

## The Difficult Daily Life of Heart Failure Bearing Patients

O difícil cotidiano dos pacientes com insuficiência cardíaca

El difícil cotidiano de los pacientes con insuficiencia cardiaca

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### ABSTRACT

**Objective:** The study's purpose has been to assess the main limitations reported by heart failure bearing patients. **Methods:** It is a secondary analysis of an exploratory study with a qualitative approach. This study was performed with 15 patients with heart failure, out of the 167 undergoing ambulatory care, and over the period from March to July 2011. The collection of primary data was based on semi-structured interviews with subsequent analysis according to the Bardin's perspective. The secondary analysis was performed according to the retrospective interpretation strategy. **Results:** There were female predominance (73.3%); incomplete elementary school (80.2%); hypertensive patients (80.2%); dyslipidemic patients (53.4%); and diabetics patients (33.3%). Concerning the daily limitations, the following stand out: impaired walking, precarious sleep pattern, fatigue, dyspnea, loss of autonomy, dependence on others, poor sleep pattern, low sexual activity. **Conclusion:** By taking into consideration the heart failure, a chronic disease, it is fundamental for nurses to look for guidelines and strategies that are able to develop the capacity for self-care, prevention and health promotion.

**Descriptors:** Heart Failure, Nursing, Self-Care.

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## RESUMO

**Objetivo:** Analisar as principais limitações relatadas por pacientes com insuficiência cardíaca. **Método:** análise secundária de um estudo exploratório, de abordagem qualitativa, realizado com 15 pacientes portadores de insuficiência cardíaca no período de março a julho de 2011, dentre os 167 em atendimento ambulatorial. A coleta de dados primários deu-se a partir de uma entrevista semi-estruturada, com posterior análise de Bardin, e para presente análise secundária foi utilizada como estratégia a interpretação retrospectiva. **Resultados:** predominância do sexo feminino (73,3%); ensino fundamental incompleto (80,2%); hipertensos (80,2%); dislipidêmicos (53,4%); diabéticos (33,3%). Quanto às limitações no cotidiano, destacam-se: deambulação prejudicada, padrão de sono precário, fadiga, dispneia, perda de autonomia, dependência de terceiros, padrão de sono precário, baixa frequência da atividade sexual. **Conclusão:** na insuficiência cardíaca, uma doença crônica, é fundamental que o enfermeiro busque por orientações e estratégias, as quais possam desenvolver a capacidade de autocuidado, prevenção e promoção da saúde.

**Descritores:** Insuficiência Cardíaca, Enfermagem, Autocuidado.

## RESUMEN

**Objetivo:** Analizar las principales limitaciones relatadas por pacientes con insuficiencia cardiaca. **Método:** análisis secundario de un estudio exploratorio, de abordaje cualitativo, realizado con 15 pacientes portadores de insuficiencia cardiaca en el período de marzo a julio de 2011, entre los 167 en atención ambulatoria. La recolección de datos primarios se dio a partir de una entrevista semiestructurada, con posterior análisis de Bardin, y para el presente análisis secundario se utilizó como estrategia la interpretación retrospectiva. **Resultados:** predominio del sexo femenino (73,3%); educación básica incompleta (80,2%); hipertensos (80,2%); dislipidémicos (53,4%); diabéticos (33,3%). En cuanto a las limitaciones en el cotidiano, se destacan: deambulación perjudicada, patrón de sueño precario, fatiga, disnea, pérdida de autonomía, dependencia de terceros, patrón de sueño precario, baja frecuencia de la actividad sexual. **Conclusión:** en la insuficiencia cardíaca, una enfermedad crónica, es fundamental que el enfermero busque orientaciones y estrategias, que puedan desarrollar la capacidad de autocuidado, prevención y promoción de la salud.

**Descriptores:** Insuficiencia cardíaca, Enfermería, Autocuidado

## INTRODUCTION

In Brazil, in 2013, 1,138,670 deaths occurred, where 29.8% (339,672) were due to Cardiovascular Diseases (CVD). Worldwide, these diseases will continue to rank among the most lethal, and by 2030, they will account for the deaths of 23.6 million individuals.<sup>1</sup>

Among cardiovascular diseases, Heart Failure (HF) accounts for approximately 4% of hospitalizations in general and 31% of hospitalizations for cardiovascular diseases in the Sistema Único de Saúde (SUS) [Brazilian Unified Health System]. The average hospitalization period is 5.8 days, and hospital mortality ranges from 5.6 to 6.0%, generating a cost in excess of R\$ 200 million, according to the Ministry of Health data.<sup>2</sup>

