

Congestive Heart Failure Awareness Assessment in a Geriatrics Out-patient Clinic in Central Arkansas

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Abstract

Background: Heart failure continues to be the leading cause of hospital admissions in adults over 65, most commonly due to poor medication compliance, lack of adequate self-care, and inadequate awareness of heart failure. Hospital admissions for heart failure are higher and health literacy is lower in Arkansas than the national average. We surveyed the heart failure knowledge level in the geriatric patients and caregivers at the University of Arkansas for Medical Sciences geriatric out-patient clinic.

Methods: 182 individuals responded to an anonymous survey regarding their knowledge of heart failure, including its etiology, risk factors, symptoms, and management.

Results: The subjects included patients and caregivers. About half the subjects were older than 70 and the majority were white women. Approximately 70% of the subjects had the incorrect understanding of the term "heart failure" and thought it meant that the heart had actually stopped working. A vast majority of the subjects were unaware that both weight gain and weight loss occurred in heart failure. Approximately one third of the subjects did not understand when medications should be taken for heart failure. Other important causes of CHF such as chemotherapy medications, radiation to the chest and kidney failure and were recognized by less than two-thirds of the respondents as potential causes of cardiac damage. Over 90% of the subjects indicated a desire for greater information and education on heart failure for both patients and caregivers.

Conclusions: The changing patterns of healthcare compensations based on factors such as health outcomes, and readmission rates, makes for good sense to pursue all avenues for improvements in patient care in order to maximize the positive results on health outcomes.

Keywords: Chronic disease; Health education; Health literacy; Heart failure; Self-care

Introduction

Congestive heart failure (CHF) is one of the most prevalent and costly chronic diseases in the United States. It is also the only cardiovascular disorder that is increasing in both incidence and prevalence, partially due to population aging [1-7]. If not managed effectively and aggressively, frequent heart failure hospitalizations can cause significant deterioration of health, functional decline and increase in morbidity and mortality [3,5,6].

In the last few decades, use of several therapeutic agents (Angiotensin and aldosterone receptor blockers, spironolactone and beta blockers) in heart failure management have enabled prolonged survival and improved quality of life [8-12]. Despite these pharmacological advances, heart failure continues to be the leading cause of hospital admissions in adults over the age of 65 years [5,13-16]. While hospital admissions for heart failure exacerbation secondary to atrial fibrillation, pneumonia or resistant hypertension may not always be avoidable, a significant number of CHF related hospital admissions secondary to preventable reasons such as improved monitoring and self-management may be averted [17-26].

Arkansas is among the six southeastern states (other five being Alabama, Mississippi, Oklahoma, Louisiana, and Georgia) that form the heart-failure belt [24]. In addition, Arkansas has a greater proportion of people with low health literacy rate compared to the national average. Majority of the individuals with low health literacy are 65 years and older, which is the segment of population with the highest incidence of heart failure [1-3]. Poor health literacy is

associated with failure to recognize/seek help for abnormal signs and symptoms, poor medication compliance, lack of adequate self-care, reduced physical and emotional well-being and decreased utilization of preventive health care services [24-29]. This inevitably leads to a greater likelihood of acute exacerbations of chronic health problems like heart failure, frequent emergency room visits, and higher rates of hospital admissions and frequent readmissions [18-23].

We wanted to explore the level of knowledge regarding heart failure among the geriatric patient population and their caregivers at the Thomas Lyon Longevity Out-patient Clinic (University of Arkansas for Medical Sciences). A survey was designed to assess the understanding of heart failure, the common causes, risk factors, signs and symptoms, as well as knowledge of common medications used in treatment of heart failure. The survey also included questions about lifestyle changes, such as diet and exercise, required for managing heart failure and also gauged their knowledge regarding early recognition of signs and symptoms that should prompt immediate medical intervention.

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Lastly, questions were included to test awareness of the importance of timely follow up and to test the distinction between acute and chronic disease.

