Self-care of individuals with heart failure

Autocuidado de indivíduos com insuficiência cardíaca

Autocuidado de individuos con insuficiencia cardiaca

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Abstract: Objective: to describe the self-care level of individuals with heart failure. **Method:** a descriptive study, performed in a cardiology outpatient clinic in Salvador, Bahia, during the period of September and October, 2017 and January, 2018. Recorded interviews were performed using appropriate instruments and applying the European Heart Failure Self-Care Behavior Scale (EHFScBs). **Result:** the sample comprised 43 individuals of the male gender (53.5%), between the ages of 51 and 60 years (34,9%), self-declared race/skin color black (46.5%), living with a partner (51.2%), low schooling (incomplete primary education 41.9%) and low income (39.5%). In relation to self-care, the average EHFScBs score was of 30.1 (±7.4). It was evidenced that 46.5% of the interviewed parties presented inadequate self-care capacity (total score between 31 and 50 points). **Conclusion:** self-care behavior was between moderate and unsatisfactory, suggesting the implementation of effective educational practices to enable individuals to handle the disease.
Descriptors: Heart Failure; Self-care; Behavior Scale; Health Education; Nursing

Resumo: Objetivo: descrever o nível de autocuidado de indivíduos com insuficiência cardíaca (IC). **Método:** estudo descritivo, realizado num ambulatório de cardiologia em Salvador, Bahia, no período de setembro e outubro de 2017 e em janeiro de 2018. Foram feitas entrevistas gravadas utilizando instrumento próprio e aplicado a Escala Europeia de comportamento do autocuidado na Insuficiência Cardíaca (EEAIC). **Resultados:** a amostra foi composta por 43 indivíduos, do sexo masculino (53,5%), entre 51 a 60 anos (34,9%), raça/cor autodeclarada negra (46,5%), vivendo com companheiro(a) (51,2%), baixa escolaridade (ensino fundamental incompleto 41,9%) e baixa renda (39,5%). Com relação ao autocuidado, o valor médio do *score* na EEAIC foi de 30,1 (±7,4). Evidenciou-se que 46,5% dos entrevistados apresentaram capacidade inadequada para o autocuidado (*score* total entre 31 a 50 pontos). **Conclusão:** o comportamento de autocuidado foi de moderado à insatisfatório sugerindo implementação de práticas educativas efetivas para capacitar os indivíduos no manejo da doença.
Descritores: Insuficiência Cardíaca; Autocuidado; Escala de avaliação comportamental; Educação em Saúde; Enfermagem

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Resumen: **Objetivo:** describir el nivel de autocuidado de individuos con insuficiencia cardiaca (IC). **Método:** estudio descriptivo, realizado en un ambulatorio de cardiología en Salvador, Bahia, en el periodo de septiembre a octubre de 2018. Fueron realizadas entrevistas grabadas utilizando instrumento propio y aplicado la Escala Europea de comportamiento del autocuidado en la Insuficiencia Cardiaca (EEAIC). **Resultados:** la muestra fue compuesta por 43 individuos, del sexo masculino (53,5%), entre 51 a 60 años (34,9%), raza/color de piel auto declarada negra (46,5%), viviendo con compañero(a) (51,2%), baja escolaridad (enseñanza fundamental incompleta 41,9%) y baja renta (39,5%). Con relación al autocuidado, el valor promedio del puntaje en el EEAIC fue de 30,1 (±7,4). Se evidenció que 46,5% de los entrevistados presentaron capacidad inadecuada para el autocuidado (puntaje total entre 31 a 50 puntos). **Conclusión:** el comportamiento del autocuidado fue de moderado a insatisfactorio, sugiriendo la implementación de prácticas educativas efectivas para capacitar los individuos en el manejo de la enfermedad.

Descriptores: Insuficiencia Cardíaca; Autocuidado; Escala de evaluación comportamental; Educación en Salud; Enfermería

Introduction

Despite advances in the treatment, the prevalence of heart failure is highly associated to the aging population and has been receiving attention due to the high number of cases and the morbidity and mortality rates (survival after 5 years of diagnosis can be of only 35%, which reduces as age increases). In Brazil, it is the first cause of hospitalization in the National Health System ("SUS") among cardiovascular diseases, in patients over the age of 60, raising the costs with hospital care and medical treatment. Roughly 12 million individuals suffer with heart failure, and 1 million new cases are diagnosed worldwide every year.[1]

