# Original Reports: Cardiovascular Disease and Risk Factors

# HOW DO DEPRESSIVE SYMPTOMS INFLUENCE SELF-CARE AMONG AN ETHNIC MINORITY POPULATION WITH HEART FAILURE?

**Objectives:** Depression is very common in patients with heart failure (HF). However, little is known about how depression influences self-care (ie, adherence to diet, medication and symptom management behaviors) in ethnic minority patients with HF. The purpose of this study was to explore the meaning of depression and how depressive symptoms affect self-care in an ethnic minority Black population with HF.

**Design:** In this mixed methods study, 30 Black patients (mean age  $59.63~SD~\pm15~years; 60\%~male)$  participated in in-depth interviews about HF self-care and mood; and completed standardized instruments measuring self-care, depression, and physical functioning. Thematic content analysis was used to explore the meaning of depression and elicit themes about how depressive symptoms affect daily self-care practices. Qualitative and quantitative data were integrated in the final analytic phase.

Results: Self-care was very poor in the sample. Forty percent of the sample had evidence of depressive symptoms (PHQ-9≥10; mean 7.59 ± 5.29, range 0 to 22). Individuals with depressive symptoms had poorer self-care (P=.029). In the qualitative data, individuals described depressive mood as "feeling blue... like I failed." "Overwhelming" sadness and fatigue influenced self-care and resulted in treatment delays. For many, spirituality was central to coping with sadness. Few discussed depressive feelings with health care providers.

**Conclusions:** Depression in ethnic minority patients with HF may be difficult to assess. Research to develop and test culturally sensitive interventions is critically needed, since

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depression influences self-care and minority populations continue to experience poorer outcomes. (Ethn Dis. 2013;23[1]:22–28)

**Key Words:** Heart Failure, Self-Care, Depression, Ethnicity

#### Introduction

Heart failure (HF) is the end stage condition of many cardiovascular diseases and a leading cause of morbidity and mortality worldwide. Ethnic minority groups are disproportionately burdened by HF as they experience higher prevalence rates and poorer outcomes including high rates of hospitalization and increased mortality.<sup>2</sup> According to the American Heart Association, among non-Hispanic Blacks aged >20 years, 4.5% of men and 3.8% of women have HF compared to 2.8% of general population. Heart failure is managed by a combination of clinician supervision and patient self-care. Self-care, which is a process of maintenance and management behaviors that encompasses adherence to treatment regimens and symptom management,3 is extremely poor in ethnic minority populations with HF. 4,5 In fact, race has been identified as a predictor of self-care.<sup>6</sup> The reason for this is not entirely clear but we have found that cultural beliefs and social norms may be factors.<sup>7</sup>

Depression that occurs in a significant portion of the population with HF has also been linked to poor clinical outcomes. <sup>8,9</sup> Nearly two-thirds to three-quarters of patients with HF experience some depressive symptoms. <sup>10</sup> About 35% of these patients report high levels of depression; and 25% to 35% of

patients report mild to moderate depressive symptoms. Worsening depressive symptoms have been shown to be associated with death or cardiovascular hospitalization after controlling for baseline depression measured by the Beck Depression Inventory (baseline BDI HR: 1.1, 95% CI: 1.06 to 1.14, P<.001).<sup>8</sup> Further, depression may be more common in certain ethnic minority groups with HF.<sup>11</sup> In our study, we sought to explore the relationship of depression and self-care among an ethnic minority Black population with HF.

In the general HF population, depression is associated with poor self-care, which is the cornerstone of HF management. One explanation is that depression may affect patients' willingness and ability to engage in the adherence and symptom management behaviors of self-care due to impaired cognition, low energy, and lack of motivation. <sup>12</sup> As a result of poor self-care, there are increased symptoms. For example, Rathman and colleagues <sup>13</sup> found that patients who reported better HF self-care were less likely to experience episodes of fluid

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accumulation, commonly associated with worsening HF symptoms. There is also compelling evidence that better selfcare is linked to improved quality of life presumably due to better functional status.<sup>14</sup> Conversely, in a study of 522 patients with HF, nonadherence to medication and dietary regimens was associated with poor perceived health and explained largely by the presence of depressive symptoms. 15 Generally, depressed patients with chronic illness report enhanced symptom burden, 16 which in HF patients has been hypothesized to interfere with ability to recognize and respond to symptoms when they occur.17

Unfortunately, given the health disparities associated with HF, most of the research in self-care has been conducted in Caucasian populations. This gap in the literature is particularly important because recent studies have reported that ethnic minority persons with HF are more likely to be depressed than Caucasians<sup>11</sup> and are often underdiagnosed.<sup>18</sup> Most studies that have examined depression in ethnic minority patients with HF have been observational and lack a cultural lens. According to Kleinman, 19 culture influences how individuals manifest and communicate depressive symptoms as well as their style of coping. Therefore, it is important to examine how ethnic minority patients with HF describe depression and cope with symptoms including family and social supports and willingness to seek treatment.