Methods

A cross-sectional design was used to survey 182 individuals over a few months period. Since caregivers are often intimately involved in assisting with all aspects of disease management, they were included in the survey if the patient was unable to comprehend or answer the questions. Consequently, a wide age range (between 30 years to over 80 years and older) of subjects were sampled. The survey was also not restricted to patients with heart failure. The subjects (either the patient or caregiver) filled out an anonymous questionnaire consisting of 14 questions with multiple parts that comprised of a total of 72 individually scored questions. Questions were formulated to assess knowledge regarding various aspects of heart failure such as mechanism and natural course, etiology, risk factors, signs and symptoms and management of heart failure. The responses were a “Yes” or “No” for every question for the participant’s ease and also to ensure a higher response and completion rate. Demographic data such as age, gender, race and educational level were also obtained from the survey. Surveys were either completed in the presence of the study staff or in some cases participants were asked to leave the completed surveys in a box.

Statistical Analysis

The analyses were performed using SAS software (version 9.3, SAS Institute Inc., Cary, NC). Categorical variables are presented as counts and percentages which were calculated using the SAS procedure PROC FREQ. Responses to questions by group (i.e. gender, race, education, age) were compared using either the chi-square test or Fisher’s exact test for contingency tables with cells having expected frequencies of five or less. The chi-square and Fisher’s exact tests were performed using the SAS procedure PROC FREQ with the options chisq and fisher.

Results

Subject demographics

The minimum age for patients in the clinic was sixty and the majority of subjects surveyed fell in the age-range 71-80 years with only four individuals who were caregivers under forty years. The majority were women (75.5%) and Caucasian (82%). Only 26 individuals were African American (17%) and 16% (29/182) did not reveal their race or ethnicity. Gender was not disclosed by 15% (27/182) of the subjects. Approximately 60% (94/157) of the subjects had a college degree, forty subjects had completed high school, four subjects had an education of less than high school and the educational level for 14% (25/182) of the subjects was unknown (Table 1). Less than 10% of the participants identified themselves as being a caregiver.

All questions were weighted equally. An incorrect response or no response was scored zero. All correct responses for each survey were added to give the total score out of the maximum score of seventy two. None of the subjects scored one hundred percent. Highest score obtained by one subject was 96% and five subjects obtained scores of 94%. Since our interest was in evaluating knowledge gaps regarding heart failure, we stratified the overall incorrect responses to the survey by age, race, gender and educational level (Figure 1).

Heart failure awareness knowledge deficiencies

Mechanism and natural course of heart failure: Most participants (90%) recognized that heart failure occurred when the heart could no

Characteristics	Number	Percentage(%)
Age		
Under 60	49	29.9
60 to 70	34	20.7
70 to 90	81	49.4
Race		
Caucasian	125	81.7
African-American	26	17.0
Native American	2	1.3
Gender		
Female	117	75.5
Male	38	24.5
Education		
Less than High School	4	2.5
High School	40	25.5
Some College	19	12.1
College Degree	94	59.9

Table 1: Demographics of CHF Awareness Respondents (n=182).

