Sociocultural Influences on Heart Failure Self-care Among an Ethnic Minority Black Population

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Background: Heart failure (HF) places a disproportionate burden on ethnic minority populations, including blacks, who have the highest risk of developing HF and experience poorer outcomes. Self-care, which encompasses adherence to diet, medication, and symptom management, can significantly improve outcomes. However, HF self-care is notoriously poor in ethnic minority black populations. Objectives: Because culture is central to the development of self-care, we sought to describe the self-care practices and sociocultural influences of self-care in an ethnic minority black population with HF. Methods: In this mixed-methods study, 30 black patients with HF (mean [SD] age, 59.63 [15] years; 67% New York Heart Association class III) participated in interviews about self-care, cultural beliefs, and social support and completed standardized instruments measuring self-care and social support. Thematic content analysis revealed themes about sociocultural influences of self-care. Qualitative and quantitative data were integrated in the final analytic phase. Results: Self-care was very poor (standardized mean [SD] Self-care of Heart Failure Index [SCHFI] maintenance, 60.05 [18.12]; SCHFI management, 51.19 [18.98]; SCHFI confidence, 62.64 [8.16]). The overarching qualitative theme was that self-care is influenced by cultural beliefs, including the meaning ascribed to HF, and by social norms. The common belief that HF was inevitable (“all my people have bad hearts”) or attributed to “stress” influenced daily self-care. Spirituality was also linked to self-care (“the doctor may order it but I pray on it”). Cultural beliefs supported some self-care behaviors like medication adherence. Difficulty reconciling cultural preferences (favorite foods) with the salt-restricted diet was evident. The significant relationship of social support and self-care (r = 0.451, P = .01) was explicated by the qualitative data. Social norms interfered with willingness to access social support, and “selectivity” in whom individuals confided led to social isolation and confounded self-care practices. Conclusions: Research to develop and test culturally sensitive interventions is needed. Community-based interventions that provide culturally acceptable resources to facilitate self-care should be explored.

KEY WORDS: ethnicity, heart failure, mixed methodology, self-care, sociocultural

Heart failure (HF) places a disproportionate burden on ethnic minority populations, including black or African Americans and Hispanic or Latinos. Blacks have the highest risk of developing HF (4.6%), followed by Hispanics (3.5%) and whites (2.4%).1 Ethnic minority patients also experience poorer outcomes, including higher morbidity and mortality rates, than other populations do.2 Self-care, which encompasses adherence to diet, medication, and symptom management, can significantly improve these outcomes.3 However, self-care is notoriously poor in ethnic minority populations with HF.4,5 In fact, ethnicity has been identified as a predictor of self-care.6 Black patients with HF report lower adherence rates to medication, diet, and symptom monitoring than do whites even after interventions to improve self-care.4,7

The reason for this is unclear. Becker et al8 posited that culture is central to the development of self-care...
strategies among chronically ill ethnic minority groups. However, the influence of culture on self-care behaviors or patient interventions has not been adequately examined in HF populations. In this study, we sought to describe the self-care practices (ie, adherence to diet, medication, and symptom management behaviors) and the sociocultural influences of self-care in an ethnic minority black population with HF. This study had 3 specific aims: (1) to describe the cultural beliefs about self-care, (2) to identify social factors that facilitate or impede HF self-care, and (3) to explore how these sociocultural factors influence self-care practices among blacks with HF.

Conceptual Model

The theoretical framework of naturalistic decision making\(^9\) (Figure) suggests that in real-world settings, people make decisions that are meaningful and familiar to them based upon the interaction between the individual, the problem, and the environment.\(^{10}\) Self-care decisions (eg, dietary choices, medication use, symptom response) are situation and context specific.\(^9\) Beliefs (ie, health beliefs) and social factors (eg, social support and social norms)\(^4,11\) affect self-care decision making primarily through the development of skill, experience, and compatibility of self-care decisions with personal values. Because culture underpins the formation of beliefs, values, and social norms,\(^8\) understanding self-care practices among members of ethnic minority groups with HF necessitates the consideration of sociocultural influences on the decision-making process of self-care. Guided by the naturalistic decision-making framework, this study addressed a critical gap in current knowledge by exploring the cultural beliefs and social factors that influence self-care practices among an understudied ethnic minority population—blacks with HF.

