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FUNCTIONALITY OF FAMILY DYNAMICS AND SELF-CARE IN
HEART FAILURE: A PILOT STUDY

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Abstract

Family represents a basic source of support for the patient with chronic illness, namely Heart Failure (HF), and it is the main structure of mutual help in difficult situations. This study was based on the questions related to the level of self-care skills in a person with HF and the influence of family functionality on the level of self-care skills in a person with HF. The purpose of the study was to determine the level of self-care skills in a person with HF and relate it to family functionality. An analytic, correlational and cross-sectional study was conducted on 103 patients with HF, attending follow-up consultation at a hospital in the Centre of Portugal. Data collection was performed through a self-administered questionnaire that included sociodemographic data, Family Apgar and the European Heart Failure Self-care Behaviour Scale (Pereira, 2013). The findings revealed that 44.7% lived in a “Highly functional family” and self-care skills level was reported by 47.1 % as “adequate self-care”. The familial functionality appears as a predictor of self-care, in which the higher it is, the higher the level of self-care skills shown. The results are consistent with national and international research, confirming the low prevalence of adequate self-care in a person with HF. However, it was confirmed that family support is predictive of the self-care in a person with HF.

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Keywords: Heart failure, self-care, family functionality, disease management.



1. Introduction

Heart Failure (HF) represents a serious public health problem with repercussions on mortality and morbidity rates (McMurray et al., 2012; Ponikowski et al., 2016).

Heart failure is a common condition throughout the world, with a prevalence of 1 to 2% in the population; rising to $\geq 10\%$ among people over 70 years of age (McMurray et al., 2012; Ponikowski et al., 2016).

The prevalence of HF in Portugal ranges from 1.36% in the 25-50 age group and 16% in the over 80 age group. Regarding hospitalizations due to HF complications, it is estimated that two-thirds of HF clients will be hospitalized on average 2 times a year, and approximately 35% of new HF cases are hospitalized within the first 12 months following diagnosis of HF (Ceia & Fonseca, 2007).

Heart failure self-management interventions that improve the knowledge and management skills of patients with heart failure for this chronic and progressive condition are advocated in clinical guidelines and widely implemented in heart failure care (McMurray et al., 2012; Ponikowski et al., 2016).

Adherence to treatment plays a particularly important role in the person with chronic disease. Non-adherence to treatment is a serious public health problem, with significant repercussions on the incidence and prevalence of numerous diseases (Osterberg & Blaschke, 2005).

Heart Failure is a chronic and progressive pathology that affects people in their quality of life, causing functional limitations that lead to a decrease in the capacity to perform daily activities and may negatively influence the quality of life. The control and treatment of the disease call for the involvement of the person in the management of his/her health condition and the development of self-care competences that allow effective management of the therapeutic regimen (Scheurer, Choudhry, Swanton, Matlin, & Shrank, 2012).

Studies have shown that the hospitalization of the person with heart failure is usually associated with the deficit of self-care competences, which results from an ineffective management of the therapeutic regimen and contributes to a high consumption of hospital resources and an increase in health expenditure (Sanf elix-Gimeno et al, 2013).

The development of self-care skills in the person with Heart Failure is one of the objectives of the long-term nursing intervention. Therefore, it is fundamental in this context to make available the same resources that enable the obtaining of information about the self-care behaviors of the person with Heart Failure (Dunbar, 2008, 2016).

The issue of adherence is of utmost importance when it comes to the heart patient, as it helps to prevent and effectively manage the disease. Non-adherence has a great impact on the life of the person with heart disease, namely in the control of symptoms, maintenance of their functional capacity and quality of life (Sanf elix-Gimeno et al, 2013).

