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## Mediation by Fatalism of the Association Between Symptom Burden and Self-care Management in Patients with Heart Failure

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### Introduction

Globally, 26 million people suffer from heart failure (HF).<sup>1</sup> In the United States, approximately 6.7 million adults over the age of 20 suffer from HF, and its prevalence is expected to reach more than 8 million by 2030.<sup>2,3</sup> The total medical costs associated with HF are projected to rise from \$30.7 billion to \$69.8 billion by 2030, which is equivalent to \$244 for every American adult.<sup>2,3</sup> Hospital admission, as well as its associated costs, is often the result of patients seeking care for escalating symptoms such as dyspnea.<sup>4,5</sup> However, even with advancements in the treatment of HF, management of symptoms by patients (i.e., self-care management) and clinicians, a critical aspect of HF treatment, is difficult.<sup>6</sup>

Symptom burden, which includes the burden of physical and psychological symptoms, is a significant problem for patients with HF.<sup>7</sup> Symptom burden refers to the number of subjectively quantifiable symptoms that adversely affect patient health and lead to multiple negative, physical, and emotional consequences.<sup>8</sup> Physical and psychological symptoms, including dyspnea, fatigue, pain, orthopnea, edema, loss of appetite, anxiety, and depression are widely reported among patients with HF.<sup>9</sup> These symptoms can significantly interfere with a patient's ability to perform daily activities. Furthermore, in a dose-dependent manner, untreated symptoms are associated with an increased likelihood of clinical events, such

as emergency department visits, hospitalizations, and mortality.<sup>10</sup> Therefore, appropriate management of symptom burden by patients with HF should not be underestimated.<sup>10</sup>

Self-care management (SCM) is a cornerstone of treatment for HF patients.<sup>11</sup> Riegel and Dickson define HF self-management (one of the three sets of activities undertaken in self-care) as activities that patients take to respond to symptoms of HF exacerbations as they arise.<sup>11–13</sup> The revised situation-specific theory of HF self-care also posits two other sets of activities, self-care maintenance and symptom monitoring.<sup>14</sup> Patients who engage in adequate self-care live longer, experience fewer hospitalizations, and possess a better quality of life.<sup>15–17</sup> Nonetheless, self-care is often poor among patients with HF.<sup>18</sup> Furthermore, culture has an impact on self-care in general. Traditional beliefs and ideas, including fatalism, cultural norms, and normative thinking can play a significant role in self-care practices.<sup>19</sup>

Fatalism is an individual's belief that events are predetermined and inevitable, and that individuals have little or no control over them.<sup>20</sup> As a result, fatalistic individuals are more likely to accept what happens in their lives without attempting to change it or engaging in behaviors that could prevent or manage an illness.<sup>21</sup> For example, fatalistic individuals with diabetes have poor medication adherence and self-care behaviors compared to those who are not fatalistic.<sup>22,23</sup> Fatalistic individuals more commonly have major misperceptions about the risks they face for heart disease and cancer.<sup>24</sup> Several investigators have shown that higher levels of fatalism are associated with worse patient outcomes.<sup>25,26</sup> Those with fatalistic attitudes believe they have little control over their health outcomes, resulting in reduced motivation to engage in self-care activities.<sup>22</sup> Clinician efforts to increase patient motivation to engage in self-care have had variable success, likely because of incomplete understanding of the factors affecting self-care management.<sup>27,28</sup> Research is needed to improve our understanding of factors associated with self-care so that more effective interventions can be designed.

Clinicians and researchers have assumed that higher symptom burden would be strongly associated with better SCM in patients with HF, because having a higher symptom burden would prompt one to engage in better self-care; however, this association is not always present or the data about the association are conflicting.<sup>29–31</sup> One hypothesis for these conflicting or non-significant findings is that there may be a relationship between symptom burden and SCM, but that it is mediated by a third variable. Fatalism is an appropriate candidate for this mediator.<sup>22</sup> Investigators indicate that increased fatalism can detrimentally affect self-care and lead to adverse health outcomes.<sup>23,32</sup> Thus, our aim was to determine whether fatalism mediates an association between symptom burden and SCM.

## Methods

### Design, Sample, and Setting

We conducted a cross-sectional secondary analysis of baseline data derived from a prospective randomized controlled trial, evaluating the impact of a 6-month dietary intervention on HF symptoms, health-related quality of life, and clinical outcomes.<sup>33</sup> This study has been fully described elsewhere,<sup>33</sup> and a brief description follows. The participants

were recruited from outpatient clinics and hospitals in Kentucky. Eligible patients were adults who could read and speak English, had a diagnosis of chronic symptomatic HF with New York Heart Association (NYHA) functional class II-IV.