Methods

In this mixed-methods concurrent nested study, qualitative and quantitative data were collected in 1 session that lasted an average of 90 minutes. Qualitative data were collected using a semistructured interview guide to elicit in-depth narrative accounts of self-care practices, identify cultural beliefs about self-care, and uncover social factors that facilitated or impeded self-care. Quantitative data about self-care, perceived social support, and illness-related factors were obtained using standardized instruments and augmented the interpretation of the qualitative findings.

Sample and Setting

After approval from the appropriate institutional review boards was obtained, 30 black adults (age >18 years) with confirmed HF were recruited and enrolled from the HF clinic and inpatient units at a large US urban medical center that provides care to an ethnically diverse population. All participants provided written informed consent and were paid $25 for completing the interview and surveys. The investigation conforms with the principles outlined in the Declaration of Helsinki.

With the use of a purposive homogenous sampling technique, individuals who could provide in-depth accounts of self-care and describe cultural beliefs and social support were enrolled. Individuals were eligible

![Figure](naturalistic_decision-making_model_of_heart_failure_self-care.png)
for participation if they met the following inclusion criteria: (1) self-identified race as black, (2) confirmed HF diagnosis based on echocardiogram or clinical evidence, and (3) able to understand English. Those with a history of prior neurological event that could cause dementia or inability to perform tests (eg, unable to communicate verbally) were excluded. Participants who met the inclusion/exclusion criteria and gave consent to be identified were referred to the research team.

**Quantitative Data Collection and Analytic Procedure**

Standardized instruments with acceptable levels of validity and reliability were used to measure HF self-care, perceived social support, and illness-related factors (New York Heart Association [NYHA] class and physical functioning). Sociodemographic data (age, gender, socioeconomic status, etc) were collected using a self-report survey.

**Self-care**

Self-care was measured using the Self-care of Heart Failure Index (SCHFI V 6.2). The SCHFI ($\alpha = .77$)$^{12}$ contains 17 items measured on a 4-point Likert scale grouped to form 3 scales: maintenance, management, and confidence. Higher scores reflect better self-care. In this study, the Cronbach $\alpha$ values were .67, .56, and .83 respectively.

**Social Support**

Perceived social support was measured using the Multidimensional Scale of Perceived Social Support (MSPSS). The MSPSS assesses the perceived adequacy of social support from family, friends, and significant others. Cronbach $\alpha$ coefficient is reported as .87, .85, and .91 for these scales, respectively,$^{13}$ and were similar in this study ($\alpha = .94, .86, and .92$).

**Illness-Related Factors**

New York Heart Association classification$^{14}$ was collected using a standardized questionnaire with adequate reliability ($\alpha = .75$).$^{11}$ The Duke Activity Status Index (DASI) a measure of physical functioning assesses an individual’s ability to perform a range of specific daily activities and has adequate correlation with functional capacity measures.$^{13}$ Cronbach $\alpha$ in this study was .77.

**Quantitative Data Analysis**

Standard descriptive statistics including means, medians, and ranges were calculated for all of the quantitative variables using SPSS version 15.0. Nonparametric statistical tests were used to protect against skewed data given the small sample size. Correlational analysis using Spearman $\rho$ examined the associations between self-care, social support, and physical functioning. Differences in self-care by NYHA classification were tested using Mann-Whitney $U$ Test.

**Qualitative Data Collection and Analytic Procedures**

An interview guide based on the naturalistic decision-making framework guiding this study consisted of a series of open-ended questions (eg, “tell me about your heart failure”) followed by more direct probes (eg, “what does heart failure mean to you?”). All interviews were tape recorded and transcribed verbatim. Accuracy of transcription was confirmed at 100%. Field notes by the interviewer supplemented the tape-recorded interviews.