The family is an important social unit capable of solving individual or collective biopsychosocial problems. The family represents a source of basic support for the patient with chronic disease, namely Heart Failure and the main structure of mutual help in difficult situations (Gray, 2006; Dunbar, 2008). Thus, due to the chronic nature of HF, family members provide social support, motivation and positive communication, which is a crucial component for the HF patient who performs effective and sustainable self-care (Gray, 2006; Dunbar, 2008). The family provides support through encouragement, empathy and

a sense of choice about self-care for the HF patient. Individuals with HF are more likely to adjust health behaviors according to family support (Scheurer et al., 2012, Dunbar, 2008, 2016). Having a cohesive and supportive family is associated with better self-care index and consequently, more effective control of the disease (Scheurer et al., 2012)

Thus, it is fundamental to develop self-care skills in people with HF with family involvement, for the control, treatment of the disease, and for the effective management of the therapeutic regimen.

2. Problem Statement

The family is the primary source of support for its members to solve problems, especially when they are associated with conditions related to health or disease. Thus, knowing more about family functioning allows the implementation of interventions focused on the family, or to inform patients who need more intense self-care intervention to better manage their disease.

3. Research Questions

3.1 What is the level of self-care skills in a person with HF?

3.2 What is the influence of family functionality on the level of self-care skills in a person with HF?

4. Purpose of the Study

This study aims to determine the level of self-care skills in a person with HF and relate it to family functionality

5. Research Methods

5.1. Study Population and Design

This is a descriptive-correlational and cross-sectional study. A non-probabilistic sampling was used for convenience that integrates subjects recruited in a certain place during a certain period of time, being accessible to the investigator by a process that does not require knowledge of the universe. The choice of this type of sample is frequent in a health context (Pais-Ribeiro, 2004).

103 patients with heart failure who were in follow-up consultations at the hospital were selected at the time of application of the questionnaire.

The inclusion criteria were: a) over 18 years of age; b) diagnosis of heart failure after hospitalization; and c) agree to participate in the study, expressed in the consent form.

The exclusion criteria were: patients diagnosed with psychiatric illness, institutionalized and not oriented in time and space (using some questions from the Folstein, Folstein and McHugh (1975) test on consciousness and time-space orientation).

5.2. Measures

Data collection was done through a self-administered questionnaire, integrating:

5.2.1. sociodemographic variables

Gender, age, marital status, residential area, schooling, occupational situation and monthly family income;

5.2.2. Family APGAR Scale

The family is an important social unit, able to solve (or help solve) individual or collective biopsychosocial problems. Family functionality translates into family dynamics and the quality of the patient's relationship with his or her family. For the operationalization of this variable, we used the family APGAR scale elaborated by Smilkstein in 1978 (Smilkstein, Ashworth & Montano, 1982), translated and adapted to Portuguese by Agostinho, & Rebelo (1988).

The scale consists of five questions, which quantify the perception that the respondent has of the family's functioning. This scale enables the characterization of the fundamental components of family function in: (a) adaptability - refers to the use of resources inside and outside the family for the solution of problems that threaten the balance of the family during the crisis; (b) partnership - refers to the sharing of decision-making and responsibilities by family members; (c) growth - comprises physical, psychic, emotional maturity and achievement achieved by family members, through mutual support and guidance; (d) affection - refers to the existence of caring or tender relationships between family members and (e) resolves - reflects a commitment to dedicate time to other family members, encouraging them physically and emotionally, which also implies a decision to share assets and space.

Each question allows three types of answers: almost always, sometimes and almost never, reflected numerically by 2, 1 and 0 points, respectively.

The final result of the scale is obtained by the sum of the scores attributed to each one of the questions, being able to vary between zero and ten points. The score totals enable the classification of the type of family relationship: (a) from seven to ten points - suggests a highly functional family;

(b) four to six points - translates a family with mild dysfunction and (c) from zero to three points - indicates a family with severe dysfunction.

The Family APGAR Scale has good internal consistency (Cronbach $\alpha = 0.866$).

5.2.3. European Heart Failure Self-care Behavior Scale (EHFScBS)

This scale was developed and published in 2003 by Jaarsma, Arestedt, Mårtensson, Dracup, and Strömberg. This scale aims to evaluate the recognition of signs and symptoms of HF decompensation and the decision making in the occurrence of these symptoms.