We used baseline data, which were collected before intervention, for analysis. Patients completed questionnaires in their homes or other place they chose. A research assistant was with the patient to assist them if they had any questions. Patients with complete data on all variables needed for the analysis (n=95) were included in the mediation analysis, whereas 120 patients with HF were included in the original study. There were no differences in demographic variables between participants included in the original study and those included in the current study.

Participants were excluded from the primary study if they had any of the following: 1) body mass index below 17 kg/m<sup>2</sup> or above 46 kg/m<sup>2</sup>; 2) underlying medical condition that caused systemic inflammation; 3) diminished appetite or difficulty absorbing food; 4) consumed dietary supplements containing lycopene or omega-3 fatty acids; 5) allergies to rice bran oil; 6) listed for a heart transplant; or 7) cognitive impairment (either diagnosed in the medical record or determined through screening).

## Procedure

This study was approved by the institutional review board of the University of Kentucky. A trained research nurse verified the eligibility of participants. Those who agreed to participate signed the consent form and provided evidence of informed consent using the teach-back method. The Montreal Cognitive Assessment was used to screen patients for cognitive function following their consent.<sup>34</sup> Participants with scores of sixteen or lower on the Montreal Cognitive Assessment were excluded from the study. Baseline questionnaires were completed by patients after they provided consent.

## Measures

### Symptom Burden

The Memorial Symptom Assessment Scale (MSAS-HF) was used to assess symptom burden. The MSAS-HF consists of 32 items derived from Portenoy's Memorial Symptom Assessment Scale, originally intended to assess the symptoms among patients with cancer.<sup>35</sup> The MSAS-HF is a comprehensive instrument that provides multidimensional information regarding a wide range of symptoms experienced by patients with HF.<sup>36</sup> The participants rate 32 possible symptoms they may have experienced during the past seven days. Depending on the presence of symptoms, the respondents were asked to rate the frequency of symptoms on a scale of 1 to 4 (occasionally to almost constantly), their severity on a scale of 1 to 4 (mild to very severe), and degree of distress experienced on a scale of 0 to 4 (not at all to very severe). A higher number signifies a higher burden from frequency, severity, and distress.<sup>35</sup> Symptom burden scores are derived by adding the mean frequency, severity, and distress scores.<sup>9</sup> Each subscale and the overall MSAS-HF scale has previously been demonstrated to be valid and reliable in patients with HF.<sup>36</sup>

## Fatalism

Fatalism was measured using a valid and reliable instrument called the Cardiovascular Disease (CVD) Fatalism Instrument.<sup>37,38</sup> The CVD Fatalism Instrument was modified from the General Health Fatalism Instrument with the permission of the original author and then psychometrically tested.<sup>37,38</sup> Several items on the original scale were revised to make them disease-specific specifically to address heart disease. For instance, the statement from the initial scale, “If someone is meant to get a serious disease, they will get it no matter what they do,” was revised to “If someone is meant to get heart disease, they will get it no matter what they do.” The general items on the original scale, such as “My health is a matter of luck” and “I often feel helpless when experiencing problems” remained unchanged.<sup>38</sup> The CVD Fatalism instrument consists of 20 items with Likert scale response options ranging from 1 (strongly disagree) to 5 (strongly agree). The scale ranges from 20 to 100, with higher scores indicating greater fatalism.<sup>38</sup> The validity and reliability of this scale have been documented in patients with HF.<sup>39</sup>

## Self-Care Management

Self-care management was evaluated using the management subscale of Self-Care of Heart Failure Index (SCHFI) version 6.0, which consists of 22 items with well-established reliability and validity in HF studies.<sup>40,41</sup> The six items of the SCM Scale are designed to assess patients’ abilities to recognize symptoms, to respond appropriately (e.g., seek medical treatment, decrease fluid intake, and take diuretics), and evaluate their response to treatment. The HF SCM subscale is scored using a Likert scale of 1 to 4 responses: 1 (never or rarely), 2 (sometimes), 3 (frequently), and 4 (always or daily).<sup>41</sup> Scores were calculated by adding each item and converting them to a 100-point scale, where higher scores indicate better SCM. An assessment score of less than 70 indicates low levels of self-care.<sup>42</sup>