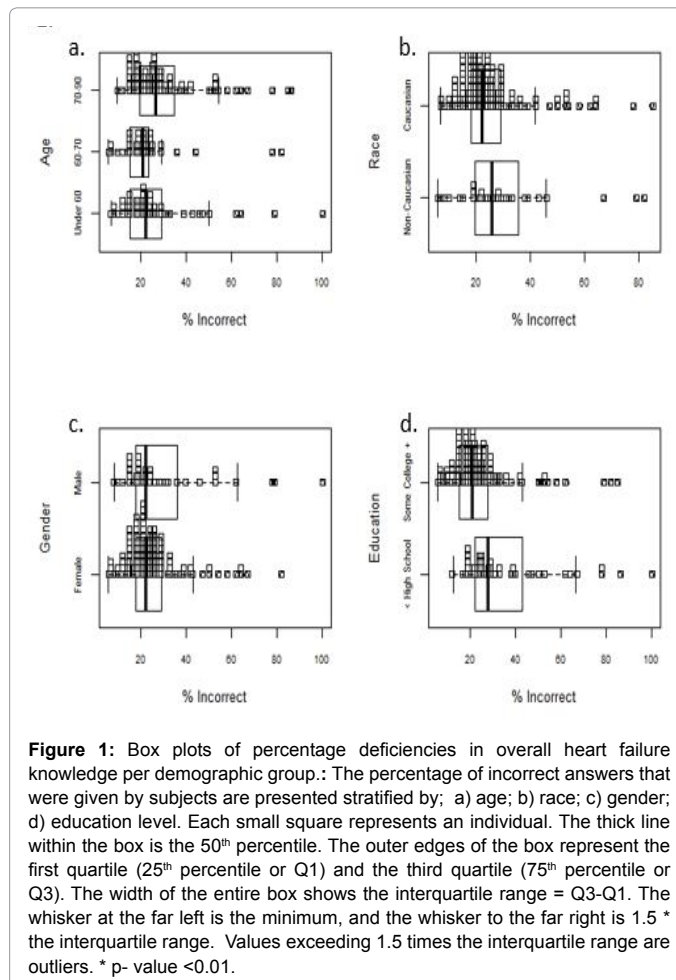
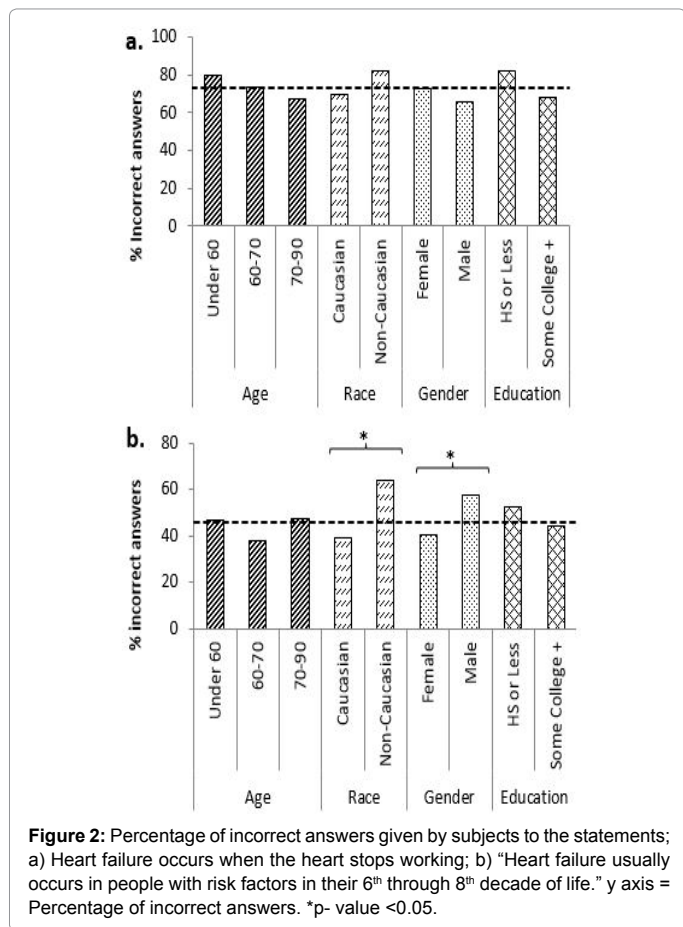


Figure 1: Box plots of percentage deficiencies in overall heart failure knowledge per demographic group.: The percentage of incorrect answers that were given by subjects are presented stratified by; a) age; b) race; c) gender; d) education level. Each small square represents an individual. The thick line within the box is the 50th percentile. The outer edges of the box represent the first quartile (25th percentile or Q1) and the third quartile (75th percentile or Q3). The width of the entire box shows the interquartile range = Q3-Q1. The whisker at the far left is the minimum, and the whisker to the far right is 1.5 * the interquartile range. Values exceeding 1.5 times the interquartile range are outliers. * p-value <0.01.

longer pump blood adequately to meet the body’s needs. However, responses to other questions pertaining to the mechanism of heart failure revealed limitations in the conceptual knowledge of the disease. Approximately 71% of the subjects had the impression that the term “heart failure” meant that the heart had actually stopped working (Figure 2a). Only about 54% of subjects were aware that heart failure



developed mostly in individuals with risk factors between sixth to eighth decades of life. The knowledge deficit was most evident in non-Caucasians (Figure 2b; $p < 0.05$).

