

## **African American Heart Failure Patients' Perspective on Palliative Care in the Outpatient Setting**

Heart failure (HF) is a progressive, incurable, complex disease that limits both the physical and psychosocial qualities of life.<sup>1,2</sup> Currently, more than 5 million people in the United States live with HF, and that number is expected to grow to more than 8 million by 2030.<sup>3,4</sup> The diagnosis of HF is expected to grow faster than other cardiovascular disease.<sup>3</sup>

In 2008, HF was listed on one in nine death certificates.<sup>5</sup> The African American population has the highest prevalence of HF at 2.8%; that number is predicted to increase to 3.6% (a 29% increase) by the year 2030.<sup>3</sup> Additionally, African Americans have a higher prevalence of risk factors, so it is not surprising that heart disease was the number one cause of mortality in 2009 for non-Hispanic blacks, accounting for 24.9% of all deaths.<sup>6</sup>

The one-year mortality rate after HF diagnosis is high, with one in five patients dying; the median length of survival being approximately five years from diagnosis.<sup>4,7,8</sup> Many patients have a progressive decline throughout their battle with HF, with periods of acute exacerbations and stability until time of death.<sup>2,9,10</sup>

There have been many advances in the management of HF; however, patients continue to have poor prognoses and quality of life. Efforts to advance the care of patients at the end of life are ongoing. In the 1990s, the Institute of Medicine and the Robert Wood Johnson Foundation called for advanced care of the dying patient.<sup>11,12</sup> Many of these efforts, however, focus on cancer patient deaths, despite the fact that heart disease has been the leading cause of death in the United States for the past 80 years.<sup>13,14</sup> Palliative care (PC) continues to be underutilized in the management of HF, even with recommendations from national HF guidelines for collaborative treatment.

## **Background and Significance**

### **Heart Failure Burden: Symptoms and Cost**

Heart failure presents unique challenges with disease progression from symptom management to advanced treatment options. Patients with HF experience a broad array of symptoms, both physical and psychosocial, similar to those with metastatic cancer.<sup>7,15,16</sup> Pain, dyspnea, and depression are the most commonly reported symptoms.<sup>17</sup> Symptoms can be distressing and decrease quality of life. A randomized controlled trial of inpatients found that initiating PC consultation at any point in the disease process improved patient symptoms of pain, dyspnea, and anxiety.<sup>18</sup> Similarly, Evangelista et al<sup>19</sup> found that HF patients who received PC as outpatients also reported greater symptom control than HF patients without PC services.

Heart failure places a significant burden on patients and families, especially toward the end of life. Support and assistance from providers in planning care is essential; prolongation of life imposes a heavy burden and suffering, not only for the patient and family, but also for the health care system.<sup>3,20</sup> The total medical cost associated with HF in 2012 was estimated at \$20.9 billion and is expected to increase to \$53.1 billion by the year 2030.<sup>3</sup> Increased use of PC by HF patients may help to decrease overall health care costs as aligning treatment plans with patient care goals may result in more conservative, and subsequently less expensive, treatment modalities.

### **Palliative Care Utilization**

As there is limited research evaluating PC usage, studies focusing on hospice were evaluated to show utilization trends at end of life for HF patients. In 2012, only 11.2% of hospice patients had a diagnosis of HF, compared to 36.9% who had a diagnosis of cancer.<sup>21</sup> In the last six months of life, the majority of those who utilize PC have a cancer diagnosis.<sup>22</sup> Additional

studies have shown minimal use of PC or hospice for non-cancer patients.<sup>23,24</sup> The majority of patients who utilize end-of-life services are Caucasian, 81.58% in 2011, compared to only 8.6% African American utilization.<sup>21</sup>

Unroe et al<sup>20</sup> found an increase in hospice use from 19% to 40% from 2000 through 2007 for hospitalized HF patients in the last six months of life. Palliative care consultations were found to be made later in the disease trajectory, with 37% of subjects classified as New York Heart Association (NYHA) functional class III and 50% NYHA functional class IV.<sup>25</sup> With PC consultations completed later in the disease trajectory, it is difficult for patients to gain the full benefit of PC, including the potential for increased quality of life.