This illness is characterized through typical symptoms such as shortness of breath and lower limb edema or fatigue, which can be accompanied by signs such as high jugular venous pressure and pulmonary crackles, declining the quality of life.[2] Accordingly, self-care is the capacity that individuals have to distinguish factors that need to be controlled or managed to regulate their own functioning and development, permitting an autonomous performance of duties towards promoting health, avoiding damage and caring for the disease, involving spiritual, physical, mental and social aspects, providing quality of life.[3]

Lack of awareness about this pathology could contribute towards aggravating the quality of life of people with heart failure, promoting social isolation, increased comorbidities, lack of

or inadequate self-care, unawareness of signs and symptoms, and non-adhesion to treatment. As a result, a clinical decline and increase in health service costs is often observed, since awareness about this new condition is considered a core component for the clinical treatment and rehabilitation.[4]

For self-care, individuals with heart failure often face limitations to their daily activities, such as impairing social interaction and progressive loss of physical autonomy.[5] This scenario is often associated to complex treatments and with the inclusion of various medications, resulting in alterations to the lifestyle, and compromising the quality of life of these people and their families, demanding permanent ongoing monitoring by the health team.[6]

For such monitoring and stratification of the heart failure symptoms, health professionals usually perform a classification of the disease. The *New York Heart Association* (NYHA) functional classification was updated in 1994, an instrument with established validity and reliability. The NYHA assesses the symptomatic effect of the cardiac disease, permitting to stratify the degree of limitation imposed by the disease in relation to routine activities. According to the association, individuals with heart failure are classified in four classes: class I - lack of symptoms during ordinary physical activities, with limitations for efforts similar to the expected in healthy individuals; class II – symptoms triggered by ordinary activities; class III – symptoms triggered by less intense activities than ordinary activities; class IV – symptoms present at rest.[6]

Also, in heart failure care, self-care scores are verified, measured through validated assessment instruments. This strategy favors identification of the weaknesses related to self-care actions, with the aim of reducing re-hospitalization rates due to acutely decompensated heart failure, in relation to the sudden appearance of fatigue, shortness of breath and edema that occurs when the cardiac function is impaired and is not able to fulfill the demands of the body.[7] As such, the following research matter was raised: what is the level of self-care of

individuals with heart failure? Accordingly, the study had the objective of describing the level of self-care of individuals with heart failure.

Method

A descriptive study, of a qualitative nature, carried out in a cardiology outpatient clinic, which comprises a healthcare complex belonging to the University Hospital in the municipality of Salvador, Bahia. The convenience sample was selected, with a total of 43 individuals having been interviewed. The approaches occurred between the months of September and October, 2017 (on Fridays) and January, 2018 (on Tuesdays and Fridays), from 1 to 7 p.m. before or after the medical appointment. The non-collection of data in the months of November and December, 2017 occurred because of the optional internship of the researcher in another state of the country.

Individuals eligible for the research were verified according to the selection of medical records, using the following inclusion criteria: confirmed heart failure diagnosis (CID: I 50); registered heart failure based on the report of events in the medical records in the last 12 months; being over the age of 18 years. Exclusion criteria were: individuals with cognitive-communication disorders (observational method or reported by family member); people with clinical evidence of decompensation at the time of the recruitment (alteration to breathing standards and/or malaise).

The purpose of the research was exposed to those who fit into the profile and they were invited to voluntarily take part by signing the written informed consent form. The structured interviews were performed in a private room. In this study, during the recruitment phase, none of the individuals were excluded in accordance with the above-mentioned criteria, and there were no refusals to participate.

Data collection was carried out by means of taped interviews using appropriate structured instrument comprising data for the characterization of the socioeconomic and

demographic profiles (gender, age, self-declared race/skin color, civil status, schooling, income and origin) and clinical data (time since diagnosis, NYHA classification, number of hospitalizations and when was the last one – where/hospitalization period). The European Heart Failure Self-Care Behavior Scale (EHFScBs) was also used, comprising 12 questions (minimum score of 12 and maximum of 60).[8]

The EHFScBs was developed by Tiny Jaarsma and collaborators in Holland, in 2003, and validated to the Portuguese language in 2013. The higher the score in this scale, the worse is the self-care behavior. It assesses the two key-behaviors for self-care in heart failure: recognition of the signs and symptoms of decompensation and decision making in the occurrence of such symptoms, guiding the health team in their individualized strategies with the consequent attainment of clinical stability.[8]

The instruments for data collection were tested in the medical assistance at the cardiology outpatient clinic, from a pre-test on August 25, 2017, when five individuals were approached. Adjustments to the instruments were required: in the item of hospitalization period the period of "days" was included; in the item on last hospitalization the period of "years" was substituted for "months". Moreover, the duration of the interview was adjusted (use of more objective questions technical terms and professional jargon to enable understanding and avoid repetition) and the need for analogical correspondence to the EHFScBs numerical answers (1= always; 2=nearly always; 3=sometimes; 4=hardly ever e; 5=never) in order to improve the understanding of the interviewed parties, due to their level of education.

