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Patterns of self-care and clinical events in a cohort of adults with heart failure: 1 year follow-up

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Abstract

Aims: Self-care is a vital component of heart failure (HF) management. The purpose of this paper was to identify patterns of self-care that would be associated with clinical outcomes.

Methods and Results: We examined self-care and outcomes in a cohort of 459 Italian HF patients. Self-care maintenance (i.e. treatment adherence) and management (i.e. self-initiated response to symptoms) were measured using the Self-Care of HF Index and consulting behaviors (i.e. consulting a provider) were measured using the European HF Self-care Behavior Scale. Latent class mixture modeling was used to identify patterns of HF self-care and hazard modeling was used to link self-care patterns to all-cause mortality and emergency room visit or hospitalization for HF. The average age of the sample was 72 years and a majority of patients were male (55%). Three patterns of HF self-care were identified: poor symptom response behaviors

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(32.9%), good symptom response (24.4%) and maintenance-focused (42.7%). Over 1 year of follow-up, 30% of patients died and 30% required emergency care/hospitalization for HF. Patients with poor symptom response behaviors had the worst outcomes. Patients with good symptom response behaviors had a lower event-risk compared with those who had poor symptom responses (adjusted hazard ratio=0.66 (0.46–0.96), $p=0.03$). Patients with poor symptom responses and those who were maintenance-focused had similar event-risk.

Conclusions: Self-care in general, and patients' ability to recognize and respond to HF symptoms in particular, is associated significantly with clinical outcomes. Routine assessment, mitigation of barriers, and interventions targeting self-care are needed to improve clinical outcomes in HF.

Keywords

heart failure; self-care; survival

Introduction

Patients living with heart failure (HF) are accountable for the vast majority of their own care even if they have access to evidence-based medical care.(1) For example, self-care of HF involves daily routine behaviors like taking prescribed medicines, engaging in health promotion behaviors like exercise (i.e. self-care maintenance).(2) Another essential component of HF self-care is the patient's ability to recognize and respond to symptoms when they occur independently (i.e. self-care management) or in consultation with a healthcare provider (i.e. consulting behaviors).(3) Interventions designed to enhance HF self-care maintenance generally reduce rates of HF hospitalization.(4) Moreover, there is evidence that better HF self-care management is associated with lower myocardial stress and systemic inflammation,(5) and better patient-reported outcomes.(6) Hence, HF self-care is an essential element of the management of HF.

Despite its importance, HF self-care is generally inadequate worldwide,(7) and patients find recognizing and responding to HF symptoms particularly difficult compared with self-care maintenance behaviors.(2, 8) Distinct and informative patterns of HF self-care behaviors have been identified in previously research,(6, 9, 10) but have not been linked directly to clinical outcomes. Hence, the clinical relevance of patterns of HF self-care behaviors observed in prior research is unclear. There is evidence, however, that patients with HF who are able to engage in effective self-care management have a reduction in clinical event-risk compared with similar patients who are unable to effectively recognize and respond to symptoms when they occur.(11) Accordingly, the aims of this study were to a) identify unique and naturally-occurring patterns of HF self-care behaviors, and b) quantify associations between patterns of self-care and clinical events during one year of follow-up.

Methods

Study design

This was a secondary analysis of data collected during a cohort study of community-dwelling Italian adults living with HF.(8, 12) The aims of the original study were to describe

and identify socio-demographic and clinical determinants of HF self-care behaviors. In brief, 1,192 heart failure patients were enrolled from outpatient centers in 28 Italian provinces. Patients were 18 years of age or greater and had a confirmed diagnosis of HF made in accordance with evidence-based guidelines;(13) all diagnoses were made by treating cardiologists based on echocardiographic evidence confirmed with clinical evidence (i.e. signs of HF like edema or elevated filling pressures and common symptoms of HF like dyspnea). Patients with an acute cardiovascular event in the preceding 3 months were excluded as were those with obvious dementia. All questionnaire data were collected in person in a private space by trained nurse research assistants. This analysis was conducted using data from an ancillary study of patients who consented to clinical events follow-up over the course of one year, and is complementary to the aims of the parent study. The Strengthening the Reporting of Observational Studies in Epidemiology Statement was used to guide our reporting of this observational study.(14)

