not appreciate the importance of monitoring fluid status by weighing themselves each day.
- Patients with low knowledge levels about HF are most likely to be older, male, and have preserved systolic function.

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Table 1
Sociodemographic and Clinical Characteristics (N=612)

Patient Characteristics	Mean (\pm SD) or % (n)
Age in years (\pm SD)	65.9 (13.0)
Gender : Female	41.3 (253)
Race : Caucasian	88.7 (543)
Education:	
<high school	19.1 (117)
high school graduate	47.9 (293)
>beyond high school	33.0 (202)
Annual household income:	
< \$20,000	35.5 (217)
\$20,001 - \$40,000	29.4 (180)
\$40,001 - \$75,000	15.5 (95)
> \$75,000	7.5 (46)
Not reported	12.1 (74)
Married	56.4 (345)
Ejection fraction % (\pm SD) (n=602)	39.7 (15.4)
< 40%	50.5 (304)
40%	49.5 (298)
New York Heart Association Class (n=611)	
Class I	10.5 (64)
Class II	54.3 (332)
Class III	31.1 (190)
Class IV	25 (4.1)
Etiology	
ischemic	47.5 (290)
hypertension	24.3 (148)
cardiomyopathy	18.2 (111)
Idiopathic/viral/other	10.0 (61)
Charlson Co-Morbidity Index	3.4 (1.8)
Anxiety (BSI:range 0-4)	0.8 (0.9)
Cardiologist	75.2 (460)

Data were available for 612 except for income (n=538), NYHA class (n=611), HF etiology (n=610) and EF (n=602)

Table 2
Frequency of Heart Failure Patients Identifying the Correct Answer on Each Item of the Heart Failure Knowledge Questionnaire, N = 612

	Correct Answer Identified
Items	N (%)
Heart failure is a condition where the heart cannot pump enough blood to meet the needs of the body	546 (89.2)
A primary cause of symptoms for heart failure is too much fluid.	424 (69.3)
You only need to weigh yourself once a week if you have heart failure	426 (69.6)
Signs and symptoms of heart failure	
Puffy legs and feet	562 (91.8)
Weight gain of 5 pounds in one week or less	474 (77.5)
Shortness of breath/difficulty breathing	596 (97.4)
Back pain	401 (65.5)
Sharp chest pain	104 (17)
Neck pain	326 (53.3)
Dry, hacking cough	265 (43.3)
Earache or ringing in ears	496 (81)
Headache	387 (63.2)
Heartburn/indigestion	273 (44.6)
Needing extra pillows to sleep	362 (59.2)
Slurred speech	313 (51.1)
Swelling in the abdomen	293 (47.9)
Fatigue	550 (89.9)
Reason it is important to seek care as soon as possible when symptoms of heart failure appear	576 (94.1)
Reason for keeping a daily diary of weight and symptoms when have heart failure	556 (90.8)
What to do if you have signs and symptoms of worsening heart failure	577 (94.3)

Table 3
Characteristics associated with higher levels of heart failure knowledge and self-care behavior by multiple linear regression, N=602, overall R²=.04, p=0.004

Variable	B	P-value	95% CI
Gender (Female)	3.608	0.002	1.335, 5.880
Age in years	-.110	0.011	-.195, -.025
Ejection fraction ($\geq 40\%$)	-2.409	0.031	-4.598, -.221
Education	1.254	.096	-.224, 2.731
NYHA class	.604	.427	-.887, 2.095
Care by cardiologist	.833	.502	-1.600, 3.267
Anxiety	-.154	.799	-1.338, 1.031
Ethnicity (Caucasian)	-.371	.826	-3.671, 2.930
Marital status (Married)	-.015	.989	-2.205, 2.175