## Demographic and Clinical Characteristics

We collected demographic information (e.g., age, sex, race/ethnicity, education, employment, and marital status) using a standard questionnaire. Trained research assistants conducted thorough patient interviews to determine NYHA classification. Patients were assigned to NYHA categories (classes II-IV) based on the extent to which their physical activity was restricted by their symptoms.<sup>43,44</sup>

## Data analysis

The study variables were descriptively analyzed, using means, standard deviations, and frequency distributions. Version 28 IBM SPSS was used to conduct statistical analyses. We used the Hayes’ PROCESS macro (Model 4) to test the mediation effect of fatalism on the association of symptom burden with SCM.<sup>45</sup> Using the PROCESS macro, simultaneous multiple regressions were run to test the total, direct and indirect effects. As shown in Figure 1, in the PROCESS macro-output, “a” represents the coefficient for the direct effect of the independent variable (i.e., symptom burden) on the mediator (i.e., fatalism), and “b” represents the coefficient for the direct effect of the mediator (i.e., fatalism) on outcome variable (i.e., SCM). Initially, we examined the direct effect (c’) of symptom burden on the dependent variable (i.e., SCM). Coefficient c’ represents the direct effect of the independent

variable on the dependent variable. To determine the mediation effect, we examine the coefficient “a\*b”, which represents the effect of the independent variable on the dependent variable through the mediator.<sup>46</sup> We used ordinary least squares (OLS) regression with 5000 bootstrapped samples. The covariates were not included in the first mediation analysis. A subsequent mediation analysis was conducted while controlling for age, sex, and NYHA class. Studies have shown that these covariates are associated with the symptom burden, SCM, and fatalism.<sup>47–49</sup> Furthermore, before performing the analysis, we checked for the possibility of a moderation effect of fatalism in the association between symptom burden and SCM and found that no moderation effect was evident.

## Results

### Sample Characteristics

Table 1 presents the characteristics of the sample. The mean age of patients was  $62 \pm 12$  years. Most patients (60%) were males, white (70%), married (49%), had received at least a high school education (89%), were retired due to illness (32%), and or were categorized as NYHA functional classes III and IV (70%). The mean score for SCM was 62.94 (SD=19.76), indicating inadequate self-care in this sample. The mean score for symptom burden was 43.27 (SD=31.81), indicating moderate to high burden among the sample participants. The mean score for fatalism was 48.5 (SD=11.07). There are no cut points for this instrument, but the possible range is 20 – 100 and the range in this sample was 23 – 76 with a median of 49 (25<sup>th</sup> percentile = 41, 75<sup>th</sup> percentile = 56), suggesting a moderate level of fatalism in this sample based on the sample mean.

### Association of Symptom Burden, Fatalism, and Self-care Management

The results of the two mediation analyses are shown in Figures 2 and 3. Our first mediation analysis was not adjusted for covariates (Figure 2). Symptom burden was significantly associated with fatalism ( $a = 0.004$ ;  $p < 0.015$ ), in that greater symptom burden was associated with higher levels of fatalistic beliefs. Fatalism was significantly associated with SCM ( $b = -9.132$ ;  $p < 0.007$ ) in that patient with higher levels of fatalism had poorer SCM. Through this indirect pathway, higher symptom burden was associated with poorer SCM.

There was a significant indirect association of symptom burden with SCM through fatalism, indicating that fatalism was a mediating factor ( $a*b = -0.040$ , 95 % confidence interval (CI)  $[-0.097, -0.002]$ ). In addition, no significant direct relationship was found between symptom burden and SCM in the presence of fatalism ( $c' = 0.081$ ; 95% CI  $[-0.048, 0.209]$ ;  $p = 0.217$ ). Fatalism mediated the relationship between symptom burden and SCM. Patients with higher symptom burden were more fatalistic, and greater fatalism was associated with worse SCM. Table 2 presents a summary of the mediation analysis and Figure 2 illustrates each path.

The second mediation model adjusting for covariates (i.e., age, sex, and NYHA class) is presented in Table 2 and Figure 3. There was a significant indirect (mediator) association of fatalism between symptom burden and SCM. ( $a*b$  effect =  $-0.044$ , 95% CI:  $-0.108$  to  $-0.004$ ). There is no definitive evidence that symptom burden is directly associated with

SCM in the presence of fatalism ( $c' = 0.013$ ; 95% CI =  $[-0.128$  to  $0.153]$ ;  $p = 0.859$ ). Figure 3 illustrates each path and summarizes the mediation analysis.

