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Emotion Regulation and Perceptions of Illness Coherence and Controllability on Regimen Adherence and Negative Cardiac Health Events in African American Women with Heart Failure

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Introduction and Background

Improving adherence to diet, medications, and exercise is critical to patients in the United States with heart failure (HF), a vulnerable population of more than 5 million people.¹ Poor adherence can trigger costly negative health events such as hospitalizations.² Improving adherence has the potential to reduce the \$24 billion spent annually on direct healthcare expenses,³ which are expected to triple over the next 20 years.³ As such, it is critical to identify predictors of poor adherence and negative health events, particularly in populations experiencing disparate health outcomes.

African American patients with HF have a greater risk of negative health events than Caucasian patients with HF.^{4–6} In addition, African Americans are highly vulnerable to social stressors, such as lower socioeconomic status, which negatively impact health.⁷ The combination of increased vulnerability to social stressors, poorer health outcomes, and the relative lack of empirical research conducted with African Americans across health conditions⁸ makes research to understand predictors of negative health events in this population critical.

Potential predictors include aversive stressors such as limited income, older age, and less education. These stressors, compounded with complex disease management, create strain beyond the scope of the disease, which may alter illness management prioritization.⁹ Compounding problems with adherence are depression^{10,11} and anxiety,^{10,12} which are 1.3 times more prevalent in African American women than in Caucasian women.^{13,14}

Patients experience competing demands between management of physical, emotional, and social needs, necessitating cognitive focus. Overwhelming demands (stressors) can elicit intense emotional responses. The recognition of factors leading to HF rehospitalizations and nonadherence for African American women needs to expand beyond clinical factors to include the cognitive and emotional processing of illness.

Illness perceptions and emotion regulation are two components of cognitive and emotional processing that may impact outcomes in patients with HF. The role of illness perceptions in

self-regulation and adaptive behavioral outcomes is well-documented,¹⁵ whereas the mechanisms by which emotion regulation may impact health behaviors such as adherence are less clear. *Emotion regulation*, the experiencing, processing, and modulating of emotional responses,¹⁶ is necessary to manage the emotional stressors common to patients with HF. A better understanding of the role of illness perceptions and emotion regulation in adherence and negative health events is essential to making gains in improving HF self-management.

The purpose of this prospective study is to gain a better understanding of illness perceptions and emotion regulation in African American women with HF, and to identify predictors of negative health events and adherence. We examined the hypothesis that difficulties with emotion regulation and negative perceptions of illness coherence and controllability are detrimental to HF self-management regimen adherence and increase negative cardiac health events (visits to emergency departments, hospitalizations, and death for cardiac reasons) in African American women with HF.

Methods

A prospective descriptive correlational design was used to complete this study.

Sample Selection

The target sample size of 60 participants was determined based on project duration and resources. With this sample size, power was sufficient (.80 or greater) to detect a small effect size expressed as Cohen's f squared of 0.14.¹⁷ This effect size corresponds to partial R-squared of 0.12 for the explanatory variables of interest. The partial R-squared will provide information on the marginal contributions of predictor variables consistent with pilot study research.

Participants were included if they were (1) African American female patients who were 45 years of age or older; (2) diagnosed with HF; (3) on physician-prescribed dietary, exercise, and medication regimens; and (4) able to understand both written and spoken English. Patients were excluded if (1) they had documented psychiatric (bipolar disorder, schizophrenia, or drug abuse) or cognitive disabilities that would limit their ability to answer survey questions, or (2) they were discharged to a long-term care facility or palliative care where independent decisions to adhere to a self-management regimen would be diminished.

Enrollment occurred between September 2014 and July 2015. All interviews and medical record reviews were completed by September 2015.

Protection of Human Subjects

Institutional and collaborative hospital review boards approved the study and all protocols. Participants completed an informed consent for the study and received a \$20 gift card for completing the interviews.

Protocol

Potential participants were identified by care providers and referred to study recruiters. Additional information about the study was given to interested potential participants by the recruiters. Interested participants completed a screening checklist, and if eligible, obtained informed consent with assistance from the recruiters. Baseline phone interviews lasting approximately 60 minutes were then completed, with a subsequent 30-day follow-up phone interview and 90-day medical record review. Due to limited resources single time points were chosen for follow up to maximize participant retention for the phone interview and to identify negative health events over a longer time period for the medical record review. Adherence and negative health events were identified at the 30-day interview, with verification of events within the 90-day medical record review.

Outcomes and Measures

Illness perceptions—The revised Illness Perception Questionnaire (IPQ-R) was used to measure perceptions of illness coherence and controllability. Lower scores on the personal and treatment control subscale indicate a lack of perceived illness controllability, and lower scores on the illness coherence subscale suggest lowered usefulness of the illness representation, or that the illness does not make sense.

Each of the items from the IPQ-R subscales are scored on a 5-point Likert-style scale, from “strongly disagree” to “strongly agree.” In previous validation testing, each of these subscales demonstrated good internal reliability (Cronbach’s $\alpha > .79$), as well as discriminant and predictive validity.¹⁸ Exploratory factor analysis was conducted for this sample, indicating items from the personal and treatment controllability were converging on a single factor. As such, these items were combined into a single subscale. Two items were removed that exhibited low item-rest correlations ($< .30$). The nine remaining items had a final subscale Cronbach’s α of .80. Items from the coherence subscale demonstrated convergence on a single factor, with good item-rest correlations ($> .30$) and a Cronbach’s α of .80.

Emotion regulation—The Difficulties in Emotion Regulation Scale (DERS) was used to measure emotion regulation at intake (Cronbach’s $\alpha = 0.93$).¹⁹ All DERS items are measured on a Likert scale with a range of 1 to 5. Summed items create an overall global score.¹⁹ Exploratory factor analysis in this study sample demonstrated a lack of unidimensionality of the 36-item scale. Items were removed based on lack of commonalities, as well as their factor loadings on the extracted factors, leaving 18 items. Reliability analysis revealed that no remaining items demonstrated low item-rest correlations ($< .35$). The abbreviated scale had an average inter-item correlation of 0.42 and good reliability with Cronbach’s α of 0.94.

Adherence—Self-reported adherence was measured using the Medical Outcomes Study Specific Adherence Scale (MOS-SAS) at follow-up for heart disease.²⁰ The MOS-SAS test measures both general adherence and cardiac disease-specific adherence.^{20–22} One adherence question related to each particular behavior was selected from the specific

adherence MOS-SAS questions (exercise, medication, and diet), and these were analyzed on a 6-point Likert scale to determine adherence since enrollment.

The 8-item MOS-SAS scale had less than optimal internal reliability in this sample, with a Cronbach's alpha of 0.64. As use of this measure in a similar population was not identified, further analysis of the scale in this sample was needed. Exploratory analysis identified that only the general adherence questions loaded on a single factor, and one of these items had a low item-rest correlation. After removal of problematic items, the four remaining general adherence items converged on a single factor, with an item-rest correlation $>.30$, and a Cronbach's alpha of .70. Single responses to diet, medications, and exercise adherence were retained for descriptive purposes only.

Negative cardiac health events—Use of healthcare resources, type of healthcare resources used, and time to first unscheduled care event or death were examined. Negative health events for patients with HF were defined as death, hospitalizations, emergency department, or urgent care visits. Due to the difficulty in isolating cardiovascular events from HF events, all negative cardiac health events were included. For the purposes of this study, occurrence of a negative cardiac health event within 90 days was examined with medical record review as the primary source of this information. Verification of events within and outside of the primary facilities was completed for the first 30 days at the follow up phone call. Events occurring between 30 and 90 days only include those events from the participating health systems.

Other variables—Several other variables were measured, including sociodemographic and clinical factors such as age, income, education, New York Heart Association functional classification (NYHA), left ventricular ejection fraction (LVEF), and comorbidities (measured with the Index of Coexistent Diseases).²³

Statistical Analyses

All data analyses were performed using SPSS 23 and STATA 14.^{24,25} Years of education years and income were evaluated as single numerical values. Because only a small number of participants were categorized as NYHA I or IV, this categorical variable was simplified to be either class I/II or class III/IV.

Results

Participant Characteristics

A total of 58 African American women diagnosed with HF were recruited from inpatient ($n = 38$, 65%) and HF clinic sites ($n = 20$, 35%). Of those participants, 54 completed the intake interviews, and 51 completed follow-up interviews and had complete medical record reviews. Those patients lost to follow-up occurred when the participant did not answer the contact phone number ($n = 4$), the participant changed their mind after starting data collection ($n = 2$), or death ($n = 1$). No differences were identified between completers and non-completers. Table 1 presents the demographic and health characteristics of the study sample.

Study participants varied in age from 49 to 84 years. No differences were noted in the demographics of the study participants between those who were recruited in the hospital and those who were recruited in clinics, except for disease severity (see Table 1). Clinically, the participants varied in symptom severity, with 32 (55%) in NYHA functional classification I/II and 26 (45%) in III/IV. Hospital-recruited participants had greater NYHA functional classifications (2.7 ± 0.8) than those recruited in clinics (1.9 ± 0.6). Documented ejection fractions indicated that 21 (39%) had an LVEF $> 40\%$ or physician-indicated preserved systolic function, whereas 33 (57%) had nonpreserved systolic function. Half of the participants completed some college ($n = 29$) and most were of lower socioeconomic status, with 82% ($n = 42$) reporting household incomes of less than \$30,000. Overall, multiple comorbid conditions were common, with the participants reporting a range of 4 to 12 illnesses, with an average of 4.8 ± 2.0 comorbid conditions. The most frequently self-reported comorbid illnesses were hypertension ($n = 49$, 91%), arthritis ($n = 41$, 76%), arrhythmias ($n = 36$, 67%), diabetes ($n = 29$, 54%), and respiratory disease ($n = 25$, 46%).

Negative Cardiac Health Events

Negative health events were relatively common in this group ($n = 28$, 48%), with first events identified as 15 hospital admissions, six emergency department visits, and seven urgent visits to healthcare providers (see Table 2). The outcome was determined based on the first negative health event; however, some participants experienced multiple events. Participant days to negative healthcare events varied over the 90-day follow-up period, with a mean of 40.9 ± 25.6 days and a range of 4–92 days.

Adherence

Overall, the mean scores of 3.8 ± 1.0 on the 5-point MOS-SAS suggest positive adherence to HF regimen self-management behaviors (see Table 3). With the single-item questions, participants reported the lowest adherence to exercise (1.9 ± 1.6) on a 1 to 5 scale, and the highest adherence to diet (4.1 ± 1.4) and medications (4.9 ± 0.7). Overall, patients perceived themselves as generally adherent, yet negative health events were common.

Emotion Regulation

Mean item responses from the abbreviated DERS items were calculated to create a 1–5 scale. On the 18-item abbreviated DERS, participants reported mean difficulty with emotion regulation as 1.8 ± 0.8 (see Table 3). The range of these mean scores (1 to 4.8) indicated that participants responding to this scale varied from having low to high difficulties with emotion regulation. The response patterns were skewed toward fewer difficulties with emotion regulation.

Illness Perceptions

The mean score of illness coherence was 3.2 ± 0.8 , with a range of mean scores from 1.6 to 5 (see Table 3). The illness coherence subscale had an almost symmetrical distribution centered on the neutral response. The adapted illness controllability subscale had a mean score of 3.9 ± 0.5 with a mean range of 2.1 to 5. The responses on the adapted illness controllability subscale were not as symmetrical, and skewed toward greater perceived

controllability. Participants responding to each of these subscales varied from very negative to highly positive perceptions of illness coherence and controllability.

Predictors and Outcomes

Two models were used to test the relationships between emotion regulation and illness perceptions with the outcomes of adherence and negative cardiac health events. Both models used a subset of the predictor variables (age, education, and NYHA functional classification). To examine the outcome variable of adherence, a linear regression model was used. As the second outcome variable was dichotomous (either an event occurred or did not), a logistic model was used.

For the linear regression model, the Breusch-Pagan/Cook-Weisberg test for heteroskedasticity was significant, indicating that it was necessary to test the relationships using robust standard errors (Baum et al., 2003). In the first linear regression model, age, education, IPQ-R adapted illness controllability, IPQ-R illness coherence, and the abbreviated DERS were predictor variables for the adherence outcome. This model was not statistically significant ($p = .434$) with no significant single relationships (see Table 4).

In the logistic regression model predicting the odds of a first emergency use of healthcare services, the predictors were age, education, illness severity using the NYHA, IPQ-R adapted illness controllability, IPQ-R illness coherence, and the abbreviated DERS. The findings were nonsignificant for predicting the use of emergent healthcare services ($p = .140$). There were limited significant single relationships between the predictor variables and healthcare use (see Table 5).

A single significant relationship existed within this second model. As shown in Table 5, NYHA was found to be associated with the use of emergent healthcare services for cardiac events ($\beta = 1.47$, $p = .027$). Although no clear relationships were found in regards to illness perceptions or emotion regulation and the outcomes of adherence and use of healthcare services for cardiac events, results of this study indicate that these concepts warrant further study.

Of potential importance, poor illness coherence, as shown in Table 4 ($\beta = -.32$, $p = .080$), may have a negative effect on general adherence. Further, in addition to NYHA contributing to odds of a negative health event, difficulties with emotion regulation, as shown by the DERS in Table 5 ($\beta = .80$, $p = .069$), may also be a contributor.

Summary of Findings

Although the results of this study demonstrated few significant relationships, several key results are critical to further discussion. The first is that these participants experienced greater negative health events than anticipated. Of the 54 participants, 28 experienced a negative health event for any reason over the 90 days, 57% of these being cardiac-related. The only clear predictor of these events was greater NYHA functional classification ($\beta = 1.47$, $p = .027$). No associations were found between predictors (emotion regulation, controllability, coherence, age, education) and general adherence. Despite the lack of significance with illness perceptions and emotion regulation, the individual impact on the

outcomes is intriguing. Emotion regulation (although not significant in these models) showed a possible greater impact on negative cardiac health events ($\beta = .80$, $p = .069$) than on general adherence ($\beta = -.10$, $p = .594$). Alternatively, perceived illness coherence showed less impact on negative cardiac health events ($\beta = -.27$, $p = .507$) than on general adherence ($\beta = -.32$, $p = .080$).

Discussion

The patients in this study were younger, had lower incomes, and experienced heightened negative cardiac health events. This sample reported many perceived strengths such as less difficulty with emotion regulation, perceptions that their illness was more controllable, and overall good general adherence. A variety of factors are associated with negative health events, and it is recognized that population groups, such as African Americans, are at a greater risk for poor HF outcomes.⁵

Adherence

The patients in the current study self-reported overall strong perceived adherence to their treatment regimen. In other studies, general non-adherence in HF patients was reported at 16%,²⁶ and mean adherence of 50.3 on a 0–100 scale in another.²⁷ General adherence instruments can be useful in screening patients for perceived issues with adherence, but may not clearly identify all adherence issues. The high levels of adherence reported by participants in this study raises question about whether the participants were over reporting or if perhaps this group is an example of higher adherence. Results from this study were unable to determine predictors of adherence.

This study identified a lack of significance between illness coherence and adherence, similar to results from a previous systematic review.²⁸ This information suggests that perceptions of understanding one's illness may not be necessary for adherent behaviors to occur. It is plausible that a newly diagnosed patient with limited illness knowledge may be very adherent, whereas someone living with the illness for years may become more lax in adherence if the illness is stable. Further, patients may become more adherent because of changes in the acuity of the illness. Beyond trajectory of the disease, it is possible that group differences may contribute to high levels of adherence. This idea is supported by results of another project in which African American participants reported cultural beliefs were shown to support medication adherence.²⁹ It is plausible that the cultural environment of these participants supports general adherence and contributed to the high levels of reported adherence.

Negative Cardiac Health Events

Compared to studies with similar samples in terms of age and disease severity, patients in this study experienced more negative health events within a shorter follow-up period.^{30,31} These differences in frequency of negative health events could be related to differences in socio-demographic factors (African American and poor), or other factors such as healthcare access.

More than half of the patients experiencing a negative health event in this study were hospitalized ($n = 15$, 54%), and several of these hospitalized patients died ($n = 5$, 18%). This would suggest that the negative health events were severe in nature. Use of healthcare services for cardiac reasons was found to be significantly associated with the patients' NYHA functional classifications in this study. Additionally, the causes for the majority of healthcare use and all deaths were related to cardiac reasons. It is apparent that a patient's cardiovascular health is of pivotal importance in preventing emergent negative health events. Other factors such as hospital recruitment and socio-demographic indices may also account for the severity of health events.

Participants in this study may have had lower socioeconomic statuses than those reported in other HF research.⁶ It is known that lowered access to financial resources is a predictor of poorer outcomes, such as increased mortality, however it is unclear why this association exists.³² Lower income levels of African American patients with HF may partially explain the presence of greater negative health events, however other factors are also likely contributors.

From the common sense model perspective, relationships exist between emotional processing, coping, and outcomes such as negative health events.¹⁸ Lee et al.³³ found that psychological distress negatively impacts health events. Emotionally distressed individuals may have difficulties regulating emotions and may increase their use of healthcare services.^{11,34–36} Further, emotional processing traits have been implicated with specific disease types, such as cardiac conditions.^{37,38}

Just as mental distress increases the risk for negative health events like hospitalization, it is plausible that coincident emotion regulation impacts the use of healthcare services (De Jong et al., 2011; Messerli-Bürge et al., 2012; Song, 2009; Zijlstra et al., 2012). The combination of demands, whether emotional or cognitive, impact health. It is essential that cognitive resources are both conserved and restored in order to respond to illness stressors (de Ridder et al., 2008; Folkman & Moskowitz, 2004).

Other Considerations

Other considerations in terms of interpreting study findings include patients' use of informal care and potential measurement issues associated with using a medical record to determine negative health events. Patients may have sought care in other settings such as alternate clinics, emergency departments, or hospitals, or received informal care from family members or other individuals in the community. In older African American patients, care is often provided by families rather than by formal care providers.³⁹ Further exploration is necessary to determine if perceptions of illness coherence impact negative health events in African American women with HF.

Studies examining relationships between illness perceptions and negative health events are uncommon in African American women with HF. Subjective perceptions of health are recognized to impact perceived control more so than health.⁴⁰ Further research is needed to examine relationships between illness perceptions and negative health events with larger sample sizes and with longitudinal designs.

Recognizing the potential impact of emotion regulation on healthcare use and outcomes in vulnerable groups could improve patient care. This is particularly relevant to patients who may have the most difficulty with emotion regulation, such as those who are younger and who are experiencing greater perceived stress. With heightened information relative to the impact of emotion regulation on negative health events, targeted cognitive-behavioral and/or mind-body interventions to improve adherence to medications, diet, and exercise can be developed. For example, yoga has been found to have a positive impact on emotion regulation⁴¹ while successfully engaging patients with HF in physical activity.⁴² Hypothetically, interventions that enhance adherence to HF regimens and improve psychological well-being may also simultaneously decrease negative health events.

Limitations

This study was an initial exploration of emotion regulation and illness perceptions in African American women with HF. The small sample size limited potential effect sizes while also potentially limiting statistical significance. The variable length of illness duration made it impossible to determine whether a patient's psychological distress was associated with a new diagnosis of HF or the impact of advancing disease. Additionally, the limited follow-up period made finding significance in relation to negative health events difficult. Finally, measures were self-report and the identification of tools validated in this population was a challenge. Further exploration of appropriate measures is necessary to determine optimal instruments for use with African American women with HF.

Implications for Practice and Research

Despite a lack of significant relationships, implications regarding study findings were identified. Because chronic illness such as HF impacts both cognitive and emotional processing of health-related information, consideration of both illness perceptions and emotion regulation may help support patients. Carefully constructed care plans should be collaboratively created with the patients and individualized to their needs, which may include adaptations based on social, cognitive, and emotional differences.

Research on African American women with HF and other chronic conditions must continue to identify sources and solutions to the health disparities in outcomes of these patients. The development of interventions that may improve emotion regulation in populations of African American women and those with chronic illnesses may be of value for decreasing negative health outcomes.

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Table 1**Demographic and Health Characteristics by Recruitment Type**

Characteristic	Overall (N=58)		Hospital (n=38)		Clinic (n=20)		p
	Mean	SD	Mean	SD	Mean	SD	
Age	64.5	9.5	66.1	10.3	61.5	6.9	.077
Income (in \$ thousands)	23.2	26.7	20.6	28.3	23.2	26.7	.296
Education (in years)	13.1	2.0	13.1	2.0	13.2	2.3	.797
NYHA	2.4	.9	2.7	.8	1.9	.6	.000
Ejection fraction (LVEF)	38.2	16.2	36.9	16.6	41.2	15.4	.372
Comorbidities (number reported)	4.8	2.0	4.9	2.0	4.6	1.9	.521
Adherence (MOS-SAS)	3.8	1.0	3.6	1.0	4.2	1.0	.091
	Percentage		Percentage		Percentage		
Negative Health Events experienced	48		58		30		.050

Note. NYHA = New York Heart Association Functional Classification; LVEF = Left Ventricular Ejection Fraction; MOS-SAS = Medical Outcomes Study – Specific Adherence Scale. Of the negative health events, 5 deaths were recorded, and all from patients recruited in the hospital.

Comparison of significance evaluated between hospital and clinic patients.

Table 2

First Event Health Outcomes of Study Patients

Negative Health Events	Number of Occurrences	mean $\pm$ SD or %
<i>Time to first event (days)</i>	28	40.9 $\pm$ 25.6
<i>Type of first event</i>		
<i>Death</i>	0	0
<i>Hospitalization</i>	15	53.6
<i>With Death as Final Outcome*</i>	5	17.9
<i>Emergency Department visit</i>	6	21.4
<i>Urgent clinic or primary care visit</i>	7	25.0
<i>Reason for first event</i>		
<i>Heart Failure</i>	12	42.8
<i>Cardiac</i>	4	14.3
<i>Other</i>	8	28.6
<i>Unable to Discern</i>	4	14.3

Note. n = 51

* All deaths were preceded by a hospitalization and occurred in patients who were originally recruited from hospital settings.

Table 3

Descriptive Statistics of Adherence, Emotion Regulation, and Illness Perceptions

Characteristic (Total scale range of scores)	Overall sample N = 54 mean $\pm$ SD or %	Results Range	Cronbach's alpha
Adherence MOS-SAS abbreviated version (0–5)	3.8 $\pm$ 1.0	1–5	.70
Emotion Regulation abbreviated version (1–5)	1.8 $\pm$ 0.8	1.0– 4.8	.94
Illness Perceptions			
<i>Illness coherence (1–5)</i>	3.2 $\pm$ 0.8	1.6–5.0	.80
<i>Illness controllability abbreviated (1–5)</i>	3.9 $\pm$ 0.5	2.1–5.0	.80

Note. MOS-SAS = Medical Outcomes Study-Specific Adherence Scale. MOS-SAS abbreviated version, emotion regulation abbreviated version, and the illness controllability abbreviated version and illness coherence subscales contain the items used for data analysis.

Table 4

Linear Regression of Adherence on Illness Perceptions and Emotion Regulation

Model	β	Robust Standard Error	t	Sig. p=	95.0% Confidence Interval for B	
DERs	-.10	.18	-.54	.594	-.46	.27
Illness coherence	-.32	.18	-1.79	.080	-.68	.04
Control	.14	.43	.32	.752	-.72	.99
Age	.01	.02	.51	.615	-.02	.04
Education	.12	.09	1.41	.165	-.05	.30
(Constant)	2.40	2.64	.91	.370	-2.94	7.74

Note. The dependent variable for all regressions was Adherence using the abbreviated 4-item MOS-SAS (Medical Outcomes Study-Specific Adherence Scale); DERs - Difficulties in Emotion Regulation (DERs 18-item abbreviated scale); Coherence - IPQ-R perceived illness coherence; Control - IPQ-R personal and treatment controllability; Education - years of education

Table 5
Logistic Regression of Negative Health Events on Illness Perceptions and Emotion Regulation

Model	β	Standard Error	Wald	Sig. p=	95.0% Confidence Interval
DERS	.80	.44	3.30	.069	.94 5.28
Illness coherence	-.27	.41	.44	.507	.34 1.70
Control	-.09	.70	.02	.902	.23 3.61
Age	.01	.04	.07	.799	.94 1.08
Education	-.02	.17	.01	.922	.70 1.38
NYHA	1.47	.66	4.91	.027*	1.19 15.83
(Constant)	-1.92	4.77	.16	.687	

Note. The dependent variable for all regressions was negative health events using a dichotomized yes/no within a 90-day medical record review; DERS - Difficulties in Emotion Regulation (DERS 18-item abbreviated scale); Coherence – IPQ-R perceived illness coherence; Control – IPQ-R personal and treatment controllability; Education – years of education; NYHA – New York Heart Association functional classifications I/II and III/IV.

* $p < .05$