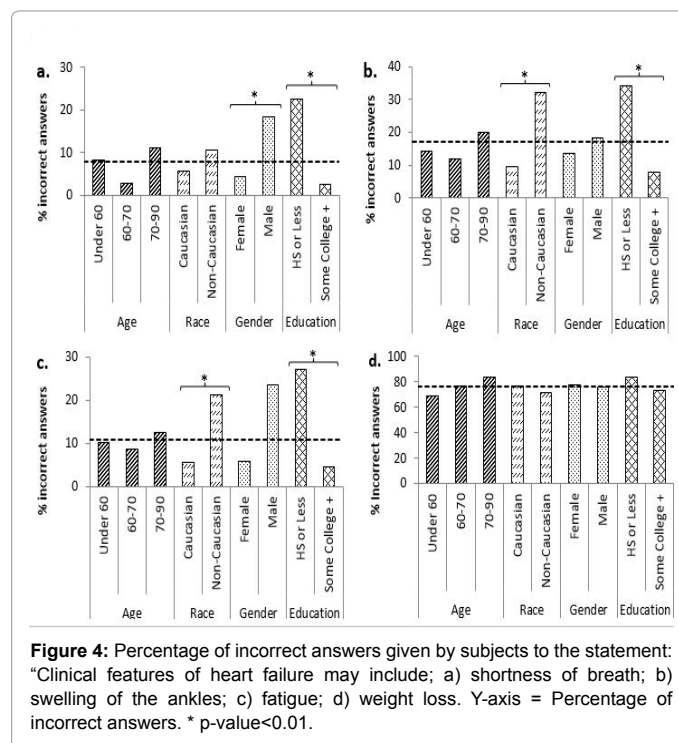
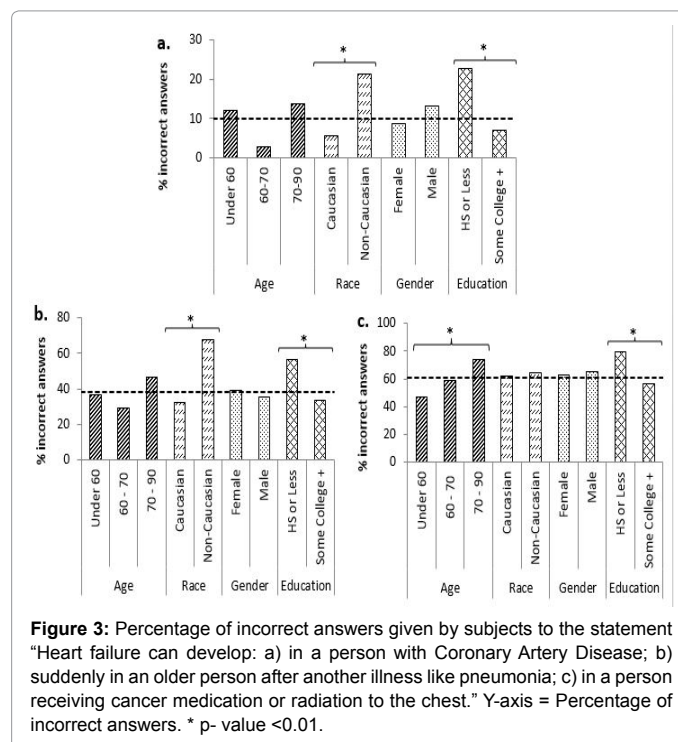
Causes of heart failure: Most participants were familiar with some of the common causes of heart failure such as coronary artery disease (90%), hypertension (83%) and valvular abnormalities (83%). About two thirds of the participants were aware of irregular heart rate (68%) contributing to heart failure. However, subjects appeared uncertain about the relationship of activity with heart failure, with about 28% associating heart failure with exercise and 40% with sedentary behavior. Overall about 38% of subjects were unaware that heart failure could develop in the elderly after pneumonia. The subjects who exhibited a significantly greater knowledge gap regarding coronary artery disease and pneumonia association with heart failure were non-Caucasians and those with lower educational levels (Figure 3a and 3b; $p < 0.01$). There was significant age-associated increase in the subjects knowledge gap regarding cancer medication and radiation as a potential cause of heart failure (Figure 3c; $p < 0.01$).

