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

Ashlea A. Lem, BSN, RN, DNP Candidate
Misty Schwartz, PhD, RN

Creighton UNIVERSITY
College of Nursing

Background & Problem

- Heart failure (HF) is a progressive, incurable, complex disease that limits both the physical and psychosocial qualities of life. [1, 2]
- Currently over five million people in the United States live with HF, and approximately 670,000 people are newly diagnosed with HF each year according to the American Heart Association. [3]
- The African American population has the highest prevalence of HF at 2.8% with a predicted increase in prevalence by 29% to 3.6% by the year 2030. [4]
- Although there have been many advances in the management of HF, patients continue to have poor prognoses and quality of life.
- Efforts to advance the care of patients at the end of life are ongoing.
- Palliative care is recommended by the American College of Cardiology Foundation/American Heart Association guidelines to be used in conjunction with HF treatment to optimize the care of HF patients throughout the trajectory of the disease. [5,6,7,8]

Purpose

- To explore, from the patient perspective, the understanding of, and feelings toward, palliative care in African American HF patients in an ambulatory cardiac care setting.

Methods

- A descriptive, qualitative approach.
- A convenience sample was recruited from a metropolitan ambulatory cardiac care center.
- Semi-structured interview protocol with open-ended and extending questions were used.
- All interviews were analyzed for common themes.
- Themes and emerging ideas were verified at random by a cardiac advanced practice registered nurse.

Participant Characteristics

- 16 participants were approached to participate of the 103 eligible African American HF patients.
- 13 participants met the inclusion criteria and agreed to participate.
- The age range of participants was 33 to 82 years, with a mean of 62.
- 5 of the 13 participants (38.4%) were female.
- 8 of the 13 participants (61.5%) were male.

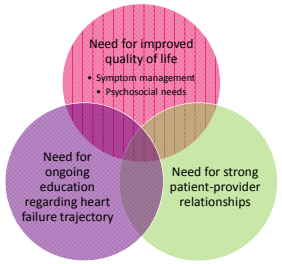
Results

- 0 of the 13 participants (0%) had no previous understanding or knowledge regarding palliative care prior to interviews.
- After explanation of palliative care:
  - 10 of the 13 participants (76.9%) believed they would benefit from palliative care.
  - 1 of the 13 participants (7.6%) did not feel palliative care to be a service they would want.
  - 2 of the 13 participants (15.3%) were unsure if they would benefit from palliative care.
- 6 of 10 participants (60%) felt it would be appropriate to have palliative care involved early on in their diagnosis and treatment of heart failure.

Themes

"(Heart failure) affects quite a bit because of the slowness. You have to slow down from doing everything. 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 have to stop, so…it affects quite a bit."

"…explain it to me so I can understand, that's all I ask. You have given me all this medical technology and I don't understand 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."



"Like I have said 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.' There is no care there."

Implications for Practice

- Facilitate open & clear communication between patients & providers.
- Increase attention to patient needs, both physical & psychosocial.
- Provide ongoing patient education on HF trajectory & palliative care.
- Focus on patient-centered care decisions based on patient's goals.
- Further development of outpatient palliative care models are needed to best serve HF patients and their families.
- Further evidence-based research is needed on the use of and outcomes with palliative care & HF.

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