Qualitative interview data were analyzed using Atlas.ti version 6.0. Preliminary analysis of interview transcripts entailed a line-by-line review that yielded clusters of data labeled into brief headings. Codes were derived from these data then summarized across cases to yield a rich descriptive analysis. Finally, emerging themes both within and across coding categories were identified. Methodological rigor was maintained through an audit trail, periodic peer debriefing, and member checking that supported the credibility of the study.

**Integration of Qualitative and Quantitative Data**

Qualitative and quantitative data were integrated in the final analytic phase. Using triangulation methods, qualitative evidence of self-care and social support was compared with the scores on the SCHFI and MSPSS, respectively. The accounts of self-care created an anchor for the next step of analysis, which entailed examining themes related to cultural beliefs and social support within the context of self-care. An informational matrix was developed to compare and contrast the emergent qualitative themes and the quantitative evidence of self-care and social support across the cases.

**Results**

The demographics and clinical characteristics of the sample of 30 black adults with HF (mean [SD] age, 59.63 [15] years; 60% male; 67% NYHA class III) are shown in Table 1. Physical functioning of the sample was moderately impaired (mean [SD] DASI, 16.80 [14.32]).

Self-care was very poor (standardized mean [SD] SCHFI maintenance, 60.05 [18.12]; SCHFI management, 51.19 [18.98]; SCHFI confidence, 62.64 [18.16]). Few (<25%) engaged in adequate self-care (≥70 on SCHFI subscales).$^{12}$ There were no significant relationships between age, length of time with HF diagnosis, and self-care. No differences were found in self-care by NYHA class.
Although 60% of the sample were single, they reported adequate social support (mean [SD] MSPSS total score, 5.25 [1.33]), defined as a score higher than the midpoint of 3.5 (Table 2).13 There was a significant relationship between social support and self-care maintenance \((r = 0.483, P = .008)\) and self-care confidence \((r = 0.384, P = .04)\). Table 3 shows the correlational analysis results of self-care, social support, and physical functioning.

### Qualitative Results

The narrative accounts of self-care revealed that overall self-care was poor and engagement in self-care varied by specific behavior. Individuals described lack of adherence to diet and symptom monitoring but good adherence to the medication regimens. Only 2 individuals engaged in self-care management of symptoms (ie, diuretic titration) typically prescribed for patients with HF. The overarching theme in the qualitative data analysis was that self-care in this ethnic minority sample was influenced by cultural beliefs, including the meaning ascribed to HF, and social norms. Examples of key themes are presented in Table 4.

### The Meaning of Heart Failure Influences Self-care

There was a common belief that HF was inevitable ("all my people have bad hearts") or attributed to "stress." This cultural belief influenced how individuals engaged in both self-care maintenance and how they interpreted and responded to their HF symptoms. Cultural beliefs supported some self-care behaviors like medication adherence, which was deemed essential ("for a long life…I take the pills"). Conversely, many expressed difficulty reconciling cultural preferences (favorite foods) with the salt-restricted diet ("our food is bad…I can’t give it up"). Because HF symptoms were seen as induced by stress or as inescapable, maintaining a low-salt diet was not recognized as important or valuable to HF self-care.

Similarly, self-care management was influenced by cultural beliefs and the attribution of HF to either stress or genetics. Consistent with this cultural meaning of HF, common symptoms were identified as "too much pressure" or "losing breath." Rather than monitoring for symptoms objectively by daily weights or assessing ankle edema, symptom monitoring was described as "body listening." Symptom management entailed strategies aimed at either reducing stress or enduring the symptom ("when it comes…just relax, that’s all I can do"). Unfortunately, this method of self-care management, although consistent with cultural beliefs, was rarely effective. The delay in symptom management led most to routinely access the emergency room for worsening symptoms.