HF is a chronic disease, constituting a complex clinical syndrome, of a systemic character, caused by dysfunction in the cardiac muscle leading to an inadequate blood supply to supply the metabolic needs of the tissues. It is esti-

mated that approximately 6.4 million Brazilians are carriers of the disease, being the most significant etiology of HF, chronic ischemic heart disease associated with arterial hypertension.<sup>3</sup>

Nevertheless, considering the world framework, it is estimated that there are 27 million<sup>2</sup> individuals with the disease, for instance, approximately 6.5 million in Europe, 5 million in the United States and 2.4 million in Japan, and still 1 million new cases diagnosed annually.<sup>4</sup> Therefore, making it a serious case of public health in several countries, where nursing care at different levels of patient care with HF should be differentiated, seeking to identify individual health needs.

Studies show that among the causes of HF hospitalization, there is usually an association of insufficient self-care practices, mainly due to ineffective management of the therapeutic regimen.<sup>5</sup> Furthermore, HF as a chronic disease may, over time, present a set of limitations reported and felt by patients with self-care impact.

Bub and Cols<sup>6</sup> describe that self-care actions constitute the practice of activities that individuals deliberately perform for their own benefit for the purpose of maintaining life, health, and well-being.

In regards to HF, the maintenance of self-care encompasses mainly adherence to pharmacological recommendations, consumption of low-salt diet, cessation of tobacco use, limited consumption of alcohol, daily monitoring of weight and signs or symptoms of disease decompensation. Bearing the aforesaid in mind, self-care is a decision-making process that patients use in choosing behaviors that maintain physiological stability, and the response to symptoms when they occur.<sup>7</sup>

The development of nursing interventions has the purpose of satisfying the needs of the patient. The actions performed by the nurse require adequate planning aiming at a better individual approach as well as a rigorous evaluation of its effectiveness in optimizing the practice of self-care and its translation into clinical outcomes.<sup>8</sup>

Given the aforementioned, the study's goal is to scrutinize the main limitations reported by heart failure bearing patients.

## METHODS

It is a quantitative and qualitative study of secondary analysis, which is based on an exploratory study performed with 15 patients from March to July 2011 in a specialized outpatient clinic of a university hospital. There were 167 patients with heart failure clinical diagnosis, and an average of 8.7 years since the initial diagnosis.<sup>9</sup> The sample was of an intentional, non-probabilistic type, using a semi-structured interview script prepared by the principal investigator and an MP3 recorder for data collection. The reports lasted 30 minutes on average, which were transcribed in full according to the Bardin's perspective.<sup>10</sup>

The original research was approved by the Ethics Committee of the Faculty of Medicine from the Universidade Federal Fluminense (UFF), under the Legal Opinion No. 026 A/2011.

After signing the Informed Consent Form (ICF), patients older than 18 years old were included, from both genders, and those with the cognitive deficit and hemodynamically unstable were excluded. And for the anonymity of the participants, the identification was by means of pseudonyms referring to precious stones.

Considering the 5 categories pointed out by the original research, “The limitations imposed by chronic heart failure” was highlighted for this analysis due to the expectancy of impact on self-care.

For this secondary analysis, the retrospective interpretation of the report of all patients was used as a strategy, with the question “What did you do before that you cannot do now after the disease diagnosis?”; then performing subsequent association of the sociodemographic characteristics and reports with the scientific evidences.

## RESULTS AND DISCUSSION

Concerning the 15 patients, there was a predominance of females, formed by 11 (73.3%) women, with an average age between 51 and 60 years old. Meanwhile, in the male gender (26.7%), the average age remained between 61 and 70 years old.

Systemic Arterial Hypertension (SAH) was found in five (33.3%) patients. And in seven subjects (46.7%), the hypertension was associated with other comorbidities.

Dyslipidemia was observed alone in two (13.3%) patients, whereas diabetes mellitus was not self-reported as the only comorbidity in this sample, where it was found only in association with other diseases. It was observed that one (6.6%) patient reported having the three main comorbidities (SAH, diabetes mellitus and dyslipidemia), while another reported bearing no disease associated with heart failure.

