

Title: The Relationship between Self-care and Health Related Quality of Life in
Older Adults with Moderate to Advanced Heart Failure

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Background: Heart failure (HF) patients who follow the treatment regimen and attend to symptoms before they escalate are assumed to have better health-related quality of life (HRQOL) than those with poor self-care, but there are few data available to support or refute this assumption.

Objective: The objective of the study was to describe the relationship between HF self-care and HRQOL in older (≥ 65 years old) adults with moderate to advanced HF. Methods: Self-care was measured using the 3 scales (maintenance, management, and confidence) of the Self-care of Heart Failure Index. Scores range from 0 to 100, with higher numbers indicating better self-care. Health-related quality of life was measured with the Minnesota Living With Heart Failure Questionnaire, a 2-subscale (physical and emotional) instrument. Lower numbers on the Minnesota Living With Heart Failure Questionnaire indicate better HRQOL. Pearson correlations, independent-samples t-tests, and linear and logistic regression modeling were used in the analysis.

Results: In 207 adults (72.9 [SD, 6.3] years), New York Heart Association class III (82%) or IV, significant linear associations were observed between self-care confidence and total ($r = -0.211$; $P = .002$), physical ($r = -0.189$; $P = .006$), and emotional HRQOL ($r = -0.201$; $P = .004$). Patients reporting better (below median) HRQOL had higher confidence scores compared with patients reporting above-median HRQOL scores (58.8 [19.2] vs 52.8 [19.6]; $P = .028$). Confidence was an independent determinant of total ($\beta_s = -3.191$; $P = .002$), physical ($\beta_s = -2.346$; $P = .002$), and

emotional (β s = -3.182; $P = .002$) HRQOL controlling for other Self-care of Heart Failure Index scores, age, gender, and New York Heart Association class. Each 1-point increase in confidence was associated with a decrease in the likelihood that patients had worse (above median) HRQOL scores (odds ratio, 0.980 [95% confidence interval, 0.963Y0.998]) with the same controls. No significant associations were found between self-care maintenance or management and HRQOL.

Conclusions: The degree of individual confidence in HF self-care is related to HRQOL, but self-reports of specific maintenance and management behaviors are not. Interventions that improve self-care confidence may be particularly important in older adults with moderate to advanced HF.

KEY WORDS: confidence, heart failure, quality of life, self-care, self-efficacy

Over the age of 65 the prevalence of heart failure (HF) is almost 1 in 100¹. Health related quality of life (HRQOL) is a determinant of both additional morbidity and mortality in this older adult HF population^{2,3}. Heart failure substantially decreases HRQOL, primarily through its symptom burden⁴. Patients with HF attempt to maintain their health and manage their symptoms using self-care strategies⁵, but increasing age and HF progression are theorized to impede decision making and activities necessary for self-care⁶. There is little empiric evidence related to the influence of self-care on HRQOL, specifically in adults 65 years of age and older with moderate to advanced HF (New York Heart Association [NYHA] class III/IV)⁷⁻¹⁰. In addition, where self-care and HRQOL have been studied, ambiguous findings have been reported⁸. We sought to address this gap by exploring the relationship between HF self-care and HRQOL in older adults with moderate to advanced HF.

Background

Self-care in HF. Self-care is a vital part of the plan of care for HF patients.^{11,12} Self-care in HF, as currently understood, describes a naturalistic decision making process involving maintenance (behaviors to maintain physiologic stability) and management (symptom response)¹². Self-care confidence (self-efficacy) is defined as the belief that one is capable of managing disease sequelae directly through personal agency. The patient's self-care confidence both mediates and moderates the relationship between self-care and outcomes¹². *In previous research, HF self-care confidence moderated the relationship between self-care and economic outcomes and mediated the relationship between social support and self-care¹². Specifically, self-care confidence decreased HF inpatient costs through the moderating effect of confidence (when high) on self-care management in a disease management intervention. As a mediator self-care confidence explained one way in which social support improved HF self-care in an urban,*

*clinic based sample*¹². However, the relationship between self-care confidence and HRQOL was not explored in that study. So it is unknown what, if any, relationship exists these two important constructs in HF.

The daily activities of self-care involve weight monitoring, strict medication regimens, low sodium diets, exercise, fluid monitoring, routine immunizations, and regular clinic visits¹³. Poor self-care is common in HF patients¹⁴ and is evidenced by skipped medication doses, dietary indiscretions, and lack of recognition of symptoms of fluid overload in its early stages¹⁵. Symptom exacerbation, disease progression and hospitalization are associated with poor self-care¹⁶. All of these factors are known to decrease HRQOL⁴.

Having multiple chronic conditions as well as anxiety and depression are factors known to complicate self-care¹⁷. Each of these factors is more prevalent in the older adult population¹⁸. Managing multiple medication and dietary regimens while determining what is causing his/her symptoms and then making decisions regarding treatment choices can stress the ability and capability of the older individual, whether patient or caregiver. In addition, there is a strong relationship between older age and deteriorating cardiac status⁷. Patients over 65 years are more likely to meet the criteria for moderate to advanced HF, meaning that they are more likely to be both symptomatic and suffer significant functional limitations. There is a greater need for self-care at the very time that they are impaired in even their basic activities of daily living. Zambroski⁷ in reviewing the literature on self-care in advanced HF notes the need for targeted and meaningful self-care strategies for those identified as “the sickest of the sick”.

HRQOL in HF. Health related quality of life has been defined as the person’s perception of the impact of their disease on four domains – physical, psychological, social, and functional status¹⁹⁻²¹. Aging and disease burden negatively impact HRQOL²² through the

person's symptom experience. The uncertain end stage trajectory of HF only increases this negative impact on the person's HRQOL^{23,24}. There has been a significant body of work exploring the relationship between HRQOL and HF in the last 10 years^{4,9,21,25,26}. Symptoms, gender, income, ethnicity, functional status, and health perception are consistently associated with HRQOL in HF patients^{20,24,27}. Health related quality of life is also associated with morbidity, mortality, and treatment choices for patients²⁸. For example, patients with poorer HRQOL have been shown to be more willing to trade survival time and take risks in treatment choices than those with better HRQOL^{29,30}.

While it is known that self-care is imperative in HF¹⁷ and improved HRQOL has been hypothesized to result from better self-care, the evidence for a HRQOL benefit from HF self-care is mixed at best^{8,17}. Taxonomic and methodologic limitations, such as: 1) lack of standard operationalization of terms and instrumentation and 2) embedding of self-care interventions in larger programs make measurement of effect problematic in clinical trials. Therefore, it is difficult to state conclusively whether better self-care improves HRQOL. This study seeks to address this issue by exploring associations between specific domains of self-care (maintenance, management, and confidence) in relation to specific domains in HRQOL (physical, emotional, and total). Careful definitions, widely used instruments, and a conceptual framework address some of the previous limitations⁸.

Conceptual Framework

From the literature it is posited that poor self-care impairs HRQOL through its effect on symptoms and functioning (dotted lines). To test this hypothesis it is necessary to first establish whether there is a relationship between self-care and HRQOL. This study seeks to test what, if any, relationship exists between self-care and HRQOL (denoted by the solid line).

Method

Setting and Sample

This is a secondary analysis of an existing national longitudinal dataset of older persons with HF collected as part of the Heart Failure Quality of Life Registry from nine samples across the United States and Australia. *The majority of the sample was enrolled from two sites in the Midwestern US (Table 1). Included were populations accrued from large and small outpatient and inpatient facilities providing an intentional heterogeneity.* Local institutional review boards approved each study and eligibility for the study was assessed by trained research assistants.

As part of the Registry, similar inclusion and exclusion criteria as well as instruments were used in the different sites. All of the subjects in the Registry were diagnosed with chronic HF with either impaired or preserved systolic function. All were cognitively intact, English speaking, and able to consent and self-report on their experience. Subjects were excluded if awaiting heart transplant, had a recent cerebrovascular event with sequelae, a major psychiatric disorder (excluding depression) or a concurrent terminal illness.

The sample for this analysis was defined by the following inclusion criteria: a HF diagnosis; 65 years of age or older; NYHA Class III or IV classification; and completion of the two instruments - the Self-Care of Heart Failure Index (SCHFI) and the Minnesota Living with Heart Failure Questionnaire (MLHFQ). Subjects were excluded if they were younger than age 65, NYHA class I or II, or did not complete both the SCHFI and MLHFQ.

Instruments

Self-care was measured by the SCHFI v.4³², a 17 item index which is comprised of 3, 4-point Likert-like scales. The SCHFI measures: 1) self-care maintenance (treatment adherence and self monitoring); 2) self-care management (decision making in response to symptoms); and

3) self-care confidence (self-efficacy in the ability to perform self-care) in these three scales. Scale scores are standardized to range from 0 - 100³³. Higher scores reflect better self-care. The reported alpha for the SCHFI is an acceptable 0.77³⁴. In this study Cronbach's alpha was 0.61, 0.63, and 0.77 for the SCHFI maintenance, management, and confidence scores respectively, which is similar to prior reports.

Health related quality of life reflects the impact of disease and its concurrent symptoms on the individual's subjective quality of life²⁷. The MLHFQ¹⁹, a widely used instrument to measure HRQOL, measures the impact of HF and its treatment on living as the person wanted to over the previous 30 days and results in three subscales – physical, emotional and total HRQOL. The MLHFQ is a 21 item instrument that uses a 6-point Likert like scale. Scores range from 0 – 105 for the total score, 0-48 for the physical dimension score, and 0-30 for the emotional dimension score, with a lower score indicating less disease impact and thus better HRQOL. Reported alphas range from 0.87 to 0.95¹⁹. In this study, Cronbach's alpha was 0.90, 0.84, 0.83 for the MLHFQ total, physical, and emotional dimension scores respectively.

A standard investigator-developed sociodemographic questionnaire was used to assess self-reported age, gender, income, education, marital status, work, ethnicity and race. Clinical characteristics (NYHA functional class and left ventricular ejection fraction) were assessed via chart review.

Analysis

The analyses included descriptive, bivariate and explanatory analyses. All analyses were performed using commercially available statistical packages including SPSS v.17 (Chicago, Illinois) or Stata v.10 MP (College Station, Texas). Statistical significance was set at $p < 0.05$ for bivariate and multivariate analyses to correct for Type I error. Standard descriptive statistics,

including appropriate measures of central tendency, dispersion, frequencies, and proportions, were used to describe sociodemographic and clinical characteristics as well as SCHFI and MLHFQ scores.

Bivariate analyses (Pearson's product moment correlation) were performed to compare baseline SCHFI scores and MLHFQ scores. Consistent with the exploratory nature of our study aims, we analyzed both continuous measures of HRQOL and evaluated associations between HF self-care and better and worse HRQOL by using, respectively, below-median and above-median MLHFQ scores. Multivariate linear and logistic modeling were used to describe the strength and direction of the relationship between baseline measures of HF self-care (all three SCHFI scores) and HRQOL controlling for a priori determined patient characteristics derived from the literature and previous studies conducted by this group. Multivariate slope coefficients or odds ratios (OR)s and 95% confidence intervals were then calculated.

Results

Sample

The sample consisted of 207 adults (72.9 ± 6.3 years); predominantly (82%) NYHA Class III HF; over half (56%) were male (Tables 2 & 3). Overall, HF self-care was poor with the sample average well-below the established cut-off for adequate self-care score (a standardized score of 70) for each of the three SCHFI scores (Table 3).

Self-care and HRQOL scores

No significant correlations were found with self-care maintenance or management and HRQOL. Significant and negative linear associations were observed between self-care confidence and total ($r=-0.211$; $p=0.002$), physical ($r=-0.189$; $p=0.006$), and emotional HRQOL ($r=-0.201$; $p=0.004$). Patients reporting better (below-median) HRQOL had higher self-care

confidence scores compared with patients reporting above-median HRQOL scores (58.8 ± 19.2 vs. 52.8 ± 19.6 ; $p = .028$).

Self-care Confidence as a Determinant of HRQOL

Self-care confidence was an independent determinant of total ($\beta = -3.191$; $p = 0.002$), physical ($\beta = -2.346$; $p = 0.002$), and emotional ($\beta = -3.182$; $p = 0.002$) HRQOL controlling for other SCHFI scores, age, gender, and NYHA class (Table 4). Each one-point increase in self-care confidence was associated with a decrease in the likelihood of worse (above-median) HRQOL scores (OR=0.980 (95% CI=0.963-0.998; $P = .026$) with the same model controls.

Discussion

This study addresses a gap in the existing science by exploring the relationship between HF self-care and HRQOL in adults with moderate to advanced HF (NYHA Class III/IV). A significant linear association between self-care confidence and HRQOL was found even when the individual scored below the established cut point for adequate self-care. This relationship was not observed between self-care maintenance and HRQOL or self-care management and HRQOL. In addition, we found that greater self-care confidence was a determinant of better HRQOL in each domain (emotional, physical, and total) and decreased the odds of poor HRQOL, even after controlling for known confounders. *While the multi-factorial nature of HRQOL may account for the modest size of the correlations and explained variance in our models, our study still suggests that the level of confidence patients have in HF self-care is associated with HRQOL physical and emotional domains.* The finding that self-care confidence provides a link between self-care and all domains of HRQOL in a symptomatic HF population is novel as well as important because of the relationship between HRQOL and further morbidity

and mortality in moderate to advanced HF populations and the amount and complexity of self-care that is expected of these individuals.

Heart failure patients identify the importance of the *lack* of confidence as a barrier to successful management of their HF³². The SCHFI asks the individual, “How confident are you...” or “Generally, how confident are you...”³⁴ followed by specific cognitive or behavioral skills related to either maintenance or management of HF. The self-care confidence scale was added to the SCHFI in response to focus group findings³². Bandura’s theoretical work on self-efficacy³⁵ was used when interpreting the narratives from the focus groups and developing the items for the scale³². Heart failure self-care confidence was originally conceptualized as a component of self-care, but subsequent work led to the hypothesis that self-care confidence mediated and moderated the relationship between self-care and outcomes¹².

This study builds on what is known from previous studies of self-care confidence in similar populations. Self-care confidence was associated with better self-care particularly in women³⁶. Self-care confidence is an important determinant of whether individuals were labeled as expert, inconsistent or novice in their adherence to HF self-care expectations³⁷. Furthermore, a systematic review of clinical trials involving hospital discharge interventions found that self-care confidence resulted in fewer readmissions to the hospital in a community based sample of older adults with chronic care needs³⁸. Self-care confidence was shown to be culturally shaped when differences were found in levels of self-care confidence by ethnicity³⁹. In a second study exploring those findings more indepth, self-care confidence was found to moderate the effect of self-care management on economic outcomes in a Hispanic sample⁴⁰. In summary, in each of these studies higher self-care confidence is associated with positive outcomes. Our study adds to these positive findings. In addition to improving self-care,

increasing the likelihood of developing expertise in self-care, reducing health care utilization and cost (from the previous studies cited), greater self-care confidence also is a determinant of better HRQOL for the older adult with moderate to advanced HF.

Self-care confidence (self-efficacy) is vital for the performance of adequate self-care for several reasons. First, how confident a person is directly affects their performance of self-care. Self-efficacy beliefs influence the choices that a person makes, the energy that they expend, how long they will persevere, how resilient they are in the face of obstacles and the amount of stress and anxiety that they experience while persevering⁴¹. In addition, self-efficacy also impacts self-care indirectly through its influence on the naturalistic decision making process involved in self-care. What individuals believe about themselves, their problem and the environment interacts with factors that influence decision making – their knowledge, experience, skill, and values¹². Second, self-care confidence can be viewed as a compensatory mechanism used by individuals to bolster their quality of life. In this view quality of life is a homeostatic, multidimensional construct. Subjective (perception) and objective (life experience) domains of quality of life are influenced by environment and personal level factors⁴². A person's quality of life is relatively stable until there is a sudden or strong stimulus. Individuals compensate for a negative impact by utilizing internal mechanisms, one of which may be self-efficacy. For example, in HF, a sudden exacerbation of symptoms may be perceived by the individual as negatively impacting his/her quality of life by threatening hospitalization or death. If individuals believe, based on past experience, that they can control their symptoms (mastery) they will implement strategies that have worked in the past. If they are successful, the episode increases their confidence while improving their quality of life. Sarker and colleagues⁴³, in a coronary heart disease sample, found that poorer self-efficacy was associated with worse quality of life

(OR = 1.6, $p < 0.0001$) independent of disease severity and depression. How capable the person felt in the situation rather than how sick or depressed they were determined their perceived quality of life. This supports the findings of the current study of a direct linear relationship between self-care confidence and HRQOL.

Self-care confidence is important in HF but there are also broader implications from this study. Self-care confidence is amenable to interventions in HF⁴⁴. The focus in past studies of human responses to serious disease has been on deficits and suffering but recent work has begun to study human strengths and abilities⁴⁵. Self-care confidence (self-efficacy) is a strength. The emerging science of positive psychology posits that the human experience is multidimensional and balanced – that humans suffer but also experience happiness and that those two states interact⁴⁶. Positive psychology interventions have been found to have lasting outcomes⁴⁶. Interventions to increase self-care confidence can be used concurrently with those that decrease suffering. For the HF population two suggested lines of inquiry may involve specific interventions. First, interventions that teach and support creative strategies in self-care may improve symptom management for patients and families and should be tested. Second, interventions to improve the appraisal (“This is a challenge and I’ve met challenges successfully before”) and response (“I *can* care for myself/my loved one”) to the situation may also decrease the likelihood of failed self-care.

This study has practice and research implications. In clinical practice the focus is often on self-care management and maintenance but our study has shown that the degree of self-care confidence also has utility. Assessing how confident an older adult is with HF self-care may identify people who are at risk for poor self-care as well as those with poor HRQOL. Individuals could possibly be identified before there is a failure in self-care potentially eliminating

subsequent unplanned hospitalization. Those individuals who score poorly for self-care confidence may benefit from earlier referral to a palliative care intervention.⁴⁷ Such an early referral would enable access to a community based team of experts in symptom management and decision making⁴⁸, particularly useful for patients without personal skill in such matters.

The research implications of this study involve advancing conceptual thinking about the HF experience. This study was designed using a conceptual model developed and previously tested³¹ on older adults in an end-stage disease population. In the prior study the relationships between the physical, psychological, and spiritual/existential domains and quality of life were tested and evidence supporting these relationships was provided³¹. In this model self-care is hypothesized to mediate and/or moderate the relationships between the fixed and modifiable domains of the individual and his/her quality of life. This study is a first step in testing this hypothesis by establishing a relationship between self-care (a hypothesized mediator) and HRQOL. Based on our conceptual model and the findings of this study we recommend future testing of whether self-care confidence mediates or moderates the relationship between physiologic, psychologic, social/cultural, and spiritual/existential variables and HRQOL in adults with moderate to advanced HF. This will move the science forward by elucidating the point at which a confidence building intervention could have potential maximum impact.

Limitations

As with any study that are certain limitations that should be kept in mind. This study was a secondary analysis of data collected for other purposes and as such some desired variables were not available. *For example, there is no information on response rates from the individual studies so there is no way of assessing whether individuals likely to score lower on self-confidence were more likely to refuse participation or fail to complete the study. In addition, the*

low Cronbach's alpha (.61 and .63) for the maintenance and management scales, while consistent with other studies, may have contributed to the non-significant findings between those variables and HRQOL. While strong Cronbach's alpha coefficients are understood to represent how well the scale items are measuring the same construct, the developers of the SCHFI have found that patients do not perceive diet, medications, and exercise (items on the management and maintenance scales) as the same (behaviors that improve HF outcomes) or internally consistent. This may explain the consistent findings. A further limitation is that the data came from one time period in one group of patients; so causality could not be addressed.

Relationships postulated here are merely associative. Future prospective studies that measure the variables over time will be needed before any predictive statements can be made. However, every attempt has been made to uphold rigor and transparency in the analysis and reporting of the findings.

Conclusion

In this study we addressed a gap in the science by exploring the relationship between HF self-care and HRQOL in older adults with moderate to advanced HF (NYHA class III/IV); specifically, we explored the association between domains of self-care (maintenance, management, and confidence) in relation to domains in HRQOL (physical, emotional, and total). We found a significant linear association between self-care confidence and HRQOL but not between self-care maintenance or management and HRQOL. In addition, we found that all domains of HRQOL- emotional, physical, and total, were influenced by self-care confidence, with each one-point increase in self-care confidence associated with a decrease in the likelihood of poorer HRQOL. Our results suggest that measuring self-care confidence and intervening to

improve that confidence *has the potential to* improve quality of life for adults with moderate to advanced HF. *Further study is warranted.*

Pre-publication final version

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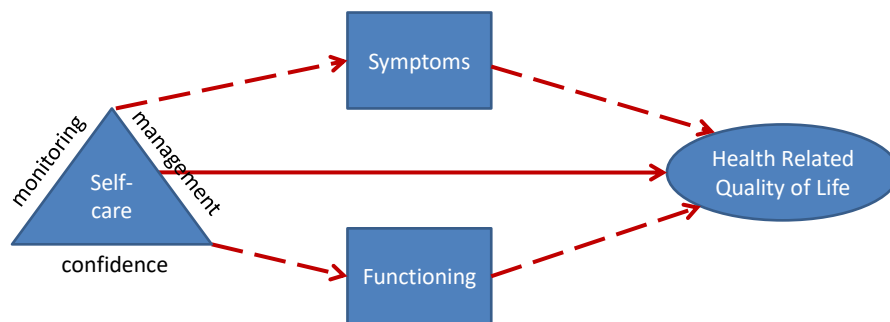
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Figure 1 Self-care and Health Related Quality of Life



Solid line denotes portion of the model being tested.

Table 1.

Heart Failure Quality of Life Registry Sampling Frame

	Percent
Ohio	48.8
Kentucky	47.9
California	1.0
Australia	2.4

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Table 2.

Demographic Characteristics

		N= 207
	Percent	Mean (SD)
Age		72.9 (6.3)
Gender		
Male	58.5	
Female	41.5	
Marital status		
Married	57.5	
Widowed	28.0	
Single	3.4	
Divorced/separated	11.1	
Ethnicity		
Caucasian	82.6	
African American	13.0	
Hispanic	1.4	
Education		
Less than high school	24.5	
High school graduate	29.1	
Business school	4.6	
Some college	16.3	
Associate degree	4.6	
Bachelor degree	12.2	
Graduate school	8.7	
Work		
Homemaker	2.9	
Full/part time work	6.9	
Disabled or retired due to HF	26.0	
Retired for non-HF reasons	55.4	
Other	2.9	
Income to make ends meet		
More than enough	33.5	
Enough	53.1	
Do not have enough	12.9	

Table 3.

Clinical Characteristics

	Percent	Mean(SD)
NYHA		
III	82	
IV	18	
Body Mass Index		28.3 (6.0)
Left Ventricular Ejection Fraction		31.7 (15.5)
MLHFQ ^a total score		43.3 (19.8)
MLHFQ ^a physical score		24.3 (6.8)
MLHFQ ^a emotional score		7.8 (6.83)
SCHFI ^b maintenance score		54.1 (23.0)
SCHFI ^b management score		56.0 (22.9)
SCHFI ^b confidence score		55.7 (19.6)

^aMinnesota Living with Heart Failure Questionnaire

^bSelf-Care of Heart Failure Index

Table 4.

Regression Analyses of Predictors of HRQOL ^a and Self-care					
	Variable	Standardized β	<i>t</i>	P	Model Statistics
Total					
HRQOL ^a	Gender	-0.001	-0.016	.987	Model $F=2.990$; $R^2=0.098$; P=.008
	Age	-0.097	-1.261	.209	
	NYHA ^b	0.131	1.763	.080	
	Self-care maintenance	-0.040	-0.471	.638	
	Self-care management	0.175	1.999	.047	
	Self-care confidence	-0.258	-3.191	.002	
Physical					
HRQOL ^a	Gender	0.014	0.191	.849	Model $F=2.537$; $R^2=0.084$; P=.022
	Age	-0.101	-1.309	.192	
	NYHA ^b	0.179	2.382	.018	
	Self-care maintenance	-0.080	-0.931	.353	
	Self-care management	0.121	1.371	.172	
	Self-care confidence	-0.184	-2.346	.020	
Emotional					
HRQOL ^a	Gender	0.058	0.769	.443	Model $F=1.961$; $R^2=0.066$; P=.074
	Age	-0.056	-0.716	.475	
	NYHA ^b	0.019	0.245	.807	
	Self-care maintenance	0.048	0.558	.578	
	Self-care management	0.097	1.085	.279	
	Self-care confidence	-0.252	-3.182	.002	

^a health related quality of life

^b New York Heart Association class

Implications

- Self-care confidence is an important link between HF self-care and health related quality of life.
- How confident a person is in HF self-care impacts both the physical and emotional components of their health related quality of life.
- Assessing how confident older adults are with self-care may identify people at risk for both poor self-care and poor HRQOL before there is a failure in self-care.

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