The data was tabulated and processed using *Microsoft Office Excel* 2016. Descriptive statistics was used and the variables were presented on tables containing absolute (n) and relative (%) frequencies. The study was approved on August 18, 2017 by the Research Ethics Committee of Professor Edgard Santos University Hospital under register 2.227.952, obeying

the ethical requirements, as provided for in Resolution 466/2012, of the National Health Council, on research involving human beings.

Results

The sample comprised 43 individuals, mostly in the age group of 51 to 60 years (34.9%), male gender (53.5%), self-declared race/skin color black (46.5%), low schooling (incomplete primary education 41.9%), living with a partner (51.2%), income lower or equal to one minimum wage (39.5%) and residing in the metropolitan region of Salvador (76.7%).

Considering the NYHA on the studied population, prevalence was for functional class II (44.2%), with this classification having been found in the records of 18.6% of the interviewed parties. In this sample, 23.2% obtained heart failure diagnosis between 2 and 5 years prior and 44.1% never had the need for hospitalization for the disease. For those that had already been hospitalized (55.9%), most were only hospitalized once and the most frequent duration was of under one month (around 5 days).

With reference to the standard of answers for each item of the EHFScBs, the distribution per item is detailed in Table 1.

Table 1 – Distribution of the individuals in accordance with the answers for each item of the European Heart Failure Self-Care Behavior Scale. Salvador-Bahia, 2017-2018.

EHFScBs	Fully agree				Totally disagree
	Score 1	Score 2	Score 3	Score 4	Score 5
1. I weigh myself every day	1 (2.3%)	1 (2.3%)	12 (27.9%)	2 (4.6%)	27 (62.8%)
2. If I am short of breath, I take it easy.	37 (86%)	4 (9.3%)	2 (4.6%)		
3. If my shortness of breath increases, I contact my doctor or nurse.	20 (46.5%)		5 (11.6%)	1 (2.3%)	17 (39.5%)
4. If my feet/legs become more swollen than usual, I contact my doctor or nurse.	26 (60.5%)		2 (4.6%)	1 (2.3%)	14 (32.5%)
5. If I gain 2 kilos in one week, I contact my doctor or nurse.	15 (34.9%)		1 (2.3%)	4 (9.3%)	23 (53.5%)
6. I limit the amount of fluids I drink (not more than 1.5-2 liters/day).	13 (30.2%)	1 (2.3%)	4 (9.3%)		25 (58.1%)
7. I take a rest during the day.	38 (88.4%)	1 (2.3%)	2 (4.6%)	1 (2.3%)	1 (2.3%)
8. If I experience increased fatigue, I contact my doctor or nurse.	22 (51.2%)	3 (7%)	2 (4.6%)	1 (2.3%)	15 (34.9%)
9. I eat a low salt diet.	34 (79%)	2 (4.6%)	3 (7%)	1 (2.3%)	3 (7%)
10. I take my medication as prescribed.	37 (86%)	5 (11.6%)	1 (2.3%)		
11. I get a flu shot every year.	26 (60.5%)	4 (9.3%)	1 (2.3%)		12 (27.9%)
12. I exercise regularly.	15 (34.9%)	1 (2.3%)	3 (7%)	1 (2.3%)	23 (58.1%)

The highest percentages under score 5 (totally disagree) were evidenced in the following actions: daily weight control, limiting the quantity of fluids and exercising regularly. Apart from not associating increased weight as a sign of heart failure decompensation. However, it also shows a focus on medical treatment and low adhesion to adequate self-care behavior.

In relation to the total score of the EHFScBs, the distribution per value of each participant is presented in Table 2. In the scale interpretation, the higher the score the worse is the self-care behavior.

Table 2 – Distribution of individuals according to the total score value of European Heart Failure Self-Care Behavior Scale. Salvador-Bahia, 2017-2018.

Score	≤20	21≥30	31≥50
n(%)	06 (13.95%)	17 (39.54%)	20 (46.51%)

In the assessment of the total score of the EHFScBs answers, a mean value of 30.1(±7.4) was verified in the sample. Emphasis was for the total score between 31 and 50 points for 46.5% of the interviewed parties (Table 2).