### **Expectations from Palliative Care**

Most research looking at PC and HF focuses on when to utilize PC versus the expectations and outcomes of the patient and family. Moreover, there is a lack of research focusing on the use of PC in the outpatient setting. Current research supports a lack of understanding of PC, finding it to be synonymous with hospice.<sup>26</sup> However after consultations, patients and family members were more satisfied with the collaborative care provided between HF and PC providers.<sup>17,26</sup> Research supports PC as a means to meet the unmet psychosocial needs of HF patients.

### **Guidelines**

The Heart Failure Society of America (HFSA), European Society of Cardiology (ESC), American College of Cardiology Foundation (ACCF), and American Heart Association (AHA) generally recommend a model of care that incorporates PC for HF patients.<sup>27-30</sup> These organizations recommend addressing PC when patients are willing to discuss it and when evidence-based practices for HF treatment are no longer sufficient to manage the patient.<sup>28-31</sup>

The ACCF/AHA recommend that PC be integrated for end-stage HF patients.<sup>30</sup> The ESC recommends a more proactive stance on the use of PC, acknowledging that palliative services are not reserved only for those at the end of life.<sup>29,31</sup> Despite guideline recommendations and recognized benefits of PC for HF patients, these services continue to be underutilized and patients miss opportunities to benefit from PC when it is instituted late in the disease process. Lack of emphasis and detail placed on these recommendations may be to blame for this underutilization.<sup>30,32,33</sup>

### **Unpredictable Trajectory**

Heart failure has a relatively unpredictable, nonlinear clinical course with periods of decompensation and stability.<sup>2,3,7,8,10</sup> The chronic nature of HF makes prognoses difficult to formulate, leading to the decrease in urgency of discussing advance care planning and end-of-life care.<sup>34</sup> Tools to predict mortality have been found to be inconsistent, especially in acute situations.<sup>8,25,35</sup> Studies show that physician barriers to adopting use of early PC are related to the unpredictability of disease trajectory.<sup>24,35,36</sup> Discussing the life-limiting nature of HF and risk of sudden cardiac death with patients is recommended and necessary, especially in light of this unpredictability.<sup>2,9,28</sup> Despite recommended guidelines and wide acknowledgment of PC as beneficial, there is a lack of evidence-based practice and valid tools regarding how and when to implement PC in HF.<sup>33</sup>

### **African American Culture, Palliative Care, and Death**

The history of African American experiences of denial of care, neglect, and betrayal, as well as ethical disparities within the American health care system, such as the Tuskegee experiments from 1932-1972, have led to a longstanding element of cultural distrust of medical professionals.<sup>44</sup> Due to the nature of American history and racism, many health care institutions

systems were viewed as discriminatory for denying care to people of color.<sup>37</sup> Personal accounts of racism run deep for some patients, making it difficult to gain trust, especially if ethnicity differs between patient and provider.<sup>37</sup>

Death within the African American population can be associated with injustices.<sup>38</sup> Important values within the African American culture include religious faith and personal struggles to signify the injustice of the larger culture.<sup>38</sup> For many African Americans, there is an acceptance of suffering as a noble deed that aligns with the suffering of the culture and with Christ's suffering in Christianity.<sup>37,39</sup> Due to this thought, many African American patients accept pain and suffering as a natural part of the aging process in life. In addition, African Americans have been found to want aggressive treatment at the end of life as hospice care is associated with giving up.<sup>40,41</sup> As with any patient, cultural heritage and personal belief play a large part in how death and end of life are perceived.<sup>37</sup> However, cultural injustices, socioeconomic status, and spiritual beliefs do not determine African Americans' view on PC and death, thus further supporting the need for providers to build a trusting relationship with patients based on open communication to explore beliefs and wishes.

