



Factors influencing self-care behaviors of African Americans with heart failure: A photovoice project



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ABSTRACT

Objectives: The purpose of this study was to understand the influences of heart failure (HF) self-care among low income, African Americans.

Background: Compared to all other racial groups, African Americans have the highest risk of developing HF, coupled with high mortality and morbidity rates.

Methods: Using the photovoice method, participants related important lifestyle factors through photography. The participants and researcher met for reflection and discussion 2 h per week for six weeks.

Results: Four themes emerged: family support gives me the push I need, social interaction lifts me up, improving my mind to lift depression can improve my heart, and it is important but challenging to follow the HF diet.

Conclusion: The findings from this study may assist policy makers, health care professionals, patients, and support systems in understanding the complexity of engaging in HF self-care. This understanding may lead to the development of appropriate patient-centered assessments and interventions.

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Heart failure (HF) affects approximately 5.1 million people in the United States. Heart failure is most common in people 65 and older, and is the number one reason older people are hospitalized.^{1–3} The prevalence of HF is projected to increase 25% in the next 15 years, yielding an estimated 6.3 million people living with HF by 2030.⁴ Heart failure is a chronic, complex syndrome that leads to high health care utilization and higher costs for care. In 2010 the estimated direct and indirect costs for the treatment of HF in the United States were \$39.2 billion, compared to \$29 billion in 2006.⁵ Heart failure is a life-limiting condition that results in death within five years of diagnosis for 50% of patients.⁶ After HF is diagnosed, the survival rate is lower in men than in women; however, fewer than 15% of women survive longer than 8–12 years.^{1,2} Approximately 300,000 deaths each year are due to HF.^{1,2}

A significant health disparity is evident when considering HF among African Americans compared to other racial and ethnic

populations in the United States. African Americans have the overall highest risk of developing HF (4.6%), followed by Hispanics (3.5%), and Caucasians (2.4%).^{7,8} Heart failure diagnosis at a younger age is more common among African Americans than Caucasians.^{7,9} Furthermore, African Americans are more likely than individuals among other ethnic groups to suffer more severe forms of HF and have a more progressive disease trajectory. African Americans living with HF are hospitalized seven to eight times more often than Caucasians.^{7,9} Additionally, African Americans are more likely than Caucasians to die within five years of HF diagnosis, which explains the decrease in HF rates for African Americans over 75 years of age.⁸

Previous investigators have identified sources for the disparate rates of HF among African American persons. Increased prevalence of hypertension (HTN), a primary cause of HF, is a serious concern among African Americans.^{10,11} Chronic poverty and experiences of racism result in chronic elevations in cortisol, which in turn increases blood pressure.^{12,13} African Americans also suffer from HTN at earlier ages⁶ and have other diseases that are more difficult to control than persons of other ethnicities.¹⁴ A lack of insurance continues to be a considerable barrier in receiving health care, and this contributes to delayed diagnosis and persistence of untreated chronic conditions. As a group, African American adults have lower rates of insurance, higher rates of inadequate insurance, or no

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insurance compared to Caucasians.¹¹ Allostatic load, the body's attempt to adapt to stressors and maintain stability,¹⁵ has been found to be higher in African Americans than Caucasians even after controlling for poverty.¹⁶ Discrimination and poverty, therefore, also contribute to health disparities among African Americans.^{16,17}

Ethnic differences related to HF exist not only in health outcomes, but also in HF self-care. Heart failure self-care includes management of multiple medications, dietary and fluid restrictions, daily weight monitoring, symptom recognition and management, and a unique balance of rest and exercise.¹⁸ Heart failure self-care is defined as a naturalistic decision-making process that involves the choice of behaviors that maintain physiological stability (self-care maintenance), the response to HF symptoms as they occur (self-care management), and the confidence (self-care confidence) to engage in each phase of self-care.¹⁸ Many persons with HF find it challenging to learn and incorporate the necessary self-care behaviors into their daily lives.¹⁹ For example, previous studies have identified that African Americans have difficulty adhering to the HF diet^{20–22} and taking their medications as prescribed.²³ The appropriate and consistent use of HF self-care can prevent hospitalization and improve health outcomes.¹⁹ Helping patients improve their HF self-care is one way to decrease morbidity and early mortality. Interventions for vulnerable populations are strengthened when they are based on the participants' understanding of the phenomenon and their self-identified needs. Therefore, the purpose of this study was to render a more complete understanding of the factors within ones living environment that influence low income, urban dwelling African Americans' engagement in HF self-care behaviors.