Ethical approval

This study complied with the Declaration of Helsinki, ethics committees at each site approved the research protocol, and informed consent was obtained from all participants. The informed consent form gave also the investigators permission to contact participants and their caregivers by phone for follow up purposes. To ensure compliance with de-identified data handling procedures, the secondary analysis presented in this paper was also reviewed and approved by the Institutional Review Board.

Measurement

All measures included had been previously translated and validated in Italian except where noted. Self-reported socio-demographics (e.g., age, gender, income, education) were collected using an investigator-developed survey. Clinical information on the patients (e.g., duration of illness, hospitalization for HF within the last year, and New York Heart Association [NYHA] functional class as assessed by clinicians at baseline) was abstracted from the medical record. Clinical information from medical records was also abstracted to complete the Charlson Comorbidity Index,(15) which considering 19 diseases. For each of these conditions a possible score of 1, 2, 3 or 6 can be attributed according to condition gravity. Possible scores range from 0 to 36 with higher score indicating higher comorbidity. Cognitive function was assessed at baseline using the Mini Mental State Examination that ranges from 0–30 with higher values indicating better cognitive function.(16) At baseline patients also completed the Minnesota Living with Heart Failure Questionnaire (MLHFQ), (17) a 21-item diseases-specific tool to measure the extent to which physical and psychological symptoms of HF affect patients' health-related quality of life (HRQOL). Scores on the MLHFQ range between 0–40 and 0–25 for the physical and psychological dimensions, respectively, with higher score indicating worse HRQOL.

Heart Failure Self-Care—Patient-reported self-care of HF was measured using the Italian version of the Self-Care of Heart Failure Index v6.2 (SCHFI),(18) which was translated as part of the parent study.(19) The SCHFI has 22 items that capture self-care maintenance (daily routine behaviors), management (symptom recognition and response behaviors), and confidence (confidence in the ability to engage effectively in self-care). Standardized scores

are calculated for each scale (range 0–100) with higher scores indicating better self-care; a cut-point of 70 has been previously established as indicating adequate self-care.(18) Factor score determinacy reliability coefficients were between 0.78 and 0.90 for the three scales in this patient sample.(20)

Consulting behaviors (e.g., the likelihood of contacting a provider in case of signs and symptoms of worsening HF) were measured with the 4-item consulting behavior subscale of the European Heart Failure Self-care Behaviour scale (EHFScBS).(21) The excellent psychometric properties of the original version of the EHFScBS have been shown to be similar in the Italian version used in this study.(20) The score was reversed and standardized on a 0 – 100 range with higher scores indicating better self-care. We chose to use the consulting behaviors subscale, as opposed to the whole EHFScBS, because these specific behaviors have been shown to be complementary to those measured with the SCHFI maintenance and management scales.(9)

Clinical events—The clinical events considered in this study were all-cause mortality, and emergency room visits or hospitalization related to HF exacerbation (e.g. dyspnea) during 12 month follow up. These data were collected by interviewing patients by phone. If the patient was not reachable at the time of follow-up (12 months), the primary caregiver was interviewed. Patients' primary caregivers had been previously designated as such by the patient and defined as the unpaid person (inside or outside the family) who provided the most informal care to the HF patient. All caregivers gave informed consent to participate.