### **Communication between Patients and Providers**

Open communication with patients and families improves patient-centered quality of care.<sup>33</sup> End-of-life care issues are difficult to discuss with patients and can be further compounded through poor communication between patient and provider. Prognostic uncertainty of HF also makes communication at the end of life difficult.<sup>35</sup> Providers feel that discussing end-of-life care may not provide the patients with hope or comfort, even when death is inevitable.<sup>36</sup> Patients indicate that they do wish to have conversations about end-of-life issues.<sup>42,43</sup> However,

even with this desire to communicate, wishes are not being discussed with providers or family members.<sup>40,41</sup>

Patients rate physician communication regarding end-of-life communication as poor, noting that rarely are prognosis, dying, or PC discussed by physicians.<sup>44</sup> Communicating about end-of-life care is less likely in HF patients compared to patients who have a terminal cancer diagnosis.<sup>24</sup> Ongoing communication between patients and providers is necessary as patient preferences change along with their predicted trajectory.<sup>31,33,43,45,46</sup> Similarly, communication is needed to clarify wishes at end of life, as individual desires vary.<sup>41,46</sup> Providers attribute lack of communication to unpredictable disease trajectory, whereas patients and care givers attribute this lack of communication to insufficient insight on what to ask providers about prognosis.<sup>47</sup> Failure to communicate end-of-life issues between providers, patients, and family members significantly limits the ability to carry out patients' wishes. Lack of communication adds to the unmet needs of the HF patient. This provides obvious evidence of a gap in the literature regarding communication needs between patients and providers regarding end of life.

### **Summary of Literature Review**

Despite the increased need and call for PC in the HF population, the literature shows that further investigation is needed for both health care providers and patients. Evidence that PC can be used throughout the disease process needs to be reinforced to increase its use.<sup>48</sup> Patients' desire to discuss end-of-life care lends itself to the notion of integration of PC consults earlier in disease processes. Open communication regarding prognosis, dying, and PC is not only desired by patients, but is also necessary. Minimal and nonspecific guidelines are available for providers regarding when and how to institute PC for HF patients. Little is documented in the literature about quality of life and expectations of African American HF patients in relation to PC

intervention. Furthermore, knowledge in this area could lend itself to assist in the more specific development of PC use in HF guidelines. The purpose of this article is to describe from the African American HF patient's perspective the understanding of PC and the unmet needs of HF patients and implications for practice.

### **Methods**

This descriptive qualitative study describes, from the patient perspective, the understanding of and feelings toward PC consultation with African American HF patients in an ambulatory cardiac care setting. After approval from the university institutional review board and health institution's nursing research council, semi-structured interviews were conducted over a 40-day time period in October and November 2013. The Trajectory Model, also known as the Corbin-Strauss Model, is a middle range nursing theory developed by Anselm L. Strauss and Juliet Corbin to be applied to those with chronic diseases.<sup>49</sup> It provided guidance in the acquisition of and application of the knowledge gained.

Interviews followed the semi-structured interview protocol with open-ended questions. The interviews maintained anonymity and sought out patient recommendations on the best approach toward the introduction and use of PC services. In addition, insight was gained on the impact of HF, HF patient needs, and recommendations for overall HF patient care. All interviews were analyzed and eight were verified at random by an advanced practice registered nurse for common themes. Three main themes emerged from the 13 semi-structured interviews: (1) need for improved quality of life, (2) need for a strong patient-provider relationship, and (3) need for ongoing education.

## **Sample and Setting**

A metropolitan ambulatory cardiac care center provided the setting for the study. A convenience sample was recruited when study personnel were available in the clinic on the day of an appointment with the nurse practitioner. The target population was limited to English-speaking, African American, HF patients older than 19 years of age receiving treatment from the nurse practitioner at the ambulatory care center with an NYHA Class of II through IV and an ACCF/AHA HF stage C or D classification. This limited the accessible population to 103 eligible participants from the total 290 nurse practitioner patient load. Gender, comorbidities, and current treatment plans were nonexclusive. Patients were excluded if they had a history of dementia, were hard of hearing, or were not of sound mind to make their own medical decisions.

## **Results**

### **Sample Description**

Sixteen individuals were approached to participate. Participants had not previously met the interviewer. All 16 qualifying individuals were invited to voluntarily complete the interview upon clinical judgment of the nurse practitioner provider caring for the patient. Of the 16 participants, 15 agreed to participate and one refused due a recent death in the family, feeling subject material would be difficult to discuss. Thirteen of the 15 total participant interviews were retained; two participant interviews were discarded due to inability to hear interview questions and cognitive ability. Participants were 33 to 82 years of age. Five of the 13 participants (38.4%) were female and eight (61.5%) were male. Interviews lasted on average 12 minutes (range 5 to 27 minutes). The overall sample of retained interviews comprised 12.6% of the eligible African American HF population at the ambulatory care clinic.