It is a self-administered instrument in which three dimensions are considered. The first dimension is associated with "complying with regimen"; the second dimension is associated with "asking for help"; and the third dimension is associated with "adapting activities". These three dimensions initially totalled 20 items, which were later reduced to 12 for the purpose of this study. Items are rated on a scale with Likert response of 5 points (1 strongly agree and 5 strongly disagree). To evaluate the psychometric properties of EHFScBS, a multicenter study was conducted in three countries. The results showed the validity and reproducibility of this instrument and also revealed its clinical usefulness in the evaluation of self-care in people with HF.

Conceptually, the 12 items of the EHFScBS were divided into three dimensions. The first dimension "Adherence to the regimen", comprises six items that measure behaviors related to restriction of liquids and sodium, regular physical exercises and prevention of influenza. The second dimension "Ask for help" comprises four items related to specialized health care seeking behaviors, when exacerbation of signs and symptoms of the disease occurs. The third dimension "Adaptive Activity" comprises two items that measure behaviors adaptive to the limitations imposed by HF.

Although the version of the EHFScBS-9 items demonstrate better psychometric results when compared to the 12-item version (Jaarsma et al., 2009), the 12-item version was chosen for this study because it presents important issues in the self-care of the person with Heart Failure.

In this work, the version of this scale translated, adapted and validated for the Portuguese population by Pereira (2013) was used.

The European Heart Failure Self-care Behavior Scale has moderate internal consistency (Cronbach $\alpha = 0.706$).

5.3. Statistical and ethical-legal procedures

The reliability was verified by the Cronbach's alpha. Using descriptive statistics, we determined frequencies and percentages, means, standard deviation and chi-square. The Mann-Whitney U test was used instead of student's t-test when the groups are not similar in size (Pestana & Gageiro, 2014). We also used multiple linear regression by stepwise method. The SPSS (Statistical Package for the Social Sciences) version 24.0 for Windows was used for the statistical analysis. The research protocol was evaluated and approved by the Ethics Committee and the informed consent statement was obtained from all the participants.

6. Findings

6.1. Sociodemographic characteristics

Table 1 shows the sociodemographic characterization of the participants according to gender; of 102 participants, 61.8% (n = 63) was male and 38.2% (n = 39) was female.

The minimum age is 29 years and the maximum 90 years, which corresponds to an average of 71.4 ± 11.4 years of age. Due to the high amplitude of variation, it was grouped into two age groups: "Age ≤ 69 years" and " ≥ 70 years". It was verified that the majority of participants (64.7%) belonged to the " ≥ 70 years" age group.

In relation to the marital status, this variable was recoded, constituting two groups: Single / widower / divorced and "Married / Civil union". It was found that the majority of the participants 70.6% (n = 72, distributed by 49 male and 23 female) lived with a companion.

Educational qualifications were regrouped into two groups, the first " ≤ 4 years of schooling" and the second "5 years of schooling". We identified 89.2% of participants (n = 91, distributed among 57 males and 34 females) with low schooling.

Regarding the labor situation, the sample mostly comprised professionally "non-active" people (88.2%) (n = 90, distributed among 56 men and 34 women).

Regarding residence, the majority of the participants lived in a "rural area" 62.7% (n = 64).

Since it is difficult to quantify the monthly income, we used levels of measurement that allowed the participants to respond at what level the value they had. Monthly income was regrouped into 2 groups: "One minimum wage", and "≥ 2 minimum wages". Thus, we find that 70.6% of the sample earned a monthly income lower than the "one minimum wage".

Table 01. Sociodemographic characteristics

8	Male		Female		Total	
	(n= 63; 61,8 %)		(n=39; 38,2%)		(n=102; 100%)	
	n	%	n	%	n	%
Age						
$\bar{X} \pm$ Std. deviation	71.1 \pm 9.0)		71.9 \pm 2.3		71.4 \pm 11.4	
Age group						
≤ 69	23	36.5	13	33.3	36	35.3
≥ 70	40	63.5	26	66.7	66	64.7
Civil status						
Single/widower/divorced	14	22.2	16	41.0	30	29.4
Married / Civil union	49	77.8	23	59.0	72	70.6
Education level						
≤ 4 years	57	90.5	34	87.2	91	89.2
≥ 5 years	6	9.5	5	12.8	11	10.8
Professional activity						
Active	7	11.1	5	12.8	12	11.8
Not active	56	88.9	34	87.2	90	88.2
Area of residence						
Urban	23	36.5	15	38.5	38	37.3
Rural	40	63.5	24	61.5	64	62.7
Monthly household income						
One minimum wage	40	63.5	32	82.1	72	70.6
≥ 2 minimum wages	23	36.5	18.0	21.4	30	29.4