Statistical Analysis—Descriptive statistics (mean $\pm$ standard deviation (SD)), number of observations and proportions, or medians with inter-quartile ranges) were used to describe the samples. Latent class mixture modeling (LCMM) was used to identify distinct profiles among HF self-care behaviors (SCHFI maintenance and management and EHFScBS consulting behaviors scales). The Vuong-Lo-Mendell-Rubin (VLMR), adjusted Lo-Mendell-Rubin likelihood ratio (LMRT),(22) and parametric bootstrap likelihood ratio tests (PBLRT) (p-value for all), model convergence (entropy near 1.0), the size of the observed profiles (not less than 5% of the sample), and classification probabilities (posterior probabilities for most likely class near 1.0) were used to assess the comparative performance of the final vs. alternative solutions (e.g. 3 vs. 2 patterns).(23)

Comparative statistics (F -statistics from analysis of variance, and χ^2) were used to compare factors among the observed patterns. We then labeled the patterns according to key differentiating aspects of HF self-care. Cox proportional hazards modeling was used to quantify differences in 12 month event-risk (all-cause death, emergency room visit for HF, or hospitalization for HF). The proportional hazards assumption was justified based on Schoenfeld residuals, and both unadjusted and adjusted hazard ratios (HR) and 95% confidence intervals (CI) are presented. LCMM was generated using Mplus v7.31 (Los Angeles, CA); all other analyses were performed using Stata MP v14 (College Station, TX).

Results

Of the 575 patients who agreed to participate in this ancillary follow-up study, 459 were reached by the investigators. Comparing patients considered in this ancillary study to the 1192 in the parent study, the differences between the two groups were that the patients in the ancillary study were slightly younger (72 vs. 73, p 0.01), with a slightly lower ejection fraction (43% vs. 46%, p <0.001) and were more frequently in NYHA functional class III and IV (63% vs. 37%, p 0.004). Socio-demographic and clinical characteristics of the sample are presented in Table 1. In brief, a slight majority of patients were male (54.9%), and the average age of the sample was 71.8 ± 12.1 years. A slight majority (54.0%) of patients had NYHA class I/II vs. III/IV HF. Self-care behaviors reported in this sample were fairly poor (maintenance 58.5 ± 17.4 , management 53.2 ± 20.9 , and consulting behaviors 47.4 ± 32.9).

Three distinct patterns of HF self-care behaviors were identified (entropy = 0.86; VLMR p <0.0001; LMRT = 40.8, p <0.0001; PBLRT p <0.0001; and posterior probabilities exceeded 0.93, all supporting a good pattern solution). Significant differences in HF self-care behaviors across the three groups are presented in Table 2. Approximately 33% of the sample had HF symptoms, but were poor at recognizing and responding to them when they occurred (i.e. self-care management was well below adequate and they reported the worst consulting behaviors); we labeled this group as having “poor symptom response behaviors.” Another group (24.4%) had HF symptoms but reported a level of symptom response behaviors known to be adequate and also reported far better consulting behaviors and self-care maintenance compared with the poor self-care group; we labeled this group as having “good symptom response behaviors.” The third group (42.7%) did not perceive HF symptoms at enrollment and therefore did not engage in self-care management behaviors, and they also reported average consulting behaviors and inadequate self-care maintenance; we labeled this group as being “maintenance-focused” because their self-care was centered on routine self-care maintenance behaviors. These three patient groups based on HF self-care also differed significantly in several demographic and clinical characteristics as presented in Table 1. In brief, patients in the poor symptom response group were older, less educated, less likely to be employed, had worse functional limitations from HF, lower ejection fraction, were on more medicines, were more likely to require home oxygen, had more comorbid conditions, had worse cognitive function, and had worse HRQOL compared with patient with other patterns of HF self-care.

Over a median follow-up time of 12 months, nearly 30% of patients died and another 30% required an emergency room visit or hospitalization for HF (Figure 1). Compared with patients who had poor symptom response behaviors and adjusting for observed differences among profiles, patients with good symptom response behaviors were much less likely to die or require emergency care or hospitalization for HF (Table 3; Figure 2). Patients who were maintenance-focused were as likely to die or require emergency care or hospitalization for HF as those who had poor symptom response behaviors in adjusted survival models.