## Discussion

In this study, we examined the mediating effect of fatalism on the relationship between symptom burden and SCM among adults with heart failure. Our findings demonstrated that fatalism acts as a mediator between symptom burden and SCM. Patients with higher symptom burden had more fatalistic beliefs about their health, which led to less engagement in self-care activities. These findings are important because the discovery of mediators provides information about the mechanisms underlying the associations between variables. Using these findings, we can build strategies and interventions to improve patient outcomes.

Fatalistic beliefs are associated with passive coping styles and poorer health outcomes.<sup>50</sup> Fatalistic beliefs result in lower odds of engaging in preventive behaviors such as regular exercise, quitting smoking, and consuming a sufficient amount of fruits and vegetables.<sup>51</sup> Urizar and Sears,<sup>50</sup> reported a greater prevalence of fatalism among patients with more severe cardiovascular disease. This finding suggests that fatalistic beliefs may be more prevalent among individuals with HF, who are likely to have a higher symptom burden. In addition to inhibiting positive health behaviors, fatalism can be experienced in response to poor health or chronic illness.<sup>52</sup>

A higher level of fatalism has been associated with an increased risk of recurrence and mortality from all causes, possibly due to a lack of empowerment.<sup>53</sup> Han Shi et al.,<sup>25</sup> found that some participants maintained a fatalistic attitude concerning their future with HF based on their experience of futility in the past, as well as acceptance of possibility of death at any time. In addition, repeated exacerbations of symptoms may demotivate patients from pursuing self-care due to fatalism and a sense of futility.<sup>25</sup> The results of our study are consistent with the findings of Dickson et al.<sup>54</sup> and others who found that SCM was influenced by spirituality and fatalism. The participants expressed a belief in God being in control, used prayer, and looked to a higher power for guidance and direction, which has elements of fatalism.<sup>54</sup> In some religions, both Christian and non-Christian, practitioners of the faith hold views that can be considered fatalistic when they place their health in God's hands. For example, Galdas et al, found that faith, spirituality, and fatalistic beliefs were often considered of greater importance than healthcare professionals' recommendations, influencing patients' acceptance of illnesses, perceptions of illnesses, and beliefs about managing their condition by changing their lifestyles.<sup>55</sup> The prevalence of fatalistic beliefs affects patients' acceptance of illness and perceptions of symptom burden, resulting in a diminished focus on self-care.<sup>50,55</sup>

Symptom burden profoundly affects patients' ability to engage in SCM, which is crucial for improving HF patients' health outcomes.<sup>5</sup> Investigators found that fatigue and breathlessness increase task difficulty, affecting both SCM and daily living activities.<sup>56</sup> Fatalism is a particularly relevant mediator in this relationship, as it captures the psychological aspect of coping with a chronic condition.<sup>57</sup> Health care providers can identify potential barriers to effective SCM and design interventions that address these beliefs by understanding the

mediating role of fatalism, which provides insight into patients' thought processes and decisions regarding their health.

The influence of traditional beliefs and ideas, including fatalism, on SCM as a whole has not been examined in many studies. Our study suggests that fatalistic beliefs in a higher power play an important role in developing self-care approaches, as well as influencing the way individuals manage illnesses. The findings of our study are consistent with those in the published literature examining traditional beliefs and ideas, including fatalism and cultural norms in health and health behaviors. This suggests that fatalism influences the behaviors of individuals who suffer from chronic illnesses and cardiovascular diseases.<sup>58,59</sup>

## Implications

Promoting an internal locus of control (i.e., belief that one's behavior are guided by their own decisions) and increasing patients' levels of perceived control (i.e., an individual's perception that their actions can directly influence their own outcomes) can be effective strategies to address fatalism and engagement in self-care.<sup>60-62</sup> We found that fatalism mediates the relationship between symptom burden and SCM in adults with HF. Despite high levels of symptom burden, patients who hold fatalistic beliefs about their health are less likely to engage in self-care activities.<sup>51</sup> However, promoting an internal locus of control can help counteract fatalistic beliefs and encourage patients to manage their own health.<sup>63,64</sup> It may be possible to motivate patients to engage in self-care behaviors by promoting the belief that their actions and behaviors can directly impact their health outcomes. Patient education, goal setting, and motivational interviewing may be effective strategies to promote internal locus of control and increased levels of perception control.<sup>61,65</sup> Promoting internal locus of control can result in improved health outcomes in patients with chronic conditions.<sup>66</sup> As a result, interventions aimed at improving SCM in adults with HF should emphasize the promotion of an internal locus of control and increased levels of perceived control to combat fatalistic beliefs and encourage active participation in self-care activities.

## Limitations

Our study has some limitations that need to be noted. First, the study sample consisted primarily of white individuals recruited from one southern state in the United States, which limits the generalizability of this study. Second, because this was a secondary analysis, variables (such as HF etiology) that were not collected in the primary study were not accounted for in our statistical analysis. We did not control for variables (other than NYHA status, age, and sex), which could have affected outcomes. Such variables include comorbidity burden, which likely increases fatalism and symptom burden, but which has a variable effect on SCM. Third, we only used baseline data in this study, our results were cross-sectional, and causality cannot be inferred directly, although mediation analysis implies causality. Mediation analysis revealed that the predictor variable affects the outcome variable through the intermediate variable, suggesting a causal pathway.<sup>46</sup> Future investigators should explore the differences in symptom burden, fatalism, and SCM status over time, especially after the implementation of interventions aimed at promoting better SCM.

## Conclusion

We aimed to provide insight into the relationship between symptom burden, fatalism, and SCM among adults with HF. We found that fatalistic attitudes play an important mediating role in the association between symptom burden and SCM, highlighting the importance of addressing both physical symptoms as well as the emotional and psychological aspects of care for patients with HF.

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There are no conflicts of interest or funding to be disclosed by the authors.

## Abbreviation

|                |   |
|----------------|---|
| <b>CVD</b>     | Cardiovascular Disease                          |
| <b>HF</b>      | Heart failure                                   |
| <b>MSAS-HF</b> | Memorial Symptom Assessment Scale-Heart Failure |
| <b>NYHA</b>    | New York Heart Association                      |
| <b>SCM</b>     | Self-Care Management                            |
| <b>SCHFI</b>   | Self-Care of Heart Failure Index                |

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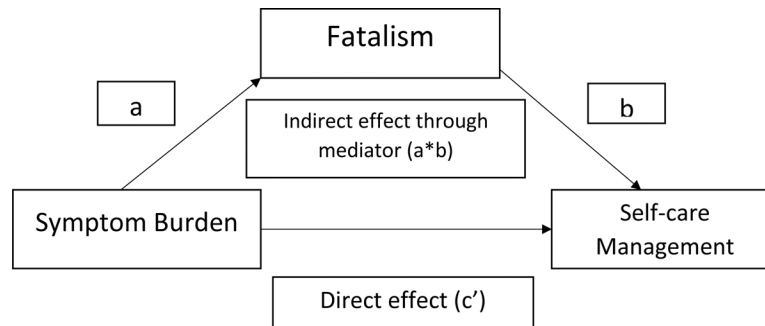
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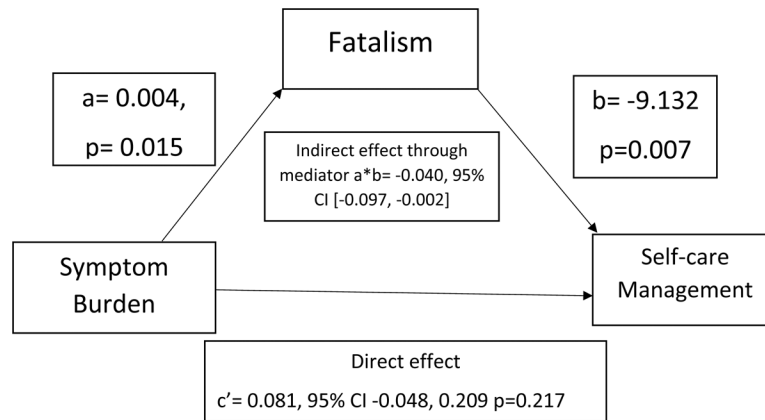
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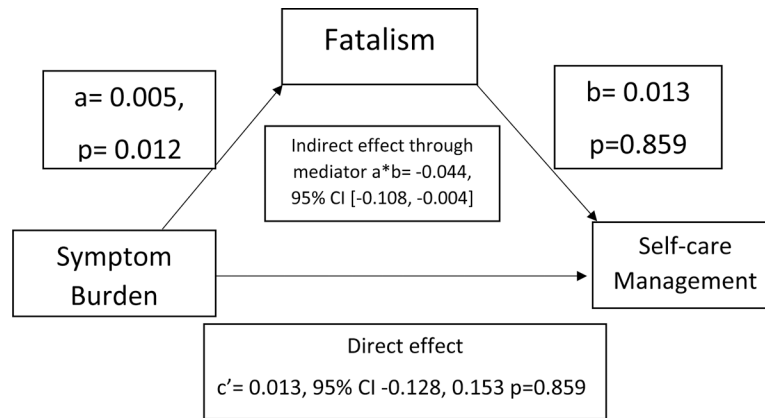
**Figure 1.**