Discussion

The NYHA functional classification is used to describe and classify the severity of the symptoms, based on the degree of tolerance to exercise and varies from the absence to the presence of symptoms even during rest. It permits the clinical evaluation of people with heart failure, therapeutic management and is related to the prognosis.[6] A higher prevalence of functional class II (44.18%) was observed, whose symptoms are triggered by daily activities. Despite presenting milder symptoms and less frequent hospitalization, the process of the disease is not always stable, and these individuals could present sudden death, without clinical aggravation.[6]

It was observed that in 18.6% of the interviewees, the functional classification was not registered on the medical records. It would not be adequate to establish in this study isolated cases for such action. It has been pointed out that fragilities in the adequate completion of the medical records extend to the professional formation and to the management process of health organizations.[9] The present study was performed in a university hospital, where the medical records are manipulated by various levels of medical formation, linked to still physical model of

medical records and also to the lack of control and of enforcement by the institution itself. Such actions could have been the cause of the sub-notification.

The transition between hospitalization to outpatient monitoring is a period of vulnerability due to the complexity of the progressive nature of heart failure, with impacts to the prognosis that can extend for up to six months after hospital discharge. In this context, the role of the health professionals is fundamental in actions that can minimize the risk of hospitalization.[10] In the studied sample, there were 44.18% that were never hospitalized for decompensation, revealing a possible improved medical condition.

Therapeutic strategies with a multidisciplinary approach are essential for maintaining functional capacity, facing and controlling the disease, given that heart failure contemplates a comprehensive view of healthcare.[11] Emphasis is given to professional nurses who in their daily practices use important methods guided to health education, favoring the approach in their nursing care.[11]

The verification of the self-care scores, measured using validated instruments, permits the identification of the weaknesses encompassing self-care actions, for subsequent preparation of interventions guided towards hospital discharge and outpatient follow-up, with the aim of reducing re-hospitalization charges due to acutely decompensated heart failure.[7] A mean total score value of EHFScBs of 30.1 (±7.4) was evidences, and about 46.5% of the participants presented a total score of between 31 and 50 points, indicating unsatisfactory self-care. Accordingly, the development of educational measures is indispensable, considering the needs identified by the patients, guided also to promoting self-care.[12]

With reference to the standards of the answers and distribution of each item of the EHFScBs, it was verified that item "1 – I weigh myself every day", has a higher concentration of answers with scores 3 (27.9%) and 5 (62.8%), indicating that the majority do not verify their weight on a daily basis. This action has a negative impact on self-care in relation to self-recognition of signs or symptoms, since adequate weight control is also important to perceive

acute decompensation, which can occur when there is significant weight gain in a short space of time(approximately >2 kg in 3 days) .[13]

In item of the EHFScBs "2- If I am short of breath, I take it easy", most of the interviewed parties was positioned under score 1 (86%) of the instrument, in which they state that if they have any shortness of breath, they decrease their rhythm. This symptom is when the cardiac output is not high enough to meet tissue oxygen needs, apart from reducing the peripheral blood supply. However, prolonged rest or inactivity can cause muscular atrophy, exacerbation of the heart failure symptoms, thromboembolism and reduced exercise tolerance.[14]

Fear of this tiredness and/or state of health standard may have directly impacted the answers to item "12 – I exercise regularly" of the EHFScBs , where the majority positioned themselves in score 5 (58,1%) of the instrument, indicating that there is a difficulty in exercising due to the health condition. Individuals with heart failure don't usually practice physical exercises due to the exacerbation of the symptoms of the disease. It is also known that exercises are beneficial in this population, however guidance as to these exercises must be individualized and in accordance with the degree of heart failure and age.[15] Inserting people with heart failure in cardiovascular rehabilitation programs may be considered a complement to the pharmacological therapy by the cardiologist, since the inclusion to programs with exercises allied to treatment with medication can improve the quality of life and reduce intolerance to physical efforts.[16]

Dyspnea and fatigue, during physical exercises, are the main clinical symptoms of heart failure, inducing patients to interrupt the activity and, in time, there are restrictions to daily activities and, due to the vicious circle of inactivity, there is a deterioration of the physical capacity and consequent decrease in the quality of life.[17] In item "7 - I take a rest during the day" of the EHFScBs, most of the participants marked score 1 (88.4%) of the instrument, fully agreeing with this affirmation.

In the beginning of the disease, these complications are manifested during the exercise, but with the evolution of the illness, the symptoms occur with progressively lesser efforts, until being observed during rest.[13] For item "3 - Para o item "3- If my shortness of breath increases, I contact my doctor or nurse" and item "8 - If I experience increased fatigue, I contact my doctor or nurse" of the EHFScBs, most of the participants were positioned in score 1 (46.5%) and (51.2%), respectively, agreeing with both affirmations.

