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Self-care in heart failure patients1

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Objective: to describe self-care behavior and its associated factors in a sample of heart failure Brazilian patients. Method: descriptive cross-sectional study with non-probabilistic sample of 116 ambulatory patients undergoing heart failure treatment. Self-care was evaluated using the Self-Care of Heart Failure Index, (scores \geq 70 points=appropriate self-care). Association tests were applied, considering a descriptive level of 0.05. Results: the mean age of participants was 57.7 (SD =11.3) years; 54.3% were male; the mean schooling was 5.5 (SD = 4.0) years; and 74.1% had functional class II-III. The mean scores on the subscales of the Self-Care of Heart Failure Index indicated inappropriate self-care (self-care maintenance: 53.2 (SD =14.3), self-care management: 50.0 (SD = 20.3) and self-care confidence: 52.6 (SD=22.7)) and it was found low frequencies of participants with appropriate self-care (self-care maintenance, 6.9%), self-care management (14.7%) and self-care confidence (19%). Higher scores of the Self-Care of Heart Failure Index were associated with: reduced left ventricular ejection fraction (p=0.001), longer time of experience with the disease (p=0.05) and joint monitoring by physician and nurse (p=0.007). Conclusion: investments are needed to improve the self-care behavior and the nursing can play a relevant role in this improvement.

Descriptors: Self-Care; Heart Failure; Nursing.

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Introduction

Self-care in chronic diseases is related to the maintenance of the appropriate level of physical and psychological well-being, decrease in morbidity and mortality and in the use and cost of healthcare, increase in patient's satisfaction, improvement of control sense and life quality, reasons by which selfcare is a central concern in the care for people with chronic diseases⁽¹⁾.

The self-care concept has evolved over the years. It is associated with autonomy, independence and individual responsibility for healthy behaviors, as well as for the development of activities required to manage and monitor health conditions⁽²⁻³⁾.

The illness experience requires that people integrate practices and recommendations to self-care, in order to maintain the greatest well-being possible. The self-care promotion is essential in chronic disease by involving activities and skills that should be learned and used by the individuals to improve their quality of life (3)

Chronic diseases are the main causes of mortality worldwide, with heart failure standing out as one of the leading causes of hospitalization and high rates of morbidity and mortality in many countries⁽⁴⁾. Heart failure (HF) is currently one of the major public health problems in Brazil, and its complex and progressive nature often results in adverse events, such as high rate of rehospitalization and mortality, which could be reduced if there were appropriate self-care⁽⁵⁾.

In HF, self-care refers to the behaviors developed by people to maintain their health (self-care maintenance) and decisions they make about worsening of symptoms when they occur (self-care management)⁽²⁾. The self-care maintenance involves adherence to pharmacological recommendations, consumption of a low-salt diet, cessation of tobacco use, limited alcohol consumption, daily monitoring of body weight, signs or symptoms, and HF decompensation. From this perspective, self-care is a decision-making process that patients use in choosing behaviors that maintain physiological stability, and response to the symptoms when they occur⁽²⁾.

Self-care has been the focus of research in the healthcare area and instruments for its evaluation have been developed. In a systematic review⁽⁶⁾, which aimed to identify the instruments to measure self-care in HF patients, 14 instruments were identified of which two had been subjected to rigorous psychometric tests: European Heart Failure Self-Care Behaviour

Scale (EHFScBS) and Self-Care of Heart Failure Index (SCHFI). Both instruments assess different aspects of self-care behavior and have been validated for use in Brazil⁽⁷⁾. The EHFScBS aims to assess the recognition of signs and symptoms of decompensation and decision-making in the occurrence of these symptoms; SCHFI, in turn, in addition to evaluating the recognition and actions to improve the signs and symptoms of clinical decompensation, includes aspects related to how confident the individual feels to perform activities related to self-care⁽²⁾.

Recent studies with samples of HF patients indicate that self-care is inappropriate⁽⁷⁻¹⁰⁾ and that individuals who participated in educational self-management programmes showed a better self-care behavior⁽¹¹⁾. Socio-demographic and clinical characteristics typical of HF are described in the literature as variables that influence self-care of HF patients. Cultural aspects and education level are also mentioned as factors that can influence self-care behavior in different nationalities⁽¹²⁻¹³⁾.

