THE IMPACT OF THE HEART FAILURE ON DAILY: PATIENT PERCEPTION OF FOLLOW-UP AMBULATORIAL

OBJECTIVE: to analyze the patients’ perception, with diagnosis of chronic heart failure, in its daily life. 

METHOD: exploratory, descriptive, qualitative study, developed with 15 patients in follow-up ambulatory, approval in the Ethical Committee, CAAE 0005.0.258.000-33. The data collection occurred from March to July of 2011, through recorded interview, analyzed according to Bardin. RESULTS: five categories were established: 1. Initiating a new life with chronic heart failure diagnosis; 2. Living with chronic heart failure and its present repercussion; 3. Changes caused by the chronic heart failure in the life of its bearer (subcategories: economic changes, social changes, emotional changes); 4. The physical modifications due to the chronic heart failure; 5. Limitations imposed by the chronic heart failure. CONCLUSION: as nurses we need to hear and listen to the patient; to turn our nursing care adequate to the real needs. DESCRIPTORS: Heart Failure; Cardiovascular Diseases; Perception; Nursing.

RESUMO
Objetivo: analisar a percepção dos pacientes, com diagnóstico de insuficiência cardíaca crônica, em seu cotidiano. Método: estudo exploratório, descritivo, qualitativo, com 15 pacientes sob acompanhamento ambulatorial, aprovado no Comitê de Ética (CAAE 0005.0.258.000-33). A coleta de dados ocorreu de março a julho de 2011, por meio de entrevista gravada, posteriormente analisada segundo Bardin. Resultados: estabelecemos cinco categorias: 1. Iniciando uma nova vida com diagnóstico de insuficiência cardíaca crônica; 2. Convivendo com a insuficiência cardíaca crônica e sua repercussão atual; 3. As mudanças causadas pela insuficiência cardíaca crônica na vida do seu portador (subcategorias: modificações econômicas, modificações sociais, modificações emocionais) 4. As modificações físicas trazidas pela insuficiência cardíaca crônica; 5. As limitações impostas pela insuficiência cardíaca crônica. Conclusