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SELF-CARE IN PATIENTS WITH HEART FAILURE

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ABSTRACT

Objectives: To adapt the Self-Care of Heart Failure Index V6.2 to Portuguese and analyze self-care capability in maintenance, management and self-confidence in patients with heart failure attending nursing care services at two Portuguese hospitals. **Method**: Exploratory study, sample of 110 patients who attended the nursing care service for patients with heart failure at two Portuguese hospitals, carried out over a six-month period. Descriptive statistics and psychometric tests were used. **Results**: Internal consistency similar to the original scale. The patients consisted mostly of older adults with low self-care literacy, low values associated with physical activity and salt control in meals taken outside the home, and inadequate control of signs and symptoms. **Conclusion**: Patients present difficulties in maintenance and management of the disease, and are self-confident regarding it. This instrument enables individualized assessment leading to decision-making and adjusted action.

Descriptors: Self-care; heart failure; patients.

INTRODUCTION

Cardiovascular diseases are the leading cause of mortality and morbidity in Europe, including Portugal. These comprise a set of diseases that affect the circulatory system, namely heart failure. The main cause of heart failure prevalence is coronary heart disease. It is estimated that about 50% of new cases will emerge in the coming years. Other relevant causes that contribute to the growth of heart failure in Europe and Portugal are high blood pressure and increased prevalence of obesity and diabetes[1-3]. In addition to these causes, age is also an important factor in the prevalence of heart failure, which makes it a serious public health problem due to marked demographic aging in Portugal, as well as in most of Europe. Heart failure prevalence is predicted to increase between 50 and 75% by 2030, presenting a worse prognosis than all malignant tumors. Given this scenario, morbidity is a serious problem, now and in the future. Heart failure affects more than 260,000 patients in Portugal, being the most frequent medical diagnosis of hospitalization in patients over 60 years of age. In 2013 the number of patients with heart failure with hospital discharge was estimated at 7762, with an average hospital stay of 9.73 days and a total of 172,805 days of hospitalization. This represents a significant economic and social burden[3]. If measures are not taken quickly, the trend is to escalate health spending, mainly related to rehospitalization.

Heart failure is defined as a syndrome originating from an abnormality of cardiac structure and function. Changes resulting from this abnormality are generally related to incompatibility between tissue metabolism requirement and the oxygen provided by the reduced ability to pump blood through the heart. This dual condition gives rise to signs and symptoms typical of heart failure, such as dyspnea, edema with higher incidence of malleolus, fatigue, coughing, high jugular venous pressure, lung crepitation, and imaging alterations of the lung structure[4]. Monitoring signs and symptoms becomes difficult because patients respond differently to changes affecting them.

Care provided to these patients is strongly correlated with initial assessment, which must be rigorous as it supports decision-making and subsequent intervention. This is directed at the precipitating factors of heart failure and naturally to its consequences. However, such intervention must be associated with continuous monitoring of patients[4], given the highly volatile situation and the risk of rapid change.

Both monitoring and intervention presuppose multidisciplinary care that covers pharmacological and non-pharmacological intervention. In order to best adapt non-pharmacological intervention, it is pertinent to use instruments that facilitate patient evaluation, so that decision-making is based on assumptions that are as objective as possible.

The recommendations published by international scientific societies[4] guide the interventions of health professionals in dealing with the needs of these patients. Therefore, such professionals, namely nurses, should be concerned with developing interventions that enable them to make decisions based on the symptomatology, promoting self-care with the main objective of managing symptoms and reducing the frequency of hospitalizations due to decompensation. The concept of the International Council of Nurses[5], which defines self-care as an activity carried out by patients involving whatever is necessary for them to remain functional and deal with individual basic and personal needs and daily life activities, places us before a complex process. This implies learning by patients, so professionals must be able to teach, train, reinforce and evaluate in order to improve patients' skills for self-care, taking into account the capacity of each patient to develop them, especially in terms of cognitive, behavioral and emotional response[6]. Among such skills we stress choosing the right foods to keep their weight under control, restricting sodium and fluid intake, ability to perform physical activity appropriate to their health condition, managing their therapy and regularly monitoring signs and symptoms, communicating them to the professional responsible for their care[4]. The main objective of this type of action is to give back to patients the responsibility for self-control of the disease, encouraging the development of the skills necessary for self-care and consequent patient stability.