In Brazil, self-care behavior is little studied and the variables that influence self-care are still little explored in this population, which motivated this study. Knowing the self-care behavior in samples of Brazilians with HF contributes to the understanding of this phenomenon and so that nurses recognize behaviors that need to be modified or added for a better disease control and consequently, a better quality of life for HF people.

Based on the above, the objectives of this study were to describe the self-care behavior of HF adult patients, by means of the SCHFI, Brazilian version; and analyze self-care based on certain socio-demographic and clinical variables and monitoring type.

Method

The cross-sectional observational study was performed with data obtained by personal interview of a non-probabilistic sample of 116 adult patients in an ambulatory care setting for HF in the period from April to September 2013. Researchers previously checked the medical records of potentially eligible patients for their recruitment. Those who met the inclusion criteria were invited to participate in the study, with a study explanation and presentation of the Informed Consent (IC). It was included all who agreed to participate in the study in the predetermined period.

The study was carried out at an ambulatory of a public teaching hospital, specialized in cardiology, in the city of São Paulo, Brazil. Such ambulatory has a multidisciplinary approach for monitoring clinically stable patients. The nursing consultation is routinely performed to those patients who need therapeutic optimization, as well as general guidance on the disease, symptoms control and treatment adherence, following the guidelines of the III Brazilian Guidelines on Chronic Heart Failure(14). However, due to insufficient number of nurses, this service is not offered to all patients who attend the service. The medical team refers to the nursing care only patients with clinical decompensation, difficulty of adherence to the treatment regimen and those in need of optimization and a better control of the therapeutic regimen.

The inclusion criteria were: regularly enrolled in the HF ambulatory of the institution where the data were collected; 18 years or older, confirmed medical diagnosis for HF, functional class I, II or III, according to the classification of the NYHA⁽¹⁴⁾, and clinical conditions that would allow them to participate in the interviews. It was excluded those with psychiatric disorders, oncological diseases, infectious diseases with repercussions on the general state or endocrine-metabolic diseases without treatment (for example, *diabetes mellitus* or thyroid diseases); patients in early postoperative period (up to 60 days postoperatively) of any surgical procedure, conditions that could interfere with usual self-care behavior.

The self-care behavior was evaluated using the Brazilian version of the Self-Care of Heart Failure Index - v 6.2 (SCHFI)⁽⁷⁾. The SCHFI is a self-care measure composed of 22 items divided into three scales: selfcare maintenance (10 items), self-care management (6 items) and self-care confidence (6 items). The scores for each domain range from 0 to 100 points, calculated from the transformation of the pure scores (each item of the scale ranges from 1 to 4). Higher scores reflect greater self-care and scores ≥70 points for each subscale indicate appropriate self-care(2). The Brazilian version of the SCHFI revealed reasonable reliability and validity estimates(7). In the present study, Cronbach's alpha coefficient for the total of the SCHFI was 0.70, and in the subscales, it ranged from 0.40 to 0.74. According to the guidelines for use of the SCHFI⁽²⁾, the "self-care management" subscale should be applied only to patients who reported difficulty to breath or swelling in the ankles in the month prior to the application of the instrument.

Regarding to socio-demographic variables, it was considered age, gender, education, ethnicity (as patient's medical record, according to the categories described by the Brazilian Institute of Geography and Statistics - IBGE); marital cohabitation, employment status (self-report for the current work situation). The clinical variables were: HF functional status (as assessed by the investigators at the data collection time, following the guidelines established by the New York Heart Association - NYHA(14), Left Ventricular Ejection Fraction (LVEF) (as recorded in the echocardiogram reports), HF etiology (as recorded in the patient's chart), time of experience with the disease (self-report of years since HF was diagnosed and/or the date of the first register of HF diagnosis at the medical record), cognitive aspect (Mini Mental State Examination - MMSE(15)) and comorbidity (Charlson Comorbidity Index - CCI)(16), classified as low (scores 1-2), moderate (3-4) and high (≥5) comorbidity index⁽¹⁶⁾. It was also assessed the type of monitoring received by the patient (if supervised exclusively by the physician or by physician and nurse).