**Table I.** Distribution of the clinical-sociodemographic characteristics of patients bearing heart failure and undergoing ambulatory care in 2011. Niterói city, Rio de Janeiro State, Brazil, 2018.

| Clinical-sociodemographic characteristics | Total (%) | Gender |        |      |        |
|---|-----------|--------|--------|------|--------|
|   |           | Female |        | Male |        |
|   | n         | n      | (%)    | n    | (%)    |
|   | 15 (100)  | 11     | (73.3) | 4    | (26.7) |
| <b>Age</b>                                |           |        |        |      |        |
| 40 to 50 y.o.                             | 1 (6.6)   | 1      | (9.1)  | -    | -      |
| 51 to 60 y.o.                             | 7 (46.7)  | 6      | (54.5) | 1    | (25)   |
| 61 to 70 y.o.                             | 4(26.7)   | 2      | (18.2) | 2    | (50)   |
| 71 to 90 y.o.                             | 3 (20)    | 2      | (18.2) | 1    | (25)   |
| <b>Marital status</b>                     |           |        |        |      |        |
| Married                                   | 8 (53.4)  | 4      | (36.4) | 4    | (100)  |
| Widowed                                   | 3(20)     | 3      | (27.2) | -    | -      |
| Divorced                                  | 2(13.3)   | 2      | (18.2) | -    | -      |
| Single                                    | 2(13.3)   | 2      | (18.2) | -    | -      |

| <b>Religion</b>                |           |   |        |   |      |
|--------------------------------|-----------|---|--------|---|------|
| Catholic                       | 7 (46.7)  | 4 | (36.4) | 3 | (75) |
| Evangelical                    | 6(40)     | 5 | (45.4) | 1 | (25) |
| No religion                    | 2(13.3)   | 2 | (18.2) | - | -    |
| <b>Education</b>               |           |   |        |   |      |
| Complete High School           | 1 (6.6)   | 1 | (9.1)  | - | -    |
| Complete Elementary School     | 1(6.6)    | - | -      | 1 | (25) |
| Incomplete Elementary School   | 12 (80.2) | 9 | (81.8) | 3 | (75) |
| Illiterate                     | 1(6.6)    | 1 | (9.1)  | - | -    |
| <b>Comorbidities</b>           |           |   |        |   |      |
| Diabetes Mellitus              | 5 (33.3)  | 3 | (27.2) | 2 | (50) |
| Dyslipidemia                   | 8 (53.4)  | 5 | (45.4) | 3 | (75) |
| Coronary Artery Disease        | 4(26.7)   | 3 | (27.2) | 1 | (25) |
| Acute Myocardial Infarction    | 2(13.3)   | 1 | (6.6)  | 1 | (25) |
| Systemic Arterial Hypertension | 12(80.2%) | 9 | (81.8) | 3 | (75) |

As for the daily modifications and limitations imposed by the disease and its symptomatology, the majority of patients mainly reported as follows: impaired walking, poor sleep pattern, dyspnea fatigue, third-party dependence, precarious and low sleep pattern frequency of sexual activity. Still about the reports, the loss of autonomy and the dependence of others point to poor self-care.

This is an important inference, since it is estimated that an increase in the incidence and prevalence of HF will occur in the next few years, especially in individuals aged between 60 and 80 years old, increasing the number of new cases and making the number of cases about 10 times.<sup>11</sup> However, in this study, the disease onset is around the age of 51 years old. HF represents one of the main causes of morbidity and mortality among the elderly and is still one of the main causes of hospitalization and use of emergency services by this population in Brazil and in the whole world.<sup>11</sup>

### The association of sociodemographic characteristics with heart failure

With 53.4% married, this data is important information associated with self-care. Because, according to the American study<sup>12</sup> published in 2008, in which the authors evaluated the perception of social support through a specific instrument comparing the results with the self-care profile in the HF patients, they concluded that individuals with HF who live in the company of someone close to you present better and greater performance in self-care activities.

Regarding the religion, here understood as spirituality, it has recently been studied in the context of chronic diseases that progress with low quality of life and sinister and predictable outcomes. Spiritual well-being has shown that it can bring benefits in the way patients with HF deal with their illness, as well as positively impact mortality from the disease.<sup>13</sup> This fact was observed, since the participants were Catholic or Evangelical and have personal beliefs, although a smaller percentage of patients said they did not follow a specific religion.