Empowering patients for self-care implies having them perform activities in a deliberate and intentional way to improve the outcomes of heart failure[7], preserving meaning in life and well-being[8]. Taking into account one of the universal requirements for self-care which prevents risks to life and promotes people's well-being[8]. Nurses use a variety of methods, combining them to regulate the body and improve the outcomes of heart failure[7] with regard to patients' needs in order to guide them, provide and maintain an environment that supports personal development, and teach them[9]. In short, train them to take responsibility for their health and well-being[10] and improve the outcomes of heart failure[7].

The Self-Care of Heart Failure Index V6.2 (SCHFI V6.2) was used as the instrument of reference. The first version, published in 2004, has been improved over the years by the author and her colleagues[7]. In 2009, Barbara Riegel and her colleagues decided to update the index, which is published in the Journal of Cardiovascular Nursing[7]. This will be the benchmark to compare the results of the present study. In this context, such an instrument is particularly useful to assess and monitor self-care in patients with heart failure.

The guiding question of this study is to culturally adjust the index and investigate the self-care capacity of patients with heart failure who attend nursing care services at Portuguese hospitals.

In view of the above, we defined as objectives to adapt to Portuguese the Self-Care of Heart Failure Index V6.2 (SCHFI V6.2), which will be known in Portugal as *Escala de Autocuidado para a Pessoa com Insuficiência Cardíaca* (EACPIC – Self-Care Scale for Persons with Heart Failure) and to analyze self-care capability in maintenance, management and self-confidence in patients with heart failure attending nursing care services at two Portuguese hospitals.

METHODS

The cross-cultural adaptation of SCHFI V6.2 was carried out following the theoretical framework behind the original index[7] and the author's specific guidelines. Firstly, the author's permission was requested to commence the translation and adaptation process into Portuguese. After the translation was completed by an expert in Portuguese and English, it was analyzed by a panel of experts and various lexical and semantic adjustments we-re made. Then the expert in both languages performed a retranslation and a pre-test was carried out to assess whether the participants clearly understood what was being asked. In view of the results, there was no need for reformulations. The last step was the final validation by the author. Consideration was given to the author's recommendation concerning the follow-up period required to participate in the study. All participants were

within the range of one to three months of follow-up in heart failure care. The sample size was calculated based on the assumptions in the literature, five times greater than the number of items in the scale[11].

A convenience sample was thus drawn from the group of patients registered in nursing care at the main hospital of a town south of Lisbon and at a hospital in Lisbon. The nursing care services of both hospitals had a total of about 200 registered patients with heart failure. Of those, 62 patients from the hospital to the south of Lisbon and 48 patients from the Lisbon hospital answered the questionnaire. The inclusion criteria were defined as follows: attending the aforementioned care; having a medical diagnosis of heart failure; having time and space orientation; this was assessed using the guidelines of the Mini Mental State Examination regarding time and space orientation; being over 18 years old and agreeing to participate in the study.

The data collection instrument used consisted of two components: a questionnaire with sociobiographical variables and the Self-Care Scale for Patients with Heart Failure (EACPIC), adapted from the original SCHFI V6.2 scale[7].

The scale consists of twenty-two items, distributed in three subscales. The first subscale, named section A of the questionnaire, is composed of 10 items related to self-care maintenance. The second subscale, designated as section B, is composed of six items related to self-care management. Section C of the questionnaire is the subscale related to self-care confidence, consisting of six items. Data were collected over six months, from September 2012 to February 2013. A sample of 110 patients was obtained.

After being gathered, the data were entered and processed in SPSS software version 2.0. A descriptive statistical analysis was performed, and means and standard deviations were calculated. The psychometric properties were verified by internal consistency (Cronbach's alpha coefficient) to allow comparison with the data from the original index[7]. At the suggestion of the author, the analysis was based on data published in 2009[7].

The ethical considerations of this investigation were guaranteed through evaluation and approval by the respective ethics committees of the hospitals where data was collected, ensuring the confidentiality and anonymity of the participants. Patients were informed about the purpose and objective of the study, and signed the informed consent before filling in the questionnaire.

RESULTS

The data analysis allowed us to verify that the 110 participants had a mean age of 66.52 years and a standard deviation of 10.73 years. Male participants predominated, 75 patients. Other equally important characteristics relate to literacy: more than half of the participants had only nine years of schooling; 10 of them could only read and write, and three could neither read nor write. Most of the subjects were already retired, with only nine professionally active. As for family/social situation, 11 lived alone. All the rest lived with relatives, mostly with their spouse.

The results obtained after administering the scale are described in the following tables: results regarding heart failure stability/maintenance, Table 1; results regarding heart failure management, Table 2; and results regarding self-confidence, Table 3.