Conceptual diagram of the mediation model: symptom burden to self-care management via fatalism (based on Hayes model 4)

“a” represents the coefficient for the direct effect of the independent variable (i.e., symptom burden) on the mediator (i.e., fatalism), and “b” represents the coefficient for the direct effect of the mediator (i.e., fatalism) on outcome variable (i.e., self-care management). Coefficient  $c'$  represents the direct effect of the independent variable on the dependent variable. Coefficient “ $a*b$ ”, which represents the effect of the independent variable on the dependent variable through the mediator.



**Figure 2.**  
 Mediation by fatalism of the association between symptom burden and self-care management without covariates  
 Coefficients for the model; CI= Confidence Interval



**Figure 3.**  
 Mediation by fatalism of the association between symptom burden and self-care management controlling for covariates  
 Coefficients for the model; CI= Confidence Interval  
 Covariates: Age, sex, and NYHA (New York Heart Association) class

**Table 1.**

## Sample Characteristics (N=95)

| Characteristics                          | Mean $\pm$ SD or n (%) |
|--|------------------------|
| Age, years                               | 62 $\pm$ 12            |
| <b>Gender</b>                            |                        |
| Male                                     | 57 (60)                |
| Female                                   | 38 (40)                |
| <b>Race</b>                              |                        |
| White                                    | 67 (70.5)              |
| Black                                    | 22 (23.2)              |
| Other                                    | 6 (6.4)                |
| <b>Marital status</b>                    |                        |
| Single                                   | 17 (17.9)              |
| Married                                  | 47 (49.5)              |
| Divorced/separated                       | 21 (22.1)              |
| Widowed                                  | 6 (6.3)                |
| Living with good friend/partner          | 4 (4.2)                |
| <b>Education level, years</b>            | 13 $\pm$ 2.6           |
| <b>Employment</b>                        |                        |
| Employed full- or part-time              | 13 (13.7)              |
| Unemployed by choice                     | 1 (1.1)                |
| Sick Leave/Disability                    | 26 (27.4)              |
| Homemaker                                | 2 (2.1)                |
| Retired due to illness                   | 30 (31.6)              |
| Retired not due to illness               | 22 (23.2)              |
| Unemployed/ Laid off                     | 1 (1.1)                |
| <b>NYHA</b>                              |                        |
| I/II                                     | 29 (30)                |
| III/IV                                   | 66 (70)                |
| Self-care Management subscale (SCHFI)    | 62.94 $\pm$ 19.76      |
| Symptom Burden (MSAS-HF)                 | 43.97 $\pm$ 31.81      |
| Fatalism scale (CVD Fatalism Instrument) | 48.5 $\pm$ 11.07       |

Abbreviations: CVD: Cardiovascular Disease, MSAS-HF: Memorial Symptom Assessment Scale-Heart Failure, NYHA: New York Heart Association, SCHFI: Self-Care of Heart Failure Index, SD: Standard Deviation.

**Table 2.**

Summary of Mediation Analysis with and without Covariates

| Relationship                                   | Direct Effect coefficient (p value) | Confidence Interval for Direct Effect         | Indirect Effect coefficient | Confidence Interval for Indirect Effect        | Conclusion        |
|--|-------------------------------------|---|-----------------------------|--|-------------------|
| <b>Mediation without Covariates (Figure 2)</b> |                                     |   |                             |  |                   |
| Symptom Burden->Fatalism->Self-care Management | 0.081 (0.217)                       | Lower Bound<br>-0.048<br>Upper Bound<br>0.209 | -0.040                      | Lower Bound<br>-0.097<br>Upper Bound<br>-0.002 | Mediation Present |
| <b>Mediation with Covariates (Figure 3)</b>    |                                     |   |                             |  |                   |
| Symptom Burden->Fatalism->Self-care Management | 0.013 (0.859)                       | Lower Bound<br>-0.128<br>Upper Bound<br>0.153 | -0.044                      | Lower Bound<br>-0.108<br>Upper Bound<br>-0.004 | Mediation Present |

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