The purpose of this mixed method study was to explore the meaning of depression among an ethnic minority black population with HF and to describe how depressive symptoms influence selfcare in this understudied population.

#### **METHODS**

This study used a mixed methods concurrent nested design in which qualitative and quantitative data were collected in one session. Since the primary aims were exploratory, the qualitative data were prioritized and quantitative data were used to describe the sample and measure depressive symptoms. In one data collection session that lasted an average of 90 minutes, qualitative data were collected using a semi-structured interview guide to elicit in-depth narrative accounts of self-care practices, mood and uncover how emotional factors facilitated or impeded selfcare. Quantitative data about self-care, depression, and illness-related factors known to be associated with depression and self-care (ie, physical functioning, sleepiness, and New York Heart Association class) were measured using standardized instruments and augmented the interpretation of the qualitative findings.

#### Sample and Setting

Thirty self-identified Black adults (aged >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 were fully informed of the study and provided written informed consent to participate in the study and audiotaped interviews. Individuals received a non-coercive incentive of \$25 for their participation. The investigation conformed to the principles outlined in the Declaration of Helsinki<sup>20</sup> and was approved by the appropriate institutional university and hospital review boards.

A purposive homogenous sampling technique was used to enroll individuals who could provide in-depth accounts of self-care and describe cultural beliefs about their HF. Inclusion criteria for participation were: 1) self-identified race as Black; 2) confirmed HF diagnosis based on echocardiogram or clinical evidence; and 3) able to understand English. Individuals with a history of prior neurological event (eg, stroke) that could cause dementia, or inability to perform tests, were excluded.

# Qualitative Data Collection and Analysis

Qualitative data collection was directed by a semi-structured interview guide that consisted of a series of open-ended questions followed by more direct probes. A research assistant trained in qualitative interviewing began each interview with general inquiry (eg, "tell me about your heart failure") and progressed through a set of questions meant to elicit accounts of daily self-care practices ("tell me about a typical day") and mood ("how do you feel..."). Using the individual's description of mood, additional probes were used to elicit a more in-depth meaning of mood including "what does <that> feel like." 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. Data collection continued until saturation was achieved,<sup>21</sup> which occurred with a sample size of 30.

Qualitative interview data were analyzed using Atlas.ti version 6.2. Preliminary analysis of interview transcripts entailed a line-by-line review that yielded clusters of data labeled into brief headings of self-care and mood. Codes derived from this data were examined and 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 and periodic peer debriefing with experts in HF and minority population research that supported the credibility of the study.<sup>22</sup>

# Quantitative Data Collection and Analysis

Standardized instruments with acceptable levels of validity and reliability were used to measure HF self-care, depression, illness related factors (physical functioning and sleepiness) and New York Heart Association (NYHA) classification. Sociodemographic data including age, sex and socioeconomic status

were collected using an investigatordeveloped self-report survey.

Heart failure self-care was measured using the Self Care of Heart Failure Index (SCHFI V. 6.2). The SCHFI<sup>23</sup> contains 17 items measured on a 4-point Likert scale grouped to form three scales: maintenance, management and confidence. Scores on each scale are standardized to 100. Higher scores reflect better self-care. In this study the Cronbach alpha were .67, .56 and .83 respectively.

Depression was measured using the Patient Health Questionnaire (PHQ-9), a reliable and well-validated tool used in medical populations.<sup>24</sup> The PHQ-9 consists of nine statements of depressive symptoms (eg, feeling down, depressed, hopeless). Responses ranged from 0 to 3 with response categories including 'not at all,' 'several days,' 'more than half the days,' and 'nearly every day.' Items are scored for a total that can range from 0 to 27. A cut-off score of  $\geq$  10 on the PHQ-9 has a sensitivity of 95% and specificity of 84% for major depressive disorder as defined by the DSM-IV.<sup>25</sup> The PHQ-9 reliability was adequate (Cronbach's alpha = .79) in this sample.