Risk factors for heart failure: The majority of the subjects were familiar with some of the common risk factors for heart failure such as family history (88%) and high cholesterol (84%) and hypertension (90%). Seventy six percent of the participants recognized diabetes as a risk factor and most (87%) correctly answered obesity to be a risk factor.

Clinical features of heart failure: While shortness of breath (92%), swelling of ankles/legs (83%), muscle weakness (82%) and fatigue

(89%), a substantial number were not aware of the weight changes seen in heart failure. Only 50% associated weight gain with this disease and 75% were unaware of the occurrence of weight loss in heart failure. In general, the understanding of signs and symptoms of heart failure was significantly worse in males, non-Caucasians and those with lower educational level (Figure 4a-d; $p < 0.01$).

Management of heart failure: Participants were generally aware



of the importance of both medication and lifestyle modifications in the management of heart failure.

Heart failure medications: Relatively few subjects had adequate knowledge of heart failure drugs. Approximately 40% of the subjects did not know that 3-4 medicines might be required to treat heart failure and only 37% were aware of the fact that medications had to be taken even when patients had no symptoms. A higher educational level was significantly associated with a lower incorrect score and males appeared to have a slightly better understanding of medication management (Figures 5a and 5b; $p < 0.05$).

Life-style modifications: Over 85% of subjects were cognizant regarding the importance of eating a healthy diet (97%), reducing alcohol intake (89%) and decreasing salt intake (91%) in a heart failure patient. Although 90% of the subjects agreed on the need to stop smoking, 23% with a lower educational level and 18% of non-Caucasians did not regard smoking cessation as important in the management of heart failure (Figure 6a; $p < 0.05$). In addition, 41% of the subjects with the same demographics were unaware that chronic heart failure was usually managed at home (Figure 6b; $p < 0.05$).

When asked about the importance of patient and caregiver education in heart failure, 91% of the subjects acknowledged that it was very important for the management of chronic heart failure and slightly more relevant in the acute heart failure management (Figure 7).

Discussion

Several studies regarding knowledge gaps, medication adherence and performance of self-care behavior among heart failure patients exist, but there is scarce literature pertaining to heart failure awareness among the general population in the United States. Our literature search (Pub Med and Google Scholar) revealed only two European