Methods

This study utilized a descriptive community-based participatory research design. The photovoice method was used for data collection and analysis. The photovoice method of research is built upon Freire's (1970/1973) theoretical literature on education for critical consciousness. Freire used picture drawings to enable people to think critically about social influences in their everyday life. In the photovoice method, the researcher provides cameras to people in the community so they may visually represent and communicate to others their experiences.²⁴ In a fundamental way, participants serve as the experts on their own lives.

Photovoice is a means of exploration in which photographs provide visual records of what the participant perceives as a benefit or potential problem. The photographs offer visual documentation of what needs to be changed, strengthened, and/or maintained. This can be an environmental concern, health condition, or social issue. Taking photographs facilitates critical dialog (participant discussion and reflection) by helping participants express things that may otherwise be difficult to vocalize. Photovoice studies have revealed culturally-specific information about the African American population's unique health conditions, needs, and assets.^{25–27} This study was approved by the university's institutional review board. The director of the housing authority granted permission to conduct the study within three buildings.

Sample and setting

This study was conducted in a large Midwestern city in which 17% of the residents have incomes at the federal poverty level, and 33% have incomes below the poverty line.²⁸ African Americans comprise 27% of the city's population and 6.5% of the state's population.²⁹ Participants were recruited from three public housing buildings for low income and disabled adults over the age of 55. The residents' average yearly income was less than \$13,537. These

buildings were selected to facilitate participation of chronically ill older adults. Travel was not needed, and the onsite meeting room was familiar, safe, and convenient for the participants. Recruitment was coordinated with case managers employed by the housing authority. Case managers reviewed the onsite health records to identify individuals with a history of HF and discussed the study with these potential participants. The case manager provided names and contact information of interested residents to the primary investigator (PI) who visited residents in their apartments to explain the study. Those who wanted to participate completed the informed consent and demographic questionnaires during this visit. Ten residents participated. Residents were divided into three groups by building. There were two groups of 4 and one group of 2.

Photovoice procedure

Three groups were conducted simultaneously, one at each site. Each group was conducted in the same manner following guidelines for photovoice projects.³⁰ Groups met for six, 2 h sessions. The PI drew from her experience on a previous photovoice study with minority participants to lead the sessions in this study. In the initial session, the PI provided education about safety, power relationships, ethics of taking photos, and how to obtain written consent. Written consent was required when photos were taken of individuals whose faces would be viewable. Prior to taking such photos, participants read off a laminated card that explained the purpose of the study and how the photograph would be used to potential photo subjects. If in agreement, the photo subjects signed a consent allowing the photo to be taken and used in a public display or in a published manuscript. Parental consent was obtained for anyone under the age of 18. Participants were given digital cameras for use during the project. Cameras were returned at the end of the study. The PI gave instruction on camera use and photographic techniques. Weekly photo assignments instructed participants with the following prompts: photograph "images representing what makes you want to, or what makes it easy to take care of yourself and your HF"; "what makes it difficult for you to take care of yourself and your HF"; and "anything else you want to express or feel is important and relates to how you take care of your HF." All photovoice sessions were audiotaped and transcribed verbatim by the PI and research assistant (RA).

At the second through fifth sessions, participants' photographs were downloaded onto the PI's computer and projected on a wall for group discussion. At the beginning of each discussion, the PI invited participants to discuss only what they were comfortable sharing. Initially, the SHOWeD questions were used as prompts to facilitate photo discussion (Box 1).^{26,31} The purpose of the SHOWeD questions is to gather further information on an image and to identify potential solutions to the problems identified.²⁶ However, participants in the first session of the first group had difficulty applying the questions to the photographs taken. For example, when the first questions were posed ("What do you See here? What

Box 1. SHOWeD acronym used for group discussion prompts.

SHOWeD is an acronym for:
 What do you See here?
 What is really Happening here?
 How does this relate to Our lives?
 Why does this situation, concern, or strength exist?
 What can we Do about it?

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