Discussion

The aim of this study was to identify patterns of HF self-care behaviors and to associate these patterns to clinical events (all-cause mortality or emergency room visit/hospitalization due to HF) in a cohort of 459 Italian HF patients. Results of this study identified not only distinct patterns of self-care behaviors, but also that these patterns were associated with different clinical event-risk during one year of follow-up.

To our knowledge this is the first study that has identified patterns of HF self-care using the two most-commonly used self-care instruments: the SCHFI and the EHFSBS. The combined use of both scales allows for full characterization HF self-care across its multiple dimensions: self-care maintenance (behaviors aimed at maintaining HF stability), self-care management (behaviors that patients perform in response to HF symptoms), consulting behaviors (consultation with a provider when HF symptoms arise, complementary to self-care maintenance and management behaviors) and self-care confidence (patient perceived self-efficacy in self-care behaviors). With the combination of these four dimensions, our analysis identified three patterns of self-care. We characterized these patterns by patient response to symptoms as follows: 1) poor symptom response behaviors, 2) good symptom response behaviors and 3) maintenance-focused. Interestingly, pattern membership was associated with a number of socio-demographic and clinical characteristics. Perhaps most notably, having poor symptom response (as compared with good symptom response or being self-care maintenance-focused) was associated with worse HF by multiple metrics: functional class, ejection fraction, and burden of HF symptoms on physical and emotional HRQOL. This is consistent with previous research demonstrating associations between worsening self-care behaviors and worse HRQOL and HF symptoms.(6)

Adjusting for the sociodemographic and clinical characteristics that significantly differed by pattern membership, we found that patterns of HF self-care predicted hazard of clinical events over a median of 12 months. Specifically, we found that patients who belonged to the “good symptom response behaviors” group were substantially less likely to die, be hospitalized or need emergency care during the follow-up period as compared to patients who belonged to the “poor symptom response behaviors” group. This adds to the growing body of literature underlining the criticality of good daily self-maintenance behaviors, and the prompt and appropriate response to HF symptoms, both individually and in concert with a consulting provider.(24, 25) Somewhat surprisingly, patients who were maintenance-focused were equally likely to die or require emergency care or hospitalization for HF as compared with those who had poor symptom response behaviors. Perception of symptoms is foundational to appropriate HF symptom response, but also is notoriously complicated for patients.(26) It is possible that some patients who reported no symptoms at baseline were indeed had class II or greater HF, but unable to recognize their symptoms. Thus, poor symptom perception might explain the finding of no difference in clinical event-risk among maintenance-focused patients as compared to poor symptom responders.

This study has important clinical and research implications. It is notable that persons with poor symptom response behaviors, while less likely to have been hospitalized in the year prior to enrollment as compared to the other groups, had markedly worse clinical event-risk

over time. This may be partially explained by previous research that has identified associations between increased delay in seeking care and multiple factors, such as the presence of certain HF symptoms (e.g. dyspnea, edema, and weight gain), greater distress with symptoms, and/or an inability to identify and respond to symptoms within the context of multimorbidity.(26–28) Thus, symptomatic persons with poor self-care behaviors may utilize less healthcare resources in the short term, but ultimately the compounding influence of poor self-care appears to result in worse clinical event-risk. From this perspective, it may be beneficial for providers to evaluate self-care adequacy along with other clinical indicators at regular visits, as “no event” is clearly not equivalent to “no problem.” In terms of evaluating self-care adequacy from both a clinical and research perspective, our analysis provides additional evidence for meaningful cut points on the SCHFI and EHFSBS. Namely, we identified that a score of approximately 70 for the SCHFI and approximately 55 for the consulting behaviors dimension of the EHFSBS were associated with better outcomes. Riegel et al.,(18) after a series of mixed method studies, proposed a score of 70 at each SCHFI scale for self-care adequacy. Results of our study, considering all-cause mortality and use of emergency services and hospitalizations, support that cut-point. While the cut-point for the EHFSBS subscale was lower than that of the SCHFI, this may be a function of good self-care maintenance, management and confidence resulting in better outcomes and less of a need for these patients to call providers for guidance. Less consulting behaviors compared with other aspects of HF self-care may indicate that patients are doing more themselves in response to symptoms instead of contacting providers.