The Duke Activity Status Index (DASI) was used to measure physical functioning. The 12 items on the scale represent major aspects of physical function (eg, personal care, ambulation, household tasks) and has adequate correlation with functional capacity measures. Participants rate how much their health affects the ability to perform each of the 12 activities. Cronbach's alpha in this study was .77.

#### New York Heart Association

New York Heart Association classification is based on physical limitation due to cardiac symptoms: no physical limitations, slight limitation of physical activity, marked limitation of physical activity and physical limitations even at rest. <sup>27</sup> In this study NYHA class was assessed using a standardized questionnaire with adequate reliability  $(\alpha = .75)^{28}$  and used to describe the sample.

Table 1. Demographic and clinical characteristics of study population

	Mean ± Standard Deviation		
Age, years	59.63 ± 15.19		
Years with HF	$5.33 \pm 7.03$		
Depression (PHQ-9)	$7.59 \pm 5.29$		
Physical Functioning (DASI)	$16.80 \pm 14.32$		
	n (%)		
Male	18 (60)		
Married/ cohabitate	12 (40)		
Single, divorced, widowed	18 (60)		
Has someone to confide in	24 (80)		
Highest education			
Less than high school	14 (46.7)		
High school	6 (20)		
College	10 (33.3)		
NYHA			
Class II	10 (33.3)		
Class III	30 (66.6)		

HF, heart failure; PHQ-9, Patient Health Questionnaire-9; DASI, Duke Activity Status Index; NYHA, New York Heart Association.

Standard descriptive statistics including means, medians and ranges were calculated for all of the quantitative variables using SPSS version 18.0. Correlations between self-care, depression and the illness-related factors were analyzed using appropriate nonparametric statistical tests to protect against skewed data given the small sample size.

### 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 depression were compared to the scores on the SCHFI and PHQ-9, respectively. There was 95% concordance between the self-care quantitative and qualitative data; and 85% concordance between the qualitative descriptions of mood and PHQ-9 scores. The accounts of self-care created an anchor for the next step of analysis, which entailed examining themes related to mood and within the context of self-care. An informational matrix<sup>29</sup> was developed to compare and contrast the emergent qualitative themes and the quantitative evidence of self-care and mood across the cases.

#### RESULTS

The study population (N=30) was 60% male, with mean age 59.63 ( $\pm$  15.19). A third (n=10) were born outside of the United States and about half reported attaining a high school diploma (mean years 10.93 years). Interestingly, although the majority of this sample was single or lived alone; most (80%) reported that they had a confidant. Table 1 shows the demographic and clinical characteristics of the sample.

Generally, self-care was very poor in the sample (standardized mean SCHFI maintenance 60.05 ± 18.12; SCHFI management 51.19 ± 18.98; SCHFI confidence 62.64  $\pm$ 18.16). Few (< 25%) engaged in adequate self-care (≥ 70% on SCHFI subscales). Women reported better self-care maintenance than men; but no significant difference in self-care management or self-care confidence. Forty percent of the sample had evidence of depressive symptoms (PHQ-9≥10; mean  $7.59 \pm 5.29$ , range 0 to 22), yet none reported taking medication for depression. Older participants (>62 years) reported greater depressive symptoms as did those with NYHA class III. There were no significant differences

Table 2. Differences in self-care, depression and physical functioning by sex, age and NYHA classification

	Sex M F	Age <62 Years ≥62 Years	NYHA Class II III
Self-Care Maintenance	$-2.150^{a}$ ( $P=.045$ )	.430 (P=.671)	.024 (P=.981)
Self-Care Management	-1.789 ( <i>P</i> =.084)	.615 (P=.546)	-1.562 ( $P=.136$ )
Self-Care Confidence	-1.080 ( $P=.294$ )	-1.415 (P=.168)	1.159 (P=.257)
PHQ-9: Depressive Symptoms	395 ( <i>P</i> =.696)	2.147 <sup>a</sup> (P=.041)	$-2.477^{a}$ ( $P=.02$ )
DASI: Physical Functioning	1.927 (P=.065)	-1.146 ( $P$ =.262)	1.714 (P=.098)

<sup>&</sup>lt;sup>a</sup> t-test is significant at P < .05.