Data were analyzed using descriptive statistics; the association of the SCHFI with the variables of interest was carried out using an ANCOVA model, controlling by the cognitive decline. All analyzes were performed using SPSS®, version 17, and the significance level adopted was of 5%.

The Ethics Committee of the institution where it was conducted approved the study (Protocol number 145.630 - 2012) and all participants signed the Informed Consent Form.

Results

Table 1 shows the socio-demographic and clinical characteristics of the participants.

Table 2 shows the descriptive statistics for the scales of self-care maintenance (maintenance), self-care management (management) and self-care confidence (confidence). The proportions of patients with appropriate self-care (score ≥70 points) were: maintenance=6.9% management=14.7% and confidence=19%

Tables 3, 4 and 5 show the results of the association tests between selected variables and the SCHFI. On the self-care maintenance scale, the care provided by the physician and nurse (p=0.007) was associated with a better self-care (Table 3). In the self-care management subscale, ejection fraction (p=0.001) and longer time of experience with the disease (p=0.05) were associated with better self-care (Table 4). There was no association

Table 1 - Socio-demographic characterization, clinical and type of monitoring of the participants (N=116). São Paulo, SP, Brazil, 2014

Variables	Mean	Standard deviation	Minimum	Maximum	N	%
Age (years)	57.7	11.3	20	81		
Education (years of study)	5.5	4.0	0	20		
Time of experience with the disease (in months)	46.7	42.4	2	149		
Ejection fraction (%)*	40.4	12.9	20	73		
Gender						
Male					63	54.3
Female					53	45.7
Ethnicity						
White					69	59.5
Black					31	26.7
Brown					16	13.8
Marital cohabitation					70	60.3
Work situation						
Works					26	22.4
Unemployed					16	13.8
Retired or pensioner					61	52.6
Sick leave					13	11.2
HF functional class (New York Heart Association)						
I					30	25.9
II					54	46.5
III					32	27.6
Cognitive impairment					52	44.8
HF Etiology						
Dilated cardiomyopathy					47	40.5
Chagas cardiomyopathy					44	37.9
Ischemic cardiomyopathy					13	11.2
Cardiomyopathy to clarify					12	10.3
High level of comorbidity CCI [†]					30	25.9
Type of monitoring						
Consultation with a physician					61	52.6
Consultation with physician and nurse					55	47.4

^{*}Missing data for a patient

Table 2 - Descriptive statistics of the *Self-Care Heart Failure Index*, Brazilian version (N=116). São Paulo, SP, Brazil, 2014

	N	Mean	Standard deviation	95% CI	Median
Self-care maintenance					
1. Do you weigh yourself?	116	1.9	0.9	[1.7;2.1]	2.0
2. Do you check if your ankles are swollen?	116	2.9	1.1	[2.7;3.1]	3.5
Do you try to avoid getting sick (for example: be vaccinated against flu, avoid contact with sick people)?	116	3.0	1.2	[2.8;3.3]	4.0
4. Do you practice any physical activity?	116	1.5	0.9	[1.3;1.7]	1.0
5. Are you assiduous in the consultations with the doctor or nurse?	116	2.9	1.4	[2.7;3.2]	4.0
6. Do you ingest a low-salt diet?	116	3.4	1.0	[3.2;3.6]	4.0
7. Do you exercise for 30 minutes?	116	1.5	1.0	[1.3;1.7]	1.0
8. Do you forget or fail to take any of your medicines?	116	3.3	0.8	[3.2;3.5]	3.0
9. Do you request foods with little salt when eating out or visiting someone?	116	1.4	0.9	[1.2;1.6]	1.0
10. Do you use a system (pillbox, reminders) to remind you about your medicines?	116	2.9	1.3	[2.6;3.2]	4.0
Total score - self-care maintenance	116	50.5	15.7	[47.6;53.4]	54.9
Self-care management*					

(continue...)

[†]Charlson Comorbidity Index

Table 2 - (continuation)

	N	Mean	Standard deviation	95% CI	Median
11. How quickly did you recognize them as symptoms of heart failure?	68	2.7	1.4	[2.3;3.1]	3.0
12. Reduce the salt at your diet	68	2.5	1.1	[2.2;2.8]	3.0
13. Reduce fluid intake	68	2.5	1.2	[2.2;2.8]	3.0
14. Take a further diuretic	68	1.6	1.0	[1.3;1.9]	1.0
15. Contact your doctor or nurse for guidance	68	3.1	1.0	[2.8;3.3]	3.0
16. Think of one of the above features you tried the last time when you had trouble to breath or swollen ankles. Are you sure this feature helped you?	68	1.4	1.6	[1.0;1.8]	0.0
Total score - self-care management	68	50.0	20.3	[45.0; 54.9]	50.0
Self-care confidence					
17. Be free of the heart failure symptoms?	116	2.4	0.9	[2.2;2.6]	2.0
18. Follow the recommended treatment?	116	3.1	0.6	[3.0;3.3]	3.0
19. Evaluate the importance of your symptoms?	116	2.6	8.0	[2.4;2.7]	2.5
20. Recognize changes in health, if they occur?	116	2.7	0.8	[2.6;2.9]	3.0
21. Do something that can relieve your symptoms?	116	2.5	0.8	[2.3;2.7]	2.0
22. Assess whether a drug works?	116	2.8	0.7	[2.7;3.0]	3.0
Total score - self-care confidence	116	58.1	18.2	[54.8;61.3]	55.6

^{*}The data of the self-care management subscale are lower because this scale is administered only to patients with heart failure symptoms in the last month.

Table 3 - Association analysis between the selected variables and the *Self-Care Heart Failure Index*, self-care maintenance subscale, Brazilian version (N=116). São Paulo, SP, Brazil, 20-p

Variables		Self-care maintenance					
	Mean	Standard deviation	Median	p* Value			
Gender				0.542			
Male	49.5	16.5	49.9				
Female	51.8	14.8	53.3				
Ethnicity				0.835			
White	50.5	16.2	50.0				
Black	51.6	14.4	53.3				
Brown	48.9	17.0	50.0				
CCI [†]				0.268			
Low	46.0	13.6	50.0				
Moderate	51.1	15.6	50.0				
High	53.4	17.2	51.7				
NYHA				0.515			
1	50.9	16.7	53.3				
II	48.8	14.3	50.0				
III	53.2	17.1	53.3				
Type of healthcare				0.007			
Medical and nursing consultation	54.8	14.6	56.6				
Medical consultation	46.7	15.8	49.9				

^{*}ANCOVA test

between the variables and the self-care confidence subscale (Table 5).

The ejection fraction had no significant negative correlation with the scores in self-care maintenance (r=-0.143; p=0.102) and the time of experience with the disease had no significant correlation with self-care maintenance (r=0.068; p=0.435).

The correlation tests between self-care management scores and ejection fraction resulted

in significant negative correlation (r=-0.361; p=0.001). The correlation between self-care management and time of experience with the disease was positive but was not significant (r=0.239; p=0.052).

There was no significant correlation between the self-care confidence scores and ejection fraction (r=0.029; p=0.816), or time of experience with the disease (r=-0.142; p=0.136).

[†]Charlson Comorbidity Index

Table 4 - Association analysis between the selected variables and the *Self-Care Heart Failure Index*, self-care management subscale, Brazilian version (N=116). São Paulo, SP, Brazil, 2014

Mariahlaa		Self-care maintenance					
Variables	Mean	Standard deviation	Median	p* Value			
Gender				0.663			
Male	48.0	22.1	35.0				
Female	52.1	18.2	40.0				
Ethnicity				0.271			
White	52	20.3	50.0				
Black	44.7	18.8	40.0				
Brown	50.5	22.9	45.0				
CCI [†]				0.942			
Low	46.1	21.5	50.0				
Moderate	50.1	20.2	45.0				
High	53.7	19.7	57.5				
NYHA				0.069			
1	41.2	16.2	30.0				
II	45.4	21.5	37.5				
III	57.2	18.1	57.5				
Type of healthcare				0.098			
Medical and nursing consultation	55.4	20.1	45.0				
Medical consultation	45.4	19.5	35.0				

^{*}ANCOVA test

Table 5 - Analysis of association between selected variables and the *Self-Care Heart Failure Index*, self-care confidence subscale, Brazilian version (N=116). São Paulo, SP, Brazil, 2014