## **Palliative Care**

None of the 13 (0%) participants had any previous understanding of or knowledge regarding PC prior to interviews. "... *I actually have no idea to be perfectly honest.*" Nor were participants aware of the availability of PC services. "*So...where do they [palliative care] come from?*"

After an explanation of PC was provided, the idea of support was well received by participants. "*Yes...well any additional support system is good!*" When participants were asked whether they felt PC services fit within their HF treatment, 10 of the 13 participants (76.9%) believed they would benefit from PC, whereas only one of the 13 participants did not feel PC was a service they would want, and two of the 13 participants were unsure.

The participant who did not feel PC was a service that would benefit his care stated "*No, because I have no pain,*" equating PC only with pain control. Of the two participants who were unsure, one felt that PC would be something that could possibly be helpful as his disease progressed. He stated he would want to reevaluate the use of PC at a later time. The second undecided participant emphasized the need to trust the PC providers, stating "*it would have to be someone that I have sit down and talk to quite a few times*" before deciding if this would be service and provider she would want involved in her care. Trust and establishing a relationship were the main factors influencing her decision.

## **Introduction to Palliative Care**

The majority, six of 10 participants (60%), who gave a recommendation for the timing of PC felt it would be appropriate to have PC involved early on in their diagnosis and treatment.

*"Probably in the beginning...I would have knew more about it [heart failure] in the*

*beginning...I probably would have responded a whole lot quicker”* The main rationale for early intervention of PC highlighted the need for education and psychosocial support early on in their diagnoses to help cope with lifestyle changes secondary to HF. Participant recommendations for introduction of PC revolved around open communication and education on PC services. *“The only way that I see that you can provide that service to me is by what you are doing now, asking questions.”*

## **Study Themes**

### **Theme 1: Need for improved quality of life**

Quality of life is a multidimensional, subjective evaluation of personal wellness. When developing individual treatment plans, it is important to understand that each unique patient has a different and dynamic definition of quality of life. Although no concrete definition of quality of life was extracted from interviews, symptoms, financial burden, and psychosocial needs emerged as key elements that influenced participants’ quality of life.

Physical symptoms were mentioned by all 13 (100%) participants during their interviews; eight of the 13 (61.5%) participants mentioned dyspnea. *“I couldn’t walk from the bedroom to the living room ‘cause I just get shortness of breath.”* Other symptoms mentioned include fatigue, edema, palpitations, and syncopal episodes. When responding to the question of “tell me how your heart failure diagnosis affects your everyday life,” physical symptoms as a limiting factor was the most commonly discussed topic and was regarded as the most difficult by seven participants. Daily limitations and the inability to work were troubling to some as they disrupted their daily routine, as was the inability to carry out activities of and independent activities of daily living. *“Um, it [heart failure] affects quite a bit because of the slowness. You have to slow*

*down from doing everything you know. You know you have to do it because you can only do it for so long a day and then you're worn out, you know. So you know you have to stop, so...it affects quite a bit.*" Many participants expressed frustration that they were unable to do what they were used to doing; however, many patients also discussed adapting to the physical change. *"I learned that there were certain things that I could and could not do."*

The unmet psychosocial needs of participants were evident throughout the interviews. An underlying concept of needing further support came through as references to generalized fear, lack of support, and social isolation. Physical symptoms and limitations created fear for patients in relation to falling or getting too short of breath to carry out daily needs. *"Certain things happen you know, it can, it can be scary, you know?"* Furthermore, the need for additional services and necessary help was limited due to financial constraints and lack of a support system for some participants.

## **Theme 2: Need for strong patient-provider relationship**

Throughout the interviews, a second common theme that emerged emphasized the need for stronger patient-provider relationships. Specifically, many participants stated the need for providers to listen and respect patients. The need for a stronger patient-provider relationship was not pinpointed solely to HF providers, but to all health care providers, as there was a strong underpinning of respect for the HF nurse practitioner and other providers in the cardiac clinic.