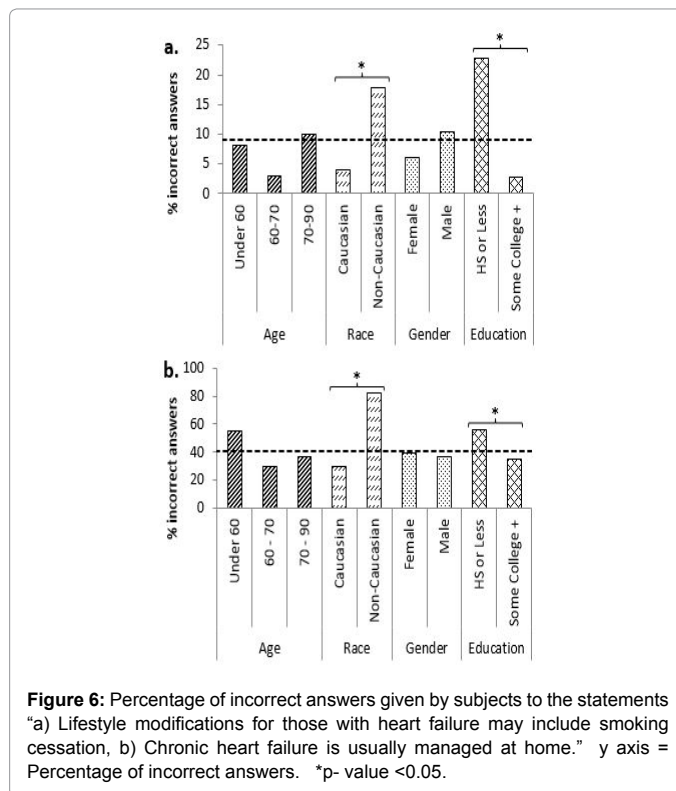


Figure 6: Percentage of incorrect answers given by subjects to the statements "a) Lifestyle modifications for those with heart failure may include smoking cessation, b) Chronic heart failure is usually managed at home." y axis = Percentage of incorrect answers. *p- value <0.05.

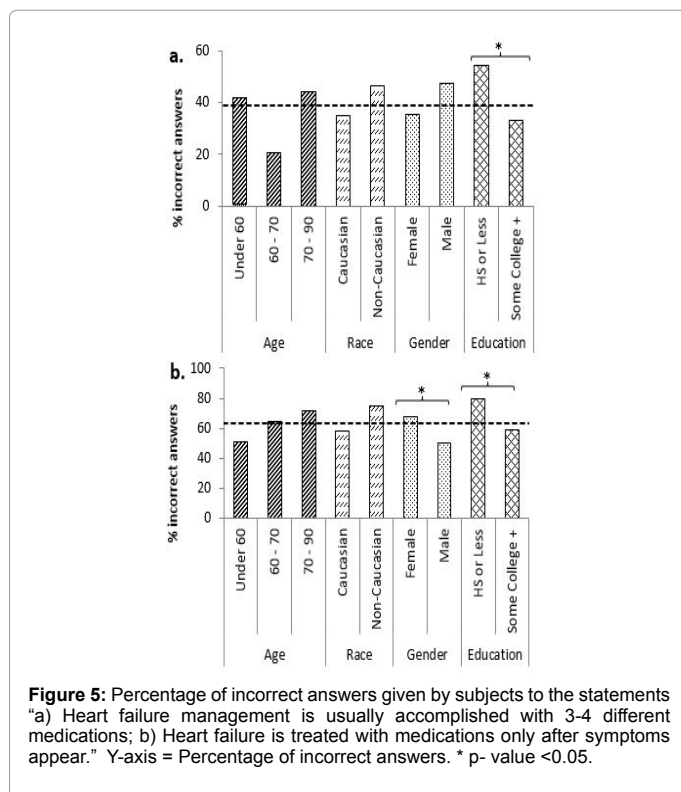


Figure 5: Percentage of incorrect answers given by subjects to the statements "a) Heart failure management is usually accomplished with 3-4 different medications; b) Heart failure is treated with medications only after symptoms appear." Y-axis = Percentage of incorrect answers. * p- value <0.05.