Observing the educational level, we detected that most of the participants addressed it as low, identified by “incomplete elementary school”, a fact that can interfere in the understanding of the guidelines and adherence to the

treatment, compromising the quality of life and self-care. Therefore, the sociodemographic characteristics, cultural aspects, level of education and specific clinics to follow up patients with HF are described in the literature as variables that influence the self-care of these patients.<sup>7</sup> Thus, the greater the individual's level of education, the greater the individual's ability to understand his/her pathology, symptomatology and better decision-making skills for health promotion, recovery, and protection.<sup>14</sup>

Often, HF is accompanied by different comorbidities that affect the treatment and the natural course of the disease. The Acute Decompensated Heart Failure National Registry<sup>15</sup> gathered information from more than 100,000 individuals hospitalized due to the decompensation of the disease and showed that 90% of the patients also had systemic arterial hypertension, chronic coronary disease and diabetes mellitus. This research testifies to the evidence of the main diseases associated with heart failure, especially ischemic arterial hypertension, found in 80% of the patients in the sample.

Patients bearing HF present important, progressive and highly limiting clinical manifestations that affect not only the physical but also the psychological dimension. Living with chronic illness implies changes in habits of the individual/family binomial and often cannot be put into practice in a gradual way, bringing significant impact on the routine of these clients.

Based on these sociodemographic characteristics, the category of "The limitations imposed by chronic heart failure" was selected, which consequently had an impact on the self-care of those investigated.

### **Secondary analysis of the daily life limitations in patients bearing heart failure and the self-care**

Initially, the following question was asked: What did you do before that you cannot do now after the disease diagnosis?

The statements pointed to the decrease of the rhythm of the activities as well as the difficulty of locomotion associated to extreme fatigue. Once, that patients need to adapt the limitations that accompany the disease and not infrequently this involves abandoning work and not performing everyday activities.

Changes in HF are not limited to the cardiac scope, since the main symptoms, fatigue and dyspnea, can impair tolerance to physical exercise. The evolution of these symptoms leads to a decrease in the level of physical activity that favors the worsening of the clinical condition and increases intolerance to activity, progressively reducing the functional capacity and quality of life of these patients<sup>16</sup> as shown in the following statements:

*"Currently, I cannot do anything. So, for instance, I cannot do laundry anymore. For me everything has to be in*

*the tank or on a table, right? I cannot sweep home that exhausts me. Nowadays, I cannot do it anymore. I have not worked for anyone for 15 years. I work on my own because on the day that I cannot go, I will not go, on the day that I feel bad, I will not go."* (Sapphira)

*"I did everything in just one day. I cleaned the house, waxed the house, did everything on the same day [...]. Not now, I have to do everything slowly, every day I do one thing."* (Sea water)

*"So, for me to go out, for me to walk. I cannot walk much because it fatigues me."* (Pearl)

These signs and symptoms of congestion such as dyspnea, nocturnal paroxysmal dyspnea, fatigue and edema are evidences found in a study that identified the main clinical manifestations in patients admitted due to decompensation of HF.<sup>17</sup>

Fatigue is the expression of innumerable sensations referred to by patients as fatigue and lack of energy<sup>18</sup> and dyspnea is a sensation of respiratory distress, being the main symptom of heart failure. Bearing this in mind, it is important the nursing team's action towards the patient, since besides the physiopathology that triggers, it also adds the emotional factor such as: anxiety and nervousness, for example, which can lead to a crisis or aggravate the symptom, consequently making it even more difficult, dyspnea control.<sup>17</sup>

Dyspnea is a clinical finding that originates from pulmonary venous hypertension and is usually caused when the patient performs physical exertion greater than his capacity. This shortness of breath may occur, sometimes, associated with respiratory discomfort at night, even when lying down. The horizontal position favors the movement of fluid into the lungs. Patients with HF might be "forced" to sleep in the seated position to prevent the phenomenon from happening,<sup>19</sup> as shown in the following statements:

*"Sometimes I have to put a lot, sometimes I even take the pillow, when I feel air shortness, a lot of things like that. So, I have to stay that way, a little like that. [patient demonstrates suspending the body]. Yes, sitting down. To be able to improve."* (Pearl)

*"Lately, I have not woken up short of breath, because I started to take my medicine again. But then, about 15 days ago, I would wake up with a breathlessness that I would sit on the bed and stand. I would lie down again, and it would return."* (Topaz)

This situation triggers poor quality sleep, and this may impair cognition and self-care practices. In other words, a compromised sleep pattern may reduce adherence to the therapeutic regimen and increase the risk of unplanned hospitalization. The understanding of sleep disorders in HF is important to adequately elaborate the therapeutic plan encompassing the multidimensionality of the disease and



offering a better care to HF bearing people.<sup>20</sup>

Patients bearing HF, in addition to physical impairment, impact on their personal and professional activities, may have the need to receive care or support from third parties, resulting in loss of self-care and self-esteem. This dependence produces uncomfortable feelings such as: embarrassment, a sense of worthlessness and sadness, as one participant says:

*"Sometimes, I'm depending on her (wife). All this agonizes me, makes me sad, and at the same time nervous, being reliant on her for everything." (Jasper)*

*"I like it that way, to take things from one place to another and not to be asking anyone, right. It's too bad for me to keep asking, 'you do it, do that'. My will is to do everything." (Ruby)*

The individual affected by a chronic disease, such as heart failure, experiences changes in their life habits due to their own pathology, such as changes in medication use (time, quantity, exchange of medication), frequent visits and/or readmissions.<sup>21</sup> The chronicity of a disease can lead, in more extreme cases, the client to totally lose their autonomy and self-care ability.

The registered nurse play an important role in patients with HF as they promote the knowledge of these individuals about their illness and treatment. When the disease is already in place, the professional's performance should be directed towards the guidance on the benefits of pharmacological and non-pharmacological treatment, management of the disease and its complications when uncontrolled, as well as adherence to healthy lifestyles.<sup>22</sup> The nurse should help the patient to create mechanisms to adapt to a still unknown lifestyle and encourage him, within his possibilities, to continue performing activities that stimulate his independence.

Another reported limitation refers to sexual life, which was cited by most patients as very compromised by HF and is believed to be related basically to two factors: the onset of feelings such as anxiety, fear of death and restriction of physical activity, as well as the use of drugs that cause erectile dysfunction and loss of libido,<sup>23</sup> as shown in the following statements:

*"Oh, tiredness. Oh, it disturbs. It disturbs (the sexual intercourse). Because it makes us tired too. Exhausted, it gives a lot of pain in the chest, if we do a lot of things like that. God forbid; I cannot take it." (Pearl)*

*"And if you go further, you probably are going to die. Sometimes I even want to, but I avoid it. It does not work; We even do it. The woman does not even know how you got. Oh God! The air is missing. It was never like this before." (Quartz)*

Several factors, including expected physiological chang-

es due to the aging process, drug-induced dysfunctions and vascular changes associated with risk factors (e.g. diabetes, hypertension, and dyslipidemias), coupled with the emotional impact of heart disease, may influence the patients' sexual life.<sup>23</sup>

Although the influence of the drugs on the sexual activity of patients with HF is not well established, it is known that research continues to be carried out, and phosphodiesterase inhibitors have been studied as possible causes of erectile dysfunction in these patients. Guidelines and clarifications should be given in order to avoid the progression of symptoms and performance are directly related to both client and partner fears.<sup>5</sup>

The evidence indicates that, in addition to the adverse reactions possibly caused by the drugs and the psychological impact of the disease, fatigue is a strong component in altering sexual habits.

The approach of the nursing team, on the subject of sexuality towards the patient, should remain frequent in all routines. Because, sexual dysfunction is related to numerous pathologies, emphasizing that it is an early marker of cardiovascular diseases. Therefore, the nurse should set aside a specific moment to approach the subject and seek to maintain a holistic view towards the patient. Not infrequently, the nurse is attached to his fears and taboos about sexuality, obstructing a creative and sensitive professional exercise.<sup>24</sup>

When we underline important aspects in the daily life of a patient bearing HF, such as difficulties in locomotion, poor self-care, dependence on others, and frequency of sexual activity, we broaden the context in which the individual is and the different forms of approach that need to be implemented by the registered nurse.

Due to the characteristics of the disease and the wide implications imposed on the patient, it is important to approach the HF in a multidisciplinary manner. Healthcare professionals who provide care to these patients need to be aware not only of their lifestyle, which has been modified, but also of their emotional and psychological states.

## CONCLUSIONS

In the analysis of the impact brought about by the disease and the main modifications of life of the patients bearing HF, the difficulties of adaptation are experienced in a very short time. If before the patients were "healthy and independent", having decision-making power, daily control, satisfactory self-care, now they suddenly need to learn how to deal with the limitations caused by heart failure, and the aspects of chronicity and symptomatology.

Evaluation, follow-up, and prevention of precipitating factors of disease decompensation are indispensable aspects for better control of heart failure. Hence, it is essential for nurses to promote strategies that enable patients to maintain health status, autonomy in self-care and increase

their life quality.<sup>25</sup>

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