6.2. Characterization of family functionality

Table 2 presents the results of the application of the family functionality assessment scale (family Apgar). It was verified that the participants obtained an average score of 6.2 ± 2.6 , whose values oscillated between 0 and 10. As for gender differences, men are more involved in a more functional family as opposed to women, but the differences are not statistically significant (Mean Rank = 53.01 vs Mean Rank = 50.41, $p > 0.05$).

In relation to family functionality, it was found that the "Highly functional family" is the most representative with 44.7%, followed by "family with mild dysfunction" with 40.8% and finally "family with severe dysfunction" with 14.6%.

Table 02. Familiar functionality characteristics

	Male		Female		Total	
	(n= 63; 61,8 %)		(n=39; 38,2%)		(n=102; 100%)	
	n	%	n	%	n	%
Family APGAR Scale						
$\bar{X} \pm$ Std. deviation	6.3 \pm 2.5		6.2 \pm 2.7		6.2 \pm 2.6	
Family functionality						

Highly functional family	29	28.2	17	16.5	46	44.7
family with mild dysfunction	27	26.2	15	14.6	42	40.8
family with severe dysfunction	7	6.8	8	7.8	15	14.6

6.3. Characterization of self-care

The results of the response patterns in each EHFScBS item are shown in table 3. We chose to present the response pattern of 12 items, once it was considered important to obtain the answer to all items to better understand the behavior of the person with HF. Thus, we considered each item as an individualized issue.

Thus, items 2, 6, 7, 9, 10 and 11 indicate a good adherence to self-care behaviors recommended by national and international guidelines for the non-pharmacological treatment of HF. However, some exceptions were noted, namely for Items 1, 3, 4, 5, 8 and 12. These results indicate difficulties in performing daily body weight monitoring and performing some regular physical activity.

With regard to items 3, 4, 5 and 8, the respondents usually did not ask for help from health professionals when signs of decompensation appear. An exception can be observed for the case of item 5, in which it seems that if there is a weight gain of 2 kilos the person with HF contacts the doctor or nurse.

Table 03. Distribution of responses for each item of the EHFScBS

	strongly agree				strongly disagree	\bar{x}	Std. deviation
	Score 1	Score 2	Score 3	Score 4	Score 5		
1. I weigh myself every day	2.9% (n= 3)	2.9% (n= 3)	13.7% (n= 14)	43.1% (n= 44)	37.3% (n= 38)	4.10	0.945
2. If I am short of breath, I take it easy	52.0% (n= 53)	40.2% (n= 41)	4.9% (n= 5)	2.9% (n= 3)	0% (n= 0)	1.58	0.721
3. If my shortness of breath increases, I contact my doctor or nurse	5.9% (n= 6)	9.8% (n= 10)	24.5% (n= 25)	54.9% (n=56)	4.9% (n= 5)	3.43	0.946
4. If my feet/legs become more swollen than usual, I contact my doctor or nurse	4.9% (n= 5)	18.6% (n= 19)	24.5% (n= 25)	51.0% (n= 52)	1.0% (n= 1)	3.24	0.934
5. If I gain 2 kg in 1 week, I contact my doctor or nurse	0% (n= 0)	22.5% (n= 23)	33.3% (n= 34)	37.3% (n= 38)	6.9% (n= 7)	3.28	0.890
6. I limit the amount of fluids I drink (not more than 1.5–2 l/day)	21.6% (n= 22)	31.4% (n= 32)	26.5% (n= 27)	15.7% (n= 16)	4.9% (n= 5)	2.52	1.145
7. I take a rest during the day	61.8% (n= 63)	22.5% (n= 23)	8.8% (n= 9)	2.9% (n= 3)	3.9% (n= 4)	1.64	1.028
8. If I experience increased fatigue, I contact my doctor or nurse	4.9% (n= 5)	8.8% (n= 9)	24.5% (n= 25)	56.9% (n= 58)	4.9% (n= 5)	3.48	0.906
9. I eat a low salt diet	15.5% (n= 16)	43.7% (n= 45)	33% (n= 33)	5.8% (n= 6)	1.9% (n= 2)	2.35	0.882
10. I take my medication as prescribed	20.4% (n= 21)	46.6% (n= 47)	29.1% (n= 30)	3.9% (n= 4)	0% (n= 0)	2.17	0.793
11. I get a flu shot every year	47.6% (n= 48)	29.1% (n= 30)	7.8% (n= 8)	4.9% (n= 5)	10.7% (n= 11)	2.02	1.313
12. I exercise regularly	4.9% (n= 5)	15.5% (n= 16)	9.7% (n= 10)	19.4% (n= 20)	50.5% (n= 51)	3.95	1.294
Total						2.96	0.565