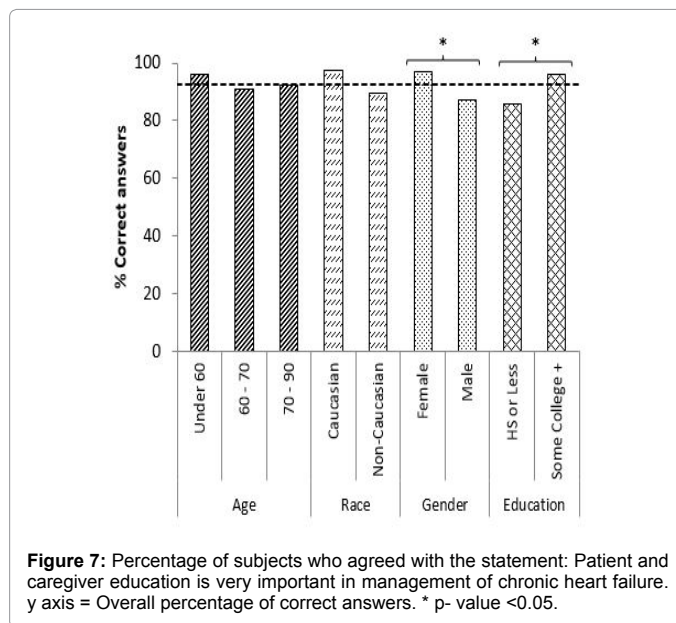


Figure 7: Percentage of subjects who agreed with the statement: Patient and caregiver education is very important in management of chronic heart failure. y axis = Overall percentage of correct answers. * p- value <0.05.

studies that addressed this issue. The Study of Heart failure Awareness and Perception in Europe (SHAPE) [30,31] and General public awareness of heart failure: results of questionnaire survey during Heart Failure Awareness Day 2011[32].

Our study is unique because we evaluated heart failure awareness in patients and their respective caregivers. The importance of the patient-caregiver dyads in chronic disease management of geriatric individuals cannot be over-emphasized since patients are often dependent on their caregivers for monitoring of health, management of medications and transportation to the healthcare provider or health facility [20,22].

Hence, the caregiver has to be as knowledgeable about the disease as the patient and in many instances, more attentive because of the higher prevalence of cognitive impairment or physical disabilities in geriatric patients. Since less than 10% of our subjects responded as caregivers, we treated the patient-caregiver team as a dyad because of the equivalent relevance of heart failure knowledge for both the patient and caregiver. Our survey was also very comprehensive with seventy-two scored responses covering various aspects of heart failure. Because of the detailed nature of the responses, only the most significant results are discussed in this paper. Another unique feature of our survey was that it was administered to all patients regardless of the diagnosis of heart failure. Our rationale for doing this was based on studies that showed that people in the geriatric age group were often unaware of the diagnosis of heart failure in spite of being on treatment for the condition [33]. Moreover, this was the target population with a high prevalence of risk factors for heart failure and hence assessment of the knowledge base of this group was essential for the design of better programs for heart failure management.

Our results were insightful in terms of the demographics and the knowledge gaps regarding the understanding of heart failure among this urban patient and caregiver dyads. Questions that elicited responses on the etiology of heart failure revealed an incorrect understanding of the meaning of heart failure in a noteworthy number of subjects. For example, 70% of the subjects believed that heart failure occurred, "when the heart stopped working." The patient is not responsible for the misconceptions about the definition of heart failure, a term that can be misleading if taken literally. Also, physicians for the most part avoid using the term "heart failure" when explaining the diagnosis to their patients because of terminal illness connotations associated with the term "failure". Our own preliminary data suggest the communication between geriatric population and primary care professionals regarding diagnosis, clinical presentation and prognosis in heart failure, PCPs in general found it difficult to explain the term heart failure to patients for a variety of reasons, some of which was attributed to the complexity of the disease and the physicians perception that the patient will be frightened by the diagnosis. Interestingly, in spite of the communication barriers and intimidating prognosis posed by the term heart failure, the medical community has been reluctant to update and redefine this term in order to make it more befitting for the current state of the disease pathophysiology. The term "congestive heart failure" does not adequately describe the majority of heart failure patients as new advanced diagnostic technology has made it less likely that persons are diagnosed with heart disease in such an advanced stage where they would present with signs and symptoms of organ congestion. A new terminology might need to be developed to describe a reduction in the heart's normal functional capacity due to disease or aging and also to emphasize the chronic nature of the disease rather than making the diagnosis sound like an end result which it implies with the current terminology.

Heart failure is a disease of aging and yet a large proportion of our subjects did not associate it with aging. It was also evident that subjects did not view heart failure as a chronic disease which could be managed at home. When asked whether chronic heart failure is "usually managed at home," only 59% agreed, which implied that a fair number of the subjects considered heart failure a medical emergency that required hospitalization or at least warranted a trip to the hospital. This may partly be because the terms heart "failure" suggested an episode that required urgent care.