		Self-care maintenance					
Variables	Mean	Standard deviation	Median	p* Value			
Gender				0.832			
Male	57.7	17.8	61.1				
Female	58.7	18.8	66.7				
Ethnicity				0.924			
White	58.6	19.2	66.7				
Black	57.7	18.5	66.7				
Brown	56.9	13.0	61.2				
CCI [†]				0.546			
Low	55.3	17.8	66.7				
Moderate	59.9	17.9	66.7				
High	57.0	19.2	58.4				
NYHA				0.478			
1	58.3	19.2	66.7				
II	59.7	17.0	66.7				
III	55.4	19.2	55.6				
Type of healthcare				0.969			
Medical and nursing consultation	58.3	16.8	61.1				
Medical consultation	58.0	19.4	66.7				

^{*}ANCOVA test

Discussion

In this study, the mean scores obtained for the scales of self-care maintenance, management and confidence of the SCHFI, version 6.2, were all below 70 points

(Table 2) which is the minimum limit score indicative of appropriate self-care. These results are similar to the studies conducted in other countries^(8-10,17-19). In another study with a sample of Brazilian residents of the State of Rio Grande do Sul, self-care maintenance

[†]Charlson Comorbidity Index

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(47.0; SD=28.3)⁽⁷⁾ and self-care confidence (58.0; SD=25.5)⁽⁷⁾ were similar to this study (50.0, SD=20.3 and 58.1; SD=18.2, respectively, as shown in Table 2). However, the same was not observed for the self-care management, which in the mentioned study had a mean score of 57.0 (SD=14.3)⁽⁷⁾ and 50.5 was obtained in this study (SD=15.7; Table 2). It is noteworthy that, in the association study⁽⁷⁾, it was excluded patients with cognitive impairment and all patients had participated in at least one nursing consultation. In this study, 44.8% of patients had cognitive decline and 52.6% have not gone through a nursing consultation (Table 1). These factors may have contributed to the differences observed between the two studies.

The appropriate self-care proportion (6.9%) in the self-care maintainance scale of this study was lower than that observed in other studies, in which the proportion ranged from 14.5 to $52.0\%^{(9-10,17-21)}$. The content of the self-care maintenance scale refers to behaviors to maintain the physiological stability⁽²⁾. Participation in multidisciplinary programmes focused on the symptoms control is a strategy commonly performed in other realities⁽²²⁾, different from the reality of the study population (52.6% are assisted only by the doctor), which could explain the results regarding self-care maintenance. This observation can be reinforced by the results of this study which showed that patients followed up also by the nurse had significantly higher scores for self-care maintenance (p=0.007) (Table 3).

Among the items of the self-care maintenance subscale, the lowest average scores were observed for the behaviors: "Do you practice any physical activity?", "Do you exercise for 30 minutes?" and "Do you request foods with little salt when eating out or visiting someone?" (Table 2). These findings are similar to those of other studies, showing that low levels of physical activity and excessive sodium intake are common among HF patients, despite possible cultural differences^(9-10,18,23). The low level of physical activity may be related to activity intolerance and exacerbation of symptoms to efforts, common in HF patients, and lack of programmes promoting physical activity by HF patients, in our environment.

On the self-care management scale, which deals with patient's responses to the symptoms when they occur, the proportion of patients with appropriate self-care (14.7%) was higher than that found in a sample of Australians $(12.0\%)^{(6)}$ and Thai $(5.0\%)^{(17)}$, but lower than it was found for samples of Italians $(24.4\%)^{(9)}$, Canadians $(21.0\%)^{(21)}$ and Chineses $(34.9\%)^{(10)}$.

The item "Take a further diuretic" had one of the lowest scores in the self-care management scale (Table 2), which may have contributed so that the mean score on this scale has fallen far below appropriate, as observed in other studies^(7,9-10). At the ambulatory where this research was conducted, to recommend the use of an extra diuretic, is not a routine practice, as well as in other countries⁽⁹⁻¹⁰⁾.