This study has limitations and strengths. First, these data were collected by convenience sampling and, because investigators did not have long-term access to the medical record, all clinical events data were collected by self-report that may be associated with recall bias. Investigators worked to balance these limitations, however, by sampling a large cohort across 28 provinces in Italy, and by consenting caregivers as secondary reporters to mitigate problems of missing data due to lost follow-up. Second, these data are from a single geographical region (Italy), and, although the findings are largely consistent with previous studies that have found associations between self-care and clinical event-risk, results should be interpreted with caution when generalizing to other countries. Finally, strengths of this work includes the large sample size and subsequent ability to identify meaningful patterns in self-care across measures that are considered the global standard. These patterns predicted clinically meaningful differences in event-risk and were in alignment with the current consensus on cut-points for evaluating adequate self-care.

Findings from this study may inform future research directions. The importance of evaluation and support of HF self-care at all dimensions is clearly an important aspect of outcomes-focused clinical management. There is little consensus on how best to implement the evaluation of patient’s self-care behaviors, however, or how to intervene to support inadequate HF self-care. In particular, it is not clear when in the trajectory of HF an assessment of self-care should occur, or how self-care should be assessed in clinical practice. Furthermore, HF self-care interventions have seen inconsistent success, and even when interventions are successful, we have very little insight into when reassessment and/or reinforcement should occur. This may be due, in part, to the complex interplay of factors that function as barriers to patient attainment of self-care expertise.(2, 26) Thus, research is

needed on how to best assess self-care within the framework of existing clinical care provision, and to elucidate heterogeneous and inconsistent responses to self-care intervention so that more targeted and effective approaches to supporting self-care can be developed.

In conclusion, we observed that, across multiple dimensions of self-care, patients fell into three distinct patterns of self-care behaviors: patients with good symptom response behaviors, patients with poor symptom response behaviors, and patients who were focused on the routine behaviors of self-care maintenance. Not surprisingly, patients with poor symptom response behaviors had notably worse clinical event-risk as compared to patients with good symptom response behaviors, demonstrating that self-care in general, and patients' ability to recognize and respond to HF symptoms in particular, is an important predictor of clinical outcomes. Further research on clinical assessment of self-care, mitigation of potential barriers to achieving sufficient self-care experience and expertise, and refinement of interventions to improve self-care are needed to improve HF outcomes.

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Figure 1: Distribution of clinical events during 12 months of follow-up.

29.6% of patients died, 13.3% required an emergency room visit for heart failure, 16.3% required hospitalization for heart failure and the remaining 40.8% remained alive without events at 12 months.

Abbreviations: ER – emergency room; HF – heart failure

Figure 2: Adjusted clinical event hazard by pattern of heart failure self-care.

Compared with patients who had poor symptom response behaviors, those with good symptom response behaviors were much less likely to die or require emergency care or hospitalization for heart failure over 12 months of follow-up. Those who were maintenance-focused were equally likely die or require emergency care or hospitalization for heart failure compared with those who had poor symptom response behaviors in adjusted survival models. **Note:** Hazard ratios shown are adjusted for age, education, New York Heart Association functional class, employment, Charlson comorbidity index, hospitalization for heart failure in the prior year, number of medications, left ventricular ejection fraction, serum sodium, serum hemoglobin, home oxygen use, and both physical and emotional health-related quality of life.

Abbreviations: HR – adjusted hazards ratio.