PHQ-9, Patient Health Questionnaire-9; DASI, Duke Activity Status Index; NYHA, New York Heart Association.

in depressive symptoms or physical functioning by sex or socioeconomic status characteristics (Table 2). However, there was a significant negative correlation between depression and physical functioning (r=-.418, P=.02). Individuals with depressive symptoms also reported poorer self-care management (P=.029).

#### Qualitative Data Results

The qualitative data revealed three themes related to mood, mostly depressive symptoms in this population. First the meaning of depression among these individuals was described in terms of a personal feeling. Depressive mood was described as "feeling blue...like I failed." Rather than using the term depression, individuals described feeling overwhelmed with sadness and lacking energy that influenced their activities of daily living including self-care. For example, one women described, "when the blues come, I stay in bed and wait for it to pass. I don't do anything...the pills don't work; why take them...some times it doesn't pass..."

A second theme revealed how individuals coped with these feelings. For many, spirituality was central to coping with sadness ("I leave it with God") with prayer articulated as central to managing the "overwhelming sadness."

Selectivity was a third important theme that emerged in the narrative accounts. In our sample, individuals were very selective in whom they entrusted with these feelings. They trusted specific social supports as confidants and rarely admitted feelings to health care providers ("I don't tell them everything").

#### **Integrated Data Results**

The integrated data provided additional insight into how mood might be influencing self-care in this population. Specifically, the relationship of mood and self-care maintenance of adherence to diet and exercise was explained in the qualitative data as lack of energy to prepare meals or engage in exercise ("...just can't do it..."). Mood also seemed to influence medication adherence, which was poorer on the SCHFI question among those with depressive symptoms.

The relationship of mood and self-care management was even more potent. The qualitative data regarding mood helped explained why only 16.7% of individuals had adequate self-care management (≥70 on SCHFI self-care management scale). When individuals felt sad or blue, they reported staying in bed; there was inaction on the part of individuals who reported "feeling

The finding that not one individual [in our study group] was taking antidepressant medication suggests that depression may be underdiagnosed or inadequately treated.

blue." Rather than taking action to ameliorate worsening symptoms of HF like fatigue, shortness of breath or fluid retention, those with depressive symptoms more often described "taking to bed" and "waiting it out." These individuals delayed treatment until symptom exacerbation prompted an emergency response.

#### **DISCUSSION**

The results of this mixed methods study provide important insight into the relationship of depression and self-care in an ethnic minority population with HF. In our study, 40% had evidence of depressive symptoms, which is consistent with the literature that reports prevalence estimates of 24-42%.8 The finding that not one individual was taking anti-depressant medication suggests that depression may be underdiagnosed or inadequately treated. Others have reported similar results.<sup>30</sup> In a large study of adult primary care patients (n=19,309) and health care providers (n=349), physicians were less likely to detect mental health problems in African Americans (odds ratio, .63) than White counterparts. 18 Further, in the general population, ethnic minority patients with depression are less likely to receive clinical treatment 31 or even seek treatment for depressive symptoms.<sup>32</sup> In a systematic review of the literature. Das et al concluded that African Americans face

barriers in the recognition and treatment of major depression including clinical presentation (ie, somatization), stigma about diagnosis and complexity related to comorbid conditions. Although these conclusions were not specific to patients with HF, they reflect our findings that an individual's manifestation and interpretation of depressive symptoms is important and may contribute to clinical diagnosis and likelihood of treatment.

Specifically, the cultural meaning of depression<sup>19</sup> as how individuals talk about mood, interpret and react to feelings was examined in our study. Feeling tired or having little energy are the most commonly reported depressive symptom reported by patients with HF.<sup>33</sup> In our sample, individuals with HF used specific words to describe depressive symptoms (eg, "feel blue") and their interpretation of symptoms as "no energy" may have interfered with seeking treatment. According to Kleinman, illness is culturally shaped. That is, how individuals perceive, experience and cope with illness is based on their explanation or meaning for that illness.<sup>34</sup> Our findings are consistent with anthropological researchers who describe illness behavior as a normative experience that is governed by cultural rules. Individuals described selectivity in whom they confided or trusted with their feelings of sadness as well as the culturally acceptable rules for "waiting for it to pass".

Individuals in our sample described coping with depressive feelings mostly by accessing social supports. As is typical of the African American culture, our sample identified specific individuals in whom they confided. These individuals included family members (spouses, children, parents) as well as friends. Generally, these significant others were members of the same culture and rarely members of the health care community. As noted above, individuals were very selective in whom they shared any personal feelings, espe-

cially mood. This theme of selectivity is a new finding in the HF literature. Evangalista and colleagues<sup>11</sup> have reported previously that having someone to confide in influences coping. They suggested that having a confidant serves as a form of social support to counteract unhealthy behaviors as well as cope with anxiety and depression.