Higher self-care management scores associated with lower ejection fraction (p=0.001) and it was expected that a longer time of experience with the disease was associated with better selfcare management performance, which did not occur (r=0.239; p=0.052). Studies with larger samples may reveal significant correlation among these variables, which would be consistent with the theoretical model of the SCHFI. This model is based on the naturalistic decision-making, where decision-making depends on the experience and knowledge that has been developed through experience⁽²⁾. For HF patients, the key to a naturalistic decision-making is the symptoms recognition, which would explain the expectation of high scores in self-care management for patients with long time of experience with the disease⁽²⁾. Self-care requires learning, understanding, interpreting and responding skills, and decision-making is an important process for the health management⁽²⁴⁾. In this study, cognitive impairment was present in most of the population evaluated (52%), which possibly may have contributed to low scores in the self-care scale. A systematic review showed that HF patients have significantly worse cognitive performance than healthy controls and ischemic heart disease patients(25). Considering the importance of the decision-making regarding the theory of self-care in HF, cognition is an important variable to be considered. The cognitive impairment has relevant prevalence in this population. Therefore, knowing the self-care behavior in patients with HF and cognitive impairment can direct the nurse to choosing the best educational strategies to assist this patient to acquire and maintain the appropriate self-care.

Although the situation of self-care in this study sample is worrying, patients who were also followed up by nurses, by not only doctors, showed higher scores on self-care maintenance and self-care management scales in the association tests (Tables 3 and 4). To better interpret the results obtained, it would be necessary to have data on the reasons why certain patients are referred for nurses monitoring. Due to the low availability of nurses to the patient demand, it is

assumed that patients who have more trouble controlling the disease are referred, which can difficult achieving the appropriate self-care. In addition, it was observed that the nursing instructions practiced in the study place, focused on specific patients' complaints without a theoretical orientation, such as HF self-care, which provides support for the establishment of programmes to develop self-care, integrating maintenance and management dimensions⁽²²⁾. Interventions that focus on specific self-care behaviors are more effective than general educational programmes⁽²³⁾. The key role of the nurse is the patient's education for early recognition of symptoms, for better decisions to be taken in the presence of symptoms and evaluation of the effectiveness of the actions taken.

The proportion of patients with appropriate self-care confidence (19.0%) was similar to those found in studies conducted in developed countries: Italy (21.2%)⁽⁹⁾ and Canada (22.0%)⁽²¹⁾. Self-care confidence requires cognitive skills that directly impact the process of therapeutic decision-making and performance of the patient's self-care⁽²⁴⁾. It is believed that the self-care confidence has moderating effect on self-care at different outcomes such as, for example, in adherence. The implementation of multidisciplinary programmes with home visits and telephone follow-up, so that the patients recognize and properly handle their symptoms is a combination whose efficacy for self-care may include the reinforcement of the patients' confidence in the field of their health condition^(8,11).

Another important consideration is that the confidence level in the self-care can be influenced by social desirability⁽²³⁻²⁴⁾, which requires caution in interpreting the results of this scale.

The Cronbach's alpha values obtained in this study, for the total score of the SCHFI (0.70), self-care maintenance (0.47) and confidence subscales (0.74) were similar to that found in the study of adaptation of the SCHFI for the Brazilian version⁽⁷⁾ (0.77, 0.43 and 0.94, respectively) and lower (0.40) to that found in the self-care management subscale (0.76). This result suggests that, in this study sample, the questions that compose this subscale deserve more attention.

Limitations

The main limitations of this study were the small sample size, study carried out with patients with mild to moderate symptoms (NYHA Class I, II and III), from a single specialized and teaching hospital, low Cronbach's

alpha values of the SCHFI, as well as cross-sectional design which does not establish temporal relationships between the variables.

Conclusions

In this study with a sample of Brazilians, self-care has been shown as inappropriate, but similar to those with patients of other countries. Other studies with Brazilian samples should be conducted in order to test the self-care model in HF and identify potential variables involved in self-care response.

The results of this research will be useful for the development of nursing interventions that can promote/improve self-care in this population, especially by means of the use of self-care model in HF to develop interventions. Educational actions, by means of nursing consultations, can and should be used to empower patients to symptoms recognition and management.

Studies that produce and synthesize evidence on interventions for self-care management/maintenance in HF patients are needed to guide therapeutic team decisions aiming a better quality of life for these patients.

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