### Spirituality Shapes Self-care

Spirituality emerged as an important cultural belief that helped shape self-care practices. Intrinsic spirituality was evident in the use of prayer to guide actions and the belief that God will "provide all that is needed." For others, extrinsic spirituality, described as religious affiliation or church attendance, enabled self-care that was perceived as "doing what the doctor says.”

### Social Norms Drive Social Supports

Another important theme that emerged in the qualitative analysis was the critical role that social supports and social norms play in daily self-care practices. Individuals described varying levels of tangible and emotional social support. Tangible support by family with self-care maintenance behaviors (eg, low-salt meal preparation) as well as other activities of daily living was influenced by social norms.

The availability of robust tangible social supports included financial assistance for medications and healthcare access that supported adherence to medication treatment ("the pills are free") and drove self-care

### Table 1 Demographics and Clinical Characteristics (n = 30)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean (SD)</th>
<th>Median (Range [Minimum-Maximum])</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>59.63 (15.19)</td>
<td>61.5 (26–98)</td>
</tr>
<tr>
<td>Years with HF</td>
<td>5.33 (7.03)</td>
<td>5.0 (0.5–31.3)</td>
</tr>
<tr>
<td>Physical functioning (DASI)</td>
<td>16.80 (14.32)</td>
<td>13.45 (0–58.20)</td>
</tr>
</tbody>
</table>

### Table 2 Social Support (n = 30)

<table>
<thead>
<tr>
<th>Support Category</th>
<th>Mean (SD)</th>
<th>Median (Range [Minimum-Maximum])</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>5.42 (1.65)</td>
<td>6.0 (1–7)</td>
</tr>
<tr>
<td>Friends</td>
<td>4.50 (2.01)</td>
<td>5.25 (1–7)</td>
</tr>
<tr>
<td>Significant others</td>
<td>5.78 (1.4)</td>
<td>6.0 (1.75–7)</td>
</tr>
<tr>
<td>Total</td>
<td>5.25 (1.33)</td>
<td>5.58 (2–7)</td>
</tr>
</tbody>
</table>

Abbreviations: DASI, Duke Activity Status Index; HF, heart failure; NYHA, New York Heart Association.
management of symptoms (“just go to the clinic”). Importantly, these resources were deemed acceptable to the group.

Adequate emotional support was limited for many and clearly influenced by social norms. A prevalent theme in this population was “selectivity” in whom individuals confided in about their diagnosis and HF symptoms. In cases where a designated confidante was not accessible (eg, in a different country or had “their own problems to deal with”), individuals described feeling alone and isolated. Men reported that they “carried the burden,” a social norm that precluded seeking help. Social isolation was compounded when individuals were unable to continue to participate in culturally based social activities and reluctant to ask for support.

Integrated Data

There was 97% concordance between the SCHFI scores and narrative accounts of self-care and 94% concordance between MSPSS scores and qualitative data regarding social support resources. When the data were integrated, the reason why self-care was so poor in this sample was clarified. Although most of the sample (60%) reported low socioeconomic status, individuals described adherence to taking medication regularly that was supported by cultural beliefs that medication was “essential to live a long life” and facilitated by tangible social resources that were acceptable within the social norms. Conversely, individuals struggled with integrating dietary restrictions into daily routine owing to cultural food preferences (“Island food...no good for the heart...but good for the soul”), especially when social norms regarding meal preparation was a barrier.

The qualitative data explained why only 16.7% of individuals had adequate self-care management (≥70 on the SCHFI self-care management scale). Those with adequate self-care management scores described monitoring symptoms by tracking daily weights and titrating diuretic medication as consistent with “doing what the doctor said.” However, for many in the sample, the belief that HF symptoms were caused by stress or were inevitable meant a passive approach (eg, “stay in bed,” “relax...let it pass”) even though they recalled receiving instructions in self-care such as monitoring daily weights.