Patients need to know they are being listened to. Participants felt that providers did not always listen to their concerns and needs. *"I know my body more than you know my body. I know how I feel. And I know how it makes me feel, you know? I know when I sick or when something wrong and I trying to tell you guys, they [providers] try to tell me something else more*

*important.*” Participants expressed frustration when they were not being heard, leading to a lack of respect both from and for the provider. The need to be heard subsequently impacts quality of life through psychosocial support of the patient, as discussed above.

Incidentally, another participant mentioned how their care changed when they were respected and listened to by providers. Respect and open lines of communication were vital for his understanding of HF and what lifestyles changes he needed to make. “...*it’s all about communication. If the communication is there then...the help you need will be there...*”

Lack of respect was mentioned by participants. “*I need a little more a little more attention with my doctor... It’s doctors that care about their patients and then there are doctors that CARE about their patients.*” Participants felt as if they were not treated as a person but just as another disease or even as an animal. Relationships are built on trust, not by shuffling another patient or disease through the health care system. “*Like I have said, uh, to a lot of those doctors, I said ‘it’s just like they did in the olden days when they brought the cattle in, they just brought them in to slaughter them. This is the way a lot of patients feel. This is what we are, we are just an animal that they are working with.’ You know, there is no care there.*” All patients require respect when receiving care. “*They [providers] walk in the room. They never smile. They never say good morning, how are you. I said, ‘they stand around like a bunch of zombies’. I said and ‘that’s not good for patients.’*”

### **Theme 3: Need for ongoing education regarding heart failure trajectory**

The final theme present throughout 10 of the 13 (76.9%) of interviews was the need for education. “*Well any education anyone would give me I would never turn it down.*” The majority of participants noted that education on HF, the disease trajectory, and treatment, including PC, is

something participants welcomed from providers. Patients felt that if providers did not bring forth concerns, or educate participants on HF, they were not able to fully act on the interventions suggested by providers. There was an emphasis on the need to be taught in a way they understand. As stated by one participant, medical jargon is a barrier to understanding.

*“...explain it to me so I can understand, that’s all I ask. That’s because like I said, you have given me all this medical technology and I don’t understand a lot of that, a lot of that I know the terms, and kinda know what they mean but you have to explain it to me so I can understand exactly what is happening to me.”*

### **Further Patient Needs**

Despite the abovementioned limitations impacting quality of life and participants’ needs, many do not elevate their concerns to providers when asked. When responding to “tell me about any of your symptoms or needs that need more care from your provider,” eight of 13 (61.5%) denied they had any concerns that required more attention. Although all eight of the participants stated they did not have current needs to be addressed, ultimately all eight (100%) discussed symptoms as a limiting factor to their daily activities. Additionally, six of the eight (75%) discussed the desire for further education on HF or PC. Of the five participants who felt they had needs to be addressed by their provider, education, symptom management, and time from provider were the items mentioned.

### **Implications for Practice**

This study provided many implications for practice. Palliative care aims to address and provide support for physical symptom management, psychosocial issues, patient goals of care, and overall holistic care for both the patient and family. Aligning with the identified themes and

patient needs found throughout participant interviews, PC is a valuable solution to meet the abovementioned needs for improved quality of life, education, and strong patient-provider relationships. Since PC is recommended by HFSA, ESC, ACCF, and AHA guidelines to be incorporated into HF patient treatment, further development of outpatient care models will help meet the recommendations for evidence-based practice.<sup>27-30</sup>

### **Attention to Patient Physical and Psychosocial Needs**

It was evident throughout the interviews that patients have daily struggles with the psychosocial aspects and physical symptoms of HF. However, they do not always voice these concerns to providers. Acknowledging patients' needs and concerns is a vital aspect to psychosocial support and physical care. By frequently inquiring about patient challenges to daily living, health care providers may find clues to further physical or psychosocial burdens that need to be addressed in order to improve patient's quality of life. Providers should focus on individualized plans of care after thoroughly assessing individual patients' needs.