Individuals that reach the hospital without swelling present significantly reduced mortality rates, whereby this clinical sign, apart from being frequent, is an important predictor for a negative outcome in acute decompensations.[14] In this research, when questioned about item "4- If my feet/legs become more swollen than usual, I contact my doctor or nurse" in the scale, most of the participants positioned themselves in score 1 (60.5%), that is, they to say, they looked for the help of health professionals when they verified their feet or legs were swollen. However, in relation to item "5 - If I gain 2 kilos in one week, I contact my doctor or nurse", the score was 5 (53.5%), indicating that when a quick weight gain was identified in a short period, assistance from health professionals was not sought, corresponding to the findings of the above mentioned authors.

There is evidence that excessive consumption of sodium and of fluids is associated to the aggravation of hypervolemia, a factor of decompensation and risk of hospitalization in symptomatic chronic heart failure. It is recommended that excessive ingestion be avoided and levels of over 7 g of sodium chloride per day.[6] In the studied sample, with reference to item "6- I limit the amount of fluids I drink (not more than 1.5-2 liters/day)" of the EHFScBs, 58.1% of those interviewed positioned themselves in score 5, indicating that they do not make any restrictions as to the quantity of liquid ingested daily. As of item "9 - I eat a low salt diet", most of the participants marked score 1 (79%), agreeing that they follow a low salt diet.

Continuous use medication that modify the evolution of heart failure are not easy to be started within a short period of hospitalization, and could experience an increase in the risk of re-hospitalization or death after discharge, due to the simple fact of lack of administration of the correct therapy.[10] Accordingly, multidisciplinary guidance of the patient and of family members is considered an essential component, with a positive impact on clinical outcomes.[6] For item "10- I take my medication as prescribed" of the EHFScBs, 86% of the interviewed parties positioned themselves in score 1, agreeing that they take their daily medication as prescribed.

Flu and pneumococcus vaccine is one of the preventive measures in heart failure, since there was a reduction in hospitalization due to cardiovascular diseases in those that were vaccinated. This recommendation is present in the last Brazilian guideline for heart failure.[6] In the studied sample, in relation to item "11 -. I get a flu shot every year" of the scale, most of the participants positioned themselves in score 1 (60.5%) of the instrument, agreeing that they take the annual flu shots.

Self-care of people with heart failure is directly related to their behavior in maintain their health and their decisions when the symptoms worsen. Maintaining self-care involves the use and daily application of: pharmacological recommendations, low salt diet, quitting smoking, limited consumption of alcoholic beverages, daily monitoring of weight and of the signs and symptoms heart failure decompensation. This is a decision-making process in which individuals chose behaviors that can maintain a physiological stability and responses to clinical manifestations when these occur.[18]

In relation to the level of self-care, it was verified that most of the participants presented moderate to unsatisfactory capacity of attention to their own needs, with a mean value obtained for the total score of the 12 items of 30.1 (±7.4) and relevance in the total score of between 31 and 50 points, for 46% of the interviewed parties, resulting in a sample with deficit in the self-care. Such answers draw attention to the need for educational practices in the outpatient clinic

environment, fomenting behavioral changes and enabling the establishment of attitudes for maintaining the health condition. The individual with heart failure should have active participation in his/her health, not only re-establishing the clinical condition, but also the awareness that self-care needs to be increasingly consolidate, with the intent of avoiding or reducing the number of re-hospitalizations due to decompensation of the disease and improving quality of life.

Conclusion

Individuals with heart failure assisted at a cardiology outpatient clinic have moderate to unsatisfactory self-care behaviors. This deficit draws attention to the implementation of effective educational practices, with the aim of qualifying these professionals to recognize and handle the symptoms, in the outpatient clinic scenario, promoting self-care.

The data obtained in the study helped in the identification of some self-care actions that need to be altered or included for better control of heart failure control and, consequently, improve the quality of life. It is suggested that health education strategies guided to self-care be implemented during the treatment of patients with heart failure. The preparation of care protocol to guide the approach of professionals and educational guides could guarantee a more efficient attention and, consequently, reduce the complication and mortality rates of the disease.

As limitations to the research the reduced size of the sample could be considered and the data collection time. An expansion in the number of interviewed parties is suggested to increase the power of the study and a follow-up of the study (new study design) and thus effectively confirm the benefits of self-care.

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3 – Andreia Santos Mendes
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