Spirituality was also central to coping with depressive feelings in this sample. An emergent theme in our study, "Turning it over to God," has been described as a coping mechanism among African American groups, most commonly low income, less educated, members of fundamentalist Christian faiths, elderly, and living in the southern United States.<sup>35</sup> Our sample shared a few of these characteristics as they were predominately low socioeconomic status, few had a high school education and most reported having cultural roots in the South. Interestingly, empirical studies have found that spirituality wellbeing as a coping mechanism is associated with less depression.<sup>36</sup> But this relationship has not been examined in HF populations experiencing depression where turning over control of illness even to a higher power may delay treatment.

In our quantitative analysis, we found a significant relationship between depression and self-care, which is consistent with the current literature on HF self-care. 12 A meta-analysis of adherence and chronic illness that included patients with HF found that depressed patients were three times more likely to be nonadherent than nondepressed patients. 37,38 Further, the COACH study, a large multi-site randomized control trial that tested the effectiveness of disease management for patients with coronary heart disease, examined depression and consulting behaviors and found patients with depressive symptoms delayed seeking treatment.<sup>39</sup> The integrated qualitative and quantitative data in our mixed methods study adds to the existing literature by elucidating

the complexity of the relationship of depression and self-care among an ethnic minority population with HF. Others have hypothesized that depression influences self-care by decreasing motivation to engage in self-care or by lack of energy<sup>38</sup> that makes self-care difficult in the absence of social supports. Our findings extend these hypotheses. Lack of motivation described by some in our sample as "why bother" was linked to limited engagement in daily maintenance behaviors of medication adherence and symptom monitoring during depressive episodes. In addition, our results suggest that culturally-driven illness behaviors when feeling depressed (eg,"taking to bed"), may be even more important in this ethnic minority population and help explain poorer outcomes. Unfortunately in patients with HF, depression that delays a timely response to HF symptoms although consistent with cultural rules of "waiting for it to pass" can be life-threatening.

Finally, we learned that depressive symptoms coupled with limited physical functioning due to HF symptoms led to social isolation. As a result, individuals were unable to access important resources both to cope with depression and engage in self-care. This is an important finding since social isolation independent of demographics and clinical status has been identified as a predictor in HF mortality. 40 Simply, the number of people an individual can ask for support is a predictor of survival. Further, social isolation increases the risk of developing depression.<sup>41</sup> In this study, individuals described social isolation and worsening depressive symptoms that prevented them from accessing culturally-acceptable social supports. Combined, these factors may contribute to health disparities experienced by ethnic minority patients with HF.

#### Limitations

A limitation to this study was the small sample size of urban-dwelling Black individuals that prevents generalization to

other ethnic minority populations. The sample was adequate for the qualitative data analysis since saturation was achieved but limited quantitative analysis. Another limitation may be that the sample was recruited from a HF clinic associated with a health care system that provides robust services including mental health and social services. Therefore, it is possible that individuals may have received care from other providers so a review of medical records would augment findings in terms of describing history of depression and perhaps explaining the lack of anti-depressants. Exploration in a rural-dwelling ethnic minority population where health care access is not convenient is also needed.

Finally, this sample had very poor self-care, which was somewhat surprising since all participants had exposure to standard patient education during the course of clinical care. Directionality, the relationship between depression and HF, was not an aim of this study. So, exploration in a larger sample with more variance in self-care and over time is warranted in order to better understand the causal relationships in this population.

#### Conclusions

Our results suggest that depression in ethnic minority patients with HF may be difficult to assess using our standard clinical language. Since depressive symptoms may vary over the course of HF illness, assessment of depression should be part of clinical practice but assessed with a measure of cultural sensitivity. In addition, efforts by clinicians to support coping mechanisms among ethnic minority populations are indicated. This will necessitate adding questions to a clinical interview that assess availability of someone to confide in. Our results along with the extant literature on spirituality, also suggest that inquiring about spirituality may be important in this population. Since depression influences self-care and minority populations continue to experience poorer outcomes, research to develop and test culturally sensitive interventions is critically needed.

#### **ACKNOWLEDGMENTS**

This study was funded by a New York University Research Challenge Fund award.

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