### **Communication**

Overall, participants had a need for stronger relationships with their providers. Lack of open, clear, and sensitive communication could be a contributing factor to the unmet needs of participants. Not only does the patient-provider relationship suffer due to lack of quality communication, it also leads to decreased quality of life due to the unmet psychosocial needs of HF patients. Communicating with patients can be a difficult task, especially when communication revolves around sensitive topics, such as advance care planning and end-of-life goals. However, as is evident from interviews, participants desire more communication and education from providers about these very issues. Patient-provider relationships will be fostered

as health care providers openly and honestly discuss patients' goals and care needs on a frequent basis. Open communication will also assist in having difficult conversations about the disease trajectory, advance care planning, and end-of-life care needs. Professional development should focus not only on general communication, but also on developing the skills necessary to carry out difficult conversations.

### **Ongoing Education**

Participants in the study continually emphasized that education is necessary and desired by patients. Participants expressed a greater need to understand their HF trajectory as well as the basic principles of PC. Providing education on the pathophysiology and symptomology of HF at a level patients comprehend is imperative to successful outcomes. Patient education must be free of medical jargon, and must be tailored to each individual patient, acknowledging that every patient has a different level of understanding and unique learning style. Additionally, it is essential that education continue over the course of the disease; as HF progresses, the educational needs of the patient and family change. Education must not only be offered at the beginning of a diagnosis; it should be an ongoing and continuous process.

### **Patient-centered Care Models**

Patient-centered care, in which the patient is the central focus, is a model that should be practiced in all care settings.<sup>50</sup> Echoing the abovementioned recommendations, patient-centered care promotes a strong patient-provider relationship and acknowledges the unique needs of each individual. Patient-centered care is shown to promote positive outcomes and satisfaction for patients and their families. This element of respect also addresses psychosocial needs, thus promoting improved quality of life.

Patients should be actively involved in all care decisions. They have the right to decide to initiate treatments just they have the right to refuse or discontinue treatment. It is necessary for providers to respect patients' wishes when considering PC and providing treatment. Patient-centered care models focus on the informed decision-making process for the patient. It is our duty as providers to continue to provide ethically sound education and support our patients throughout all aspects of care.

### **Further Research and Development for Outpatient Palliative Care Use**

Palliative care models and implementation of outpatient PC with HF patients is slowly emerging, as is supporting evidence-based research.<sup>17</sup> Palliative care continues to be underutilized due to the unpredictable trajectory of HF and current focus on life preservation.<sup>2,16,34</sup> Further development of care models is needed to best serve patients and their families. In addition, research and development will need to focus on system development for PC referral protocols, understanding and overcoming barriers to PC use, and professional development for health care providers on collaborative models of care for HF patients.

Once outpatient PC programs are initiated, it will be necessary to evaluate and prove the effectiveness of such care. In order to bring about quality improvement, it will be necessary to assess the feasibility of such programs, as well as the impact of such programs on HF hospital admissions and readmissions, emergency room utilization, and the cost savings when PC is in place for HF patients. From a HF patient standpoint, it will be necessary for outcome assessments to address symptom burden, quality of life, educational needs, and overall patient and family satisfaction.

### **Limitations to Study**

This study, while providing useful information to improve the use of PC in HF patients, does have limitations. Due to the small sample size and participants from a single ambulatory care setting, generalization of results is limited. Additionally, neither socioeconomic status nor specific treatment modalities for each patient were gathered, which also limits generalizability.

### **Conclusion**

The findings of this study provide significant insight into the needs of African American HF patients, as well as practice implications for these patients. Although PC was an unknown service to all of the participants, it was a welcome concept by most after PC was discussed. The underlying themes of improving quality of life, improving patient-provider relationships, and increasing patient education could all be addressed through PC consultation. Despite guideline recommendations and recognized benefits of PC, this concept continues to be underutilized in the outpatient setting. Further dedication to research and process improvement is needed to implement PC in the outpatient setting and evaluate outcomes with HF patients. Providers need to be attentive to the needs of their patients, giving patients their undivided attention and addressing patient concerns as they face the unpredictable trajectory of HF through open communication and ongoing education.

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