Coronary artery disease and hypertension, the two leading causes

of heart failure, were recognized by a majority of the subjects however, it is still a cause of concern that about 10% to 17% of the subjects surveyed did not attribute these as major risk factors for heart failure. This lack of awareness regarding the etiology of heart failure was most conspicuous in subjects of ethnic minorities and those with a lower educational level.

On questions regarding treatment and monitoring of the disease, the participants scored relatively high but the responses suggested gaps in knowledge. For example, 61% of the subjects knew that heart failure management required at least 3 or more medications, which included ace-inhibitors, diuretics and beta-blockers. However, 63% of the respondents were under the impression that medication for heart failure should only be taken when a person developed symptoms of heart failure. Subjects associated weight gain with heart failure much more than weight loss. This exhibits lack of familiarity with the concept of chronic heart failure in which weight loss is an ominous indicator of poor prognosis and potential development of cardiac cachexia [34]. Close monitoring of chronic heart failure and attention to nutrition can delay and potentially even prevent cardiac cachexia in the elderly [34,35].

Other important causes of CHF such as chemotherapy medications, radiation to the chest and kidney failure and were recognized by less than two-thirds of the respondents as potential contributors to cardiac damage. Knowledge regarding life-style modifications in heart failure management were found to be in the high range with most subjects (over 85%) answering those questions correctly. There was a tendency towards non-Caucasians and less educated subjects not identifying several poorer lifestyle choices such as smoking.

Our study was limited because it was a single site survey of predominantly elderly Caucasian women attending an urban outpatient clinic at a university. The number of non-Caucasians and males in our study was relatively small and although there were statistically significant racial and gender differences, these might not be representative of the general population. Arkansas is largely a rural state with forty four percent of the people (as compared to 19% of the US population) residing in agricultural areas. Health care disparity research indicates that the underlying basis for the racial and ethnic differences is in large part socio-economic, which in turn also influences education and access to resources [36,37]. Sixty one of Arkansas' seventy five counties are medically underserved so it not surprising that there is a higher incidence of chronic diseases, lower health literacy and reduced life expectancy in many regions of southern United States [24]. The Delta region of eastern Arkansas is one of the worst in terms of health outcomes and is home to a predominant non-Caucasian and socially disadvantaged population [38].

The Heart Failure Society of America (HFSA) has been promoting patient and caregiver education for decades and provides excellent educational material for the public on heart failure, but in spite of this hospitalization and readmissions secondary to heart failure and related societal burden continues to be high in the elderly [39]. Distribution of educational handouts and brochures about heart failure in out-patient clinics is perhaps a quick and easy means of creating awareness but the sphere of influence by this method is only limited to those who have access to healthcare facilities. Creative ways for mass educational campaigns could be employed such as those used by the European Society of Cardiology that is able to reach a larger audience by celebrating an annual heart failure awareness day [32]. Apart from education, we have previously shown that positive self-stereotypes of aging can also mitigate cardiovascular stress [28].

Our goal is to conduct this survey on a larger scale and include health centers that represent a diverse socioeconomic strata and ethnic minorities. Needless to say, study of heart failure awareness in the rural areas of the country will require a much simpler survey design based on focus groups with the local population and the educational materials will have to be stratified for different levels of health literacy [25-27,40].

Our results indicated that an overwhelming 90% of the subjects' surveyed voted for a greater education on heart failure for both patients and caregivers. These were very encouraging results because they indicated that the subjects realized the importance of heart failure and were motivated to learn.

Conclusion

The rapid increase in population growth and changing patterns of healthcare compensations based on factors such as health outcomes, and readmission rates, makes for good sense to pursue all avenues of patient care improvements to maximize the positive results on health outcomes of patients suffering from CHF. Future research should also address the communication difficulties faced by healthcare providers, patients and caregivers in discussing the diagnosis of cardiovascular problems, and in particular understanding all aspects of heart failure and its management.

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