Table 1 – EACPIC results for maintenance/stability

Listed below are common instructions given to persons with hearth failure. How often do you do the following?

Section – A	Never or rarely	Sometimes	Frequently	Always or daily
1. Weight yourself alone?	14	**39-35,5%**	33	23
2. Check your ankles for swelling?	8	23	32	**46-41,8%**
3. Try to avoid getting sick (e.g., flu shot, avoid ill people)?	25	17	**36-32,7%**	24
4. Do some physical activity?	**52-47,3%**	25	15	14
5. Follow doctor or nurse orders?	1	7	23	**77-70,0%**
6. Eat a low salt diet?	6	7	29	**65-59,1%**
7. Exercise for 30 minutes?	**41-37,3%**	23	19	24
8. Forget to take one of your medicines?	**85-77,3%**	10	2	9
9. Ask for low salt items when eating out?	**31-28,2%**	23	25	28
10. Use a system (pill box, reminders) to help you remember your medicines?	34	79	11	**55-50.0%**

Source: Survey data, 2013

Table 2 – EACPIC results for symptom management

In the past month, have you had trouble breathing or ankle swelling?

Section - B	No answer	I did not have them	I did not recognize them	Not quickly	Somewhat quickly	Quickly	Very Quickly
11 – How quickly did you recognize them as symptoms of heart failure?	13	**38-34,5%**	7	10	19	20	3

If you have trouble breathing or ankle swelling, how likely are you to try one of these remedies?

	Not likely	Somewhat likely	Likely	Very Likely
12 – Reduce the salt in your diet	10	9	**48-43,6%**	38
13 – Reduce your fluid intake	14	13	**45-40,9%**	30
14 – Take an extra diuretic (water pill to eliminate fluid)	24	5	27	**47-42,7%**
15 – Call your doctor or nurse for guidance	5	3	25	**72-65,5%**

16 – Think of a remedy you tried last time you had trouble breathing or ankle swelling

	I did not try anything	Not sure	Somewhat sure	Sure	Very sure
How sure are you that the remedy helped or did not help?	18	11	12	**32-29,1%**	28

Source: Survey data, 2013

Table 3 – EACPIC results for self-confidence

Self-confidence of patients with heart failure				
Section – C In general, how confident are you that you can:	Not Confident	Somewhat Confident	Very Confident	Extremely Confident
17. Keep yourself free of heart failure symptoms?	14	27	**45-40,9%**	18
18. Follow the treatment advice you have been given?	3	46	**59-53,6%**	1
19. Evaluate the importance of your symptoms?	2	13	**50-45,5%**	44
20. Recognize changes in your health if they occur?	3	16	**45-40,9%**	43
21. Do something that will relieve your symptoms?	6	27	**46-41,8%**	29
22. Evaluate how well a remedy works?	9	18	**48-43,6%**	32

Source: Survey data, 2013

Regarding the mean values of the scores and the internal consistency of the scale, these are represented by subscales in Table 4 compared to the values of the original index.

Table 4 – Comparison of results between SCHFIV6.2 and EACPIC

SCHFIV6.2 n=130 and EACPIC n=100						
SCHFI V6.2 = EACPIC p<0,05	SCHFIV6.2 Mean 2009	EACPIC Mean 2014	SCHFIV6.2 Standard Deviation	EACPIC Standard Deviation	SCHFIV6.2 Cronbach's Alpha 2009	EACPIC Cronbach's Alpha 2014
Maintenance Scale **n=110**	70,5	54,58	14,3	16,95	0,553	0,646
Management Scale **n=110**	65,4	64,30	22,4	21,97	0,597	0,572
Confidence Scale **n=110**	70,2	69,58	16,6	20,13	0,827	0,845

Source: Survey data, 2013

DISCUSSION

The mean age of participants is 66.52 years, which is above the national average. Data on the prevalence of the disease in Portugal shows percentages of 1.65% for the 25-50 age group and 16% for adults above 80[12]. Due to technical and scientific advances in recent years, treatment of hitherto potentially life-threatening diseases is now possible. Associated with an increase in average life expectancy, this enhances the prevalence of heart failure, which is expected to increase from 50 to 70% by 2030, especially in older adults. The data found corroborate national data. Patients with heart failure are generally older and fragile, with a higher prevalence of men. They are usually patients who have other associated diseases, such as diabetes, high blood pressure and respiratory diseases, which makes them a particularly vulnerable group[3]. Also contributing to this vulnerability is low literacy among patients. The participants in this study had, on average, only nine years of schooling, and some did not know how to read or write. This leads to difficulties in communicating with health professionals, which influences adherence to recommendations and decision-making related to the disease, with difficulty in understanding the real relationship between adopting pharmacological and non-pharmacological remedies and effective control of the disease[6].