6.4. Level of self-care skills

In relation to the determination of self-care level, two groups were formed based on the cut off in the median. It was found that 47.1% (n = 48, distributed among 32 men and 16 women) of the participants presented adequate self-care and the differences between gender were not statistically significant.

Table 04. Level of self-care skills in a person with HF

	Male (n= 63; 61.8 %)		Female (n=39; 38.2%)		Total (n=102; 100%)		χ^2 p
	n	%	n	%	n	%	
Adequate self-care skills	32	50.8	16	41.0	48	47.1	$X^2= 0.923$
Self-care deficit skills	31	49.2	23	50.9	54	52.9	p= 0.337

6.5. Family Functionality and Self Care

We analysed the correlations between self-care and "family functionality", which is moderate (r = 0.252, p = 0.01). The value of family Apgar accounts for 5.4% of the variability of self-care

Table 05. Multiple linear regression between self-care and family functionality]

	Coefficients		F (p)	t	p	R (R ²)
	Unstandardized Coefficients	Standardized Coefficients				
<i>Constant</i>	3.091					
<i>adaptability (to the use of resources inside and outside the family for the solution of problems that threaten the balance of the family during the crisis)</i>	-0.177	-0.224	5.293 (0.023)	-2.301	0.023	0.224 (0.050)

7. Conclusion

This study aimed to determine the level of self-care skills in a person with HF and to relate it to family functionality.

We found that only 47.1% of the participants presented adequate self-care skills. Family functionality appears as a predictor of self-care, and the higher this is, the higher the level of self-care skills.

For health professionals, including nurses, understanding the reasons for self-care deficits is a fundamental part of the art of caring. Thus, the deficit of self-care in HF may be related to the deficient attention that is being given to patients and their families, since no specific protocols are observed.

As for nurses, these are, by the nature of nursing therapeutics, a facilitator in promoting the dispositions of the patient and the family necessary for change or awareness so that people can experience better health.

Caring for people with chronic diseases implies, on the part of the nurses, an articulated intervention centered on the person and the family, with the purpose of enabling them to take care of themselves, in order to manage their illness, to prevent complications and to achieve a quality life.

In short, the nurse performs the role of educator as a means for the patient and the family to obtain resources and support for the person in order to improve their level of preparation to participate in the

decision-making process and involvement in the clinical management of the patient and the disease and increase the degree of individual and social responsibility in the evolution of the disease and quality of life.

The main limitations of this study were a limited sample size, performed with people with HF from a single specialized and teaching hospital, as well as a cross-sectional design that did not allow for the investigation of temporal relations between the variables. Another limitation was due to the very high average age and the low level of education of the respondents, so the researchers had to read the questions aloud and note down the responses. This procedure may have contributed to some bias, since the responses could be given in a way that pleases the investigator.

Nevertheless, the findings of this study indicate that there is an urgent need to plan and implement timely interventions in this group of people by trained nurses, in order to ensure that these HF patients get the appropriate care they deserve.

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