Table 1:

Patient characteristics by pattern of self-care (n=459)

Characteristic	Poor Symptom Response Behaviors n=151 (32.9%)	Good Symptom Response Behaviors n=112 (24.4%)	Maintenance- Focused n=196 (42.7%)	F, p-value; χ^2 , p-value; K- Wallis, p-value
Age (in years)	74.7±10.2	70.5±13.9	70.4±12.0	6.6, 0.002
Gender (n(%) female)	60 (39.7%)	58 (51.8%)	89 (45.4%)	3.8, 0.151
Education * (%)	35 (23.2%)	29 (25.9%)	75 (38.3%)	10.5, 0.005
Married (%)	85 (56.3%)	59 (52.7%)	115 (58.7%)	1.0, 0.593
Currently employed (%)	13 (8.6%)	29 (25.9%)	46 (23.5%)	14.5, <0.001
Months with heart failure	48 [24–96]	38 [24–71]	36 [24–60]	5.8, 0.056
NYHA functional class				
I or II	54 (35.8%)	63 (56.3%)	131 (66.8%)	33.5, <0.001
III or IV	97 (64.2%)	49 (43.7%)	65 (33.2%)	
Ejection fraction	38.8±11.5	45.7±11.5	44.6±10.0	14.1, <0.001
Number of medications	6 [4–8]	4 [3–6]	4 [3–6]	22.9, <0.001
Hospitalized last year (%)	44 (29.1%)	49 (43.8%)	111 (56.6%)	26.1, <0.001
Home oxygen (%)	46 (31.1%)	18 (16.5%)	25 (12.8%)	18.7, <0.001
Sodium	139.8±14.8	141.2±21.0	140.3±19.0	0.2, 0.859
Hemoglobin	12.3±1.8	12.5±2.0	12.6±1.9	0.8, 0.434
Charlson index	3.2±1.3	2.8±1.0	2.8±1.2	4.9, 0.008
Body mass index	26.6±4.2	26.2±5.1	26.6±5.0	0.4, 0.696
MMSE Total Score	22.1±6.6	25.9±5.2	25.3±5.4	18.0, <0.001
Physical quality of life	24.2±8.4	22.8±8.5	16.6±5.0	50.8, <0.001
Emotional quality of life	13.2±5.2	12.5±6.0	9.5±5.7	21.3, <0.001

* = professional/high school/university vs. not

MMSE = Mini Mental Status Exam; NYHA = New York Heart Association

Table 2:

Latent patterns of heart failure self-care behaviors (n=459)

Heart Failure Self-Care Behaviors	Poor Symptom Response Behaviors n=151 (32.9%)	Good Symptom Response Behaviors n=112 (24.4%)	Maintenance-Focused n=196 (42.7%)	F, p-value
Self-Care Maintenance	51.80±14.91	65.89±16.60	59.46±17.86	23.6, <0.001
Self-Care Management	38.68±12.76	72.72±11.81	-	487.3, <0.001
Consulting Behaviors	36.03±30.67	55.24±33.61	51.60±31.94	14.5, <0.001
Self-Care Confidence	47.60±15.39	70.88±20.65	61.53±21.58	47.4, <0.001

Table 3:

Event-risk by latent pattern of heart failure self-care behaviors (n=459)

Pattern of Self-Care Behaviors	Unadjusted Hazard Ratio	Adjusted Hazard Ratio [†]
Good Symptom Response [*]	0.679 (0.494–0.933), p=0.017	0.664 (0.459–0.959), p=0.029
Maintenance-Focused [*]	0.757 (0.579–0.990), p=0.042	0.758 (0.552–1.040), p=0.086

^{*} = relative to patients with “poor symptom response behaviors”

[†] = adjusted for other factors observed to be different across groups (i.e. age, education, New York Heart Association functional class, employment, Charlson comorbidity index, hospitalization for heart failure in the prior year, number of medications, left ventricular ejection fraction, serum sodium, serum hemoglobin, home oxygen use, cognitive function, and both physical and emotional quality of life).