In the cultural adaptation of the scale, it was found that in the **maintenance subscale**, reliability was very close to the SCHFI V6.2 version[7]; however, the results of our study show a higher value for Cronbach's alpha. Regarding the mean scores, there is a decrease in this subscale compared to the reference value of the original scale, which may be associated with the fact that the patients who participated in the study had a high mean age and low literacy in general, data close to those of a study developed by Chen et al[14]. The items of this subscale that present lower values are related to "physical activity" and "salt intake control." Some studies point to the fact that patients become physically fatigued easily and therefore resort to rest and little physical activity, which is contrary to scientific evidence, which recommends an individualized and adapted program of physical exercise[13]. Regarding the **management subscale**, the Cronbach's alpha value, as well as the mean score, is similar to the SCHFI V6.2 version. When analyzing the results, it is observed that these are the four mean items with the lowest alpha values. They refer to decision making related to very concrete actions, such as "reduce salt," "reduce fluid intake," "take a water pill" and "contact the health care provider for advice," which are intentional interventions to better control the symptoms, namely "breathing problems" or "ankle swelling." For patients with heart failure, living with the chronicity of the disease implies adopting new lifestyles, which is a challenge because it concerns breaking with lifelong habits. It is essential to understand how patients learn to self-care, that is, how they can identify signs

and symptoms of decompensation that lead to hospitalization, such as dyspnea, ankle swelling and getting easily fatigued[15]. In Portugal, health/disease processes are still based on a curative and non-preventive paradigm with little individual autonomy, because patients are taught, but do not practice what they learn, and therefore do not develop practical skills that are essential for their autonomy and, consequently, self-care[16]. Regarding the confidence subscale, the results show cultural adaptation data similar to those of the SCHFI V6.2 version. This is the component of the overall scale with the highest alpha. The fact that patients feel very confident about "symptom control," "treatment," "enhancement of symptoms," "health changes," "intervention in symptom relief" and "evaluation of action effectiveness" suggests that, in general, patients feel confident. But from a global perspective, they have difficulties to exert proper management. This confidence may have an interpretation that does not coincide with the semantic meaning of the word, that is, some patients see heart failure as an acute disease, convinced that it is cured when there are no signs and symptoms. This view leads to poor self-care, that is, there is a gap between learning and apprehending self-care[15]. In order to overcome this barrier, self-care is nowadays considered a tool of intervention and research in several settings, mainly because it is recognized as a key component to be used in non-pharmacological treatment of the disease. Practical application of self-care by patients is a continuous exercise whose results can be observed in the medium and long term[17].

Heart failure is one of the main complications of coronary artery disease and high blood pressure, with cardiovascular diseases being the main cause of death in developed countries. In the knowledge that this mortality is decreasing due mainly to scientific and technological advance, it is important to mention that heart failure is a rising syndrome, inversely proportional to the trend of mortality from cardiovascular diseases, and is the main cause of hospitalization in people over 60[18-19]. In this sense, it is a priority to instruct patients with the aim of developing their autonomy, that is, instruct them in self-care, especially focusing on the unique capacities of each patient, thus contributing to the reduction of disability/dependence and to improved quality of life.

CONCLUSION

In the present study, SCHFI V6.2 was adapted for the Portuguese population with the name *Escala de Autocuidado para a Pessoa com Insuficiência Cardíaca* (EACPIC – Self-Care Scale for People with Heart Failure). It is an essential instrument to assess very specific parameters of self-care in patients with heart failure, enabling individualized intervention aimed at health gains, namely reducing rehospitalization due to decompensation, leading to better quality of life. The results illustrate the limitations of patients in Portugal, especially concerning age and literacy, which are fundamental aspects in obtaining effective results in self-care. It should be noted that the increased prevalence of heart failure demands investing in patient empowerment with regard to disease management, in order to reduce decompensation and consequent suffering. Self-care draws on the knowledge, skills and motivation of patients with heart failure, and is an efficient and cost-effective way to maintain and manage the disease more confidently. Further studies should be developed using this tool with similar populations to help heart failure patients and their families acquire self-care knowledge. A limitation of the study was the great mobility of human resources, especially nurses, during the period in which data collection was carried out. Another limitation was that the project was developed without any kind of financial support.

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