Although most in this sample were only moderately impaired in physical functioning as measured by the DASI, narratives revealed that they were limited in their ability to engage in social activities, which led to social isolation. The significant quantitative association of social support measured by the MSPSS and self-care maintenance (r = 0.483, P < .01) was also explicated by the qualitative data. Social norms (“we don’t ask for help”) interfered with willingness to access tangible or emotional support resources, especially when the family was scattered, and ultimately influenced self-care practices.

Discussion

To our knowledge, this is the first study to look at how sociocultural factors influence self-care among ethnic
minority black patients with HF. Although we have long believed that cultural food preferences make it difficult for many patients with HF to adapt to a low-salt diet, this study provided insight into why current education initiatives may be ineffective. This population struggled with reconciling food preferences with diet adherence for several reasons. For many, cultural food was an integral part of one’s ethnic identity and there were clear social norms around food preparation and participating in meals. The “distaste” for food other than cultural favorites was also barrier. These findings are consistent with the extant literature examining culture and diet adherence. None of the subjects in our study reported receiving any advice on how to adapt recipes that might result in low-salt alternatives. This finding supports the situation-specific theory of self-care, which is based on the naturalistic decision-making theoretical framework that guided this study. Specifically, according to the situation-specific theory of self-care, to adhere to the low-salt diet recommendations, patients with HF must have the skill to prepare low-salt meals and there must be compatibility with one’s values. That is, the diet choices should be perceived as important and beneficial to be embraced. Oneenez et al reported similar themes in their grounded theory of secondary heart prevention. Although medication adherence was supported by cultural beliefs, benefits of lifestyle changes that included diet modification were met with skepticism and therefore not enacted.

The findings of this study are also generally consistent with the theory of naturalistic decision making. Individuals described making decisions in real-world settings that were influenced by their environment and its available resources. These real-world decisions especially around symptom management were often described as ambiguous or met with uncertainty, which is consistent with the premises of the naturalistic decision-making framework. The influence of multiple players in the self-care decisions was also apparent as individuals described the role that social factors played in self-care decisions. It was clear from the narratives that cultural beliefs influenced decision making directly through compatibility of the prescribed self-care behavior with one’s values but also indirectly. That is, cultural beliefs and social norms influenced how individuals developed skill and experience or, among this population, failed to develop skill and lacked experience in self-care decision making. According to the naturalistic decision-making theory, the key to effective decision making is experience. Naturalistic decision makers use prior experience to identify similarities of the current problem with a past situation. Use of experience that includes recollection of cues and expected outcomes guides decision making in the situation at hand. The sample in this study lacked experience in effective self-care behaviors. Nonetheless, decisions were driven by experience that included recognizing when to access emergency care and seemed to be guided by the individual’s expectations that were based upon the cultural meaning of HF.

Stress as a primary etiology of HF, along with the inevitability of HF reported in our study, is consistent with other studies exploring ethnic minority groups with coronary heart disease. However, the lack of active symptom management practices in this sample was alarming. In our prior work, we identified that individuals struggle with symptom recognition and management because of lack of knowledge, impaired symptom perception, and lack of experience in managing symptoms. Our finding that the meaning of HF, with its cultural roots, plays a significant role in how individuals recognize and manage symptoms reflects the anthropological lens that “illness is culturally constructed.” Explanatory Model of Illness suggests that illness behaviors including how individuals perceive, experience, and cope with an illness is strongly influenced by social norms and cultural rules. The participants in our study perceived and labeled symptoms in terms of the cultural meaning of HF, for example, as “losing breath” and “tiring out.” They monitored symptoms accordingly using “body listening” tactics. This finding expands upon our previous work that conceptualized “body listening” as the individualized way of recognizing unique and often vague symptoms of worsening HF by adding a previously missing cultural dimension.

Our results regarding spirituality are consistent with others who have studied self-management by ethnic minority populations with chronic diseases. Harvey and Silverman found differences by race in how older adults use spiritually in self-management of coronary heart disease. African Americans were more likely to endorse the belief that God was in control of their life and worked directly through healing as well as through their physicians providing care. Similarly, Mansfield et al found that African Americans create a belief system that is grounded in “divine intervention” with God as healer and physicians as facilitators. This culturally based belief system enabled individuals to understand and take control of their illness experience. According to Polzer and Miles, when individuals consider the role of God to be that of healer, a more passive role in illness management is likely. In our study, there was evidence of intrinsic spirituality, which others have defined as the belief that a higher power exists as well as extrinsic spirituality that shaped self-care practices. Participants used prayer to guide some self-care decisions and at times looked to a “higher power” to intervene. Our mixed-methods design that included quantitative
measures of self-care adds to this important body of literature by elucidating how self-care as measured by the SCHFI is influenced by spirituality.

The importance of social support to HF self-care has been defined as the provision of emotional and tangible resources by lay caregivers including patient partners, children, siblings, and neighbors that enables patients to engage in better HF self-care. Our study extends what is known by providing insight into another dimension of social support—social norms and the critical influence social norms play in accessing social support and practicing self-care. Although the importance of social norms and health behaviors is well established, very few studies have examined social norms in HF self-care. In a systematic review of the literature, Gallant described the relationship of social support and chronic illness self-management. Interestingly, they reported a 2-way causal relationship of social support and self-management that was influenced by social norms. In a sample of adults with diabetes, healthy diet and fitness trends that were perceived positively among social contacts supported diabetes self-management behaviors. Conversely, food-related social norms negatively influenced self-management when individuals were reluctant to “draw attention” to special dietary needs. In another study, patients with asthma who were unable to manage negative social situations among peers and family purposively limited those social interactions. These findings echo our results that social norms have potent effects on self-care. When shared social norms precluded access to social support either in terms of a reluctance to be seen as ill among peers or as interfering with self-care, social situations were avoided. Unfortunately, in our population, this resulted in social isolation for many.

The current literature also supports our finding that the influence of social support on self-care may be behavior specific. That is, when a specific behavior is socially constructed within a culture (eg, diet/meals), the influence of social norms is greater than that of individual behaviors like medication adherence. Further investigation within and across cultures is indicated.

Limitations

We acknowledge several limitations to this study. The small sample size of urban-dwelling black individuals prevents generalization to other ethnic minority populations and limited quantitative analysis. Although 33% were born outside the United States, most had been in the United States since childhood or as young adults and spoke English sufficiently to obtain consent. Therefore, some degree of acculturation may have taken place. Examination of these findings in a larger sample with a measure of acculturation would add to our findings. The sample lived in a setting with access to robust social services and healthcare resources. Exploration in a rural-dwelling ethnic minority black population where healthcare access is not convenient is indicated. Finally, our sample had very poor self-care. It would be interesting to examine these themes in a sample with more variance in self-care and over time to characterize the contribution of cultural beliefs and social norms to self-care–related health outcomes. Further study of a larger sample of blacks with HF but with more variance in self-care is also indicated to examine the relationship of factors (eg, age, length of time with HF) typically associated with HF self-care.

Conclusions

Our findings that sociocultural factors influence HF self-care among a minority population help explain why self-care is notoriously poor in certain groups. Globally, much of the HF self-care education has been constructed and is delivered by the dominant culture. The lack of culturally acceptable interventions may impede the uptake of self-care behaviors especially when there is a perceived lack of fit with cultural beliefs. Consideration of cultural beliefs including spirituality and social norms by healthcare providers is essential to HF care. A discussion of the meaning of HF, cultural food preferences, and assessment of social support that extends beyond tangible resources is recommended. As the prevalence of HF worldwide continues to rise, research to develop and test culturally sensitive interventions is critically needed, especially because minority populations continue to experience poor outcomes. Community-based interventions (eg, cultural groups or faith-based) that reduce social isolation and provide acceptable social support resources to facilitate self-care among ethnic minority individuals with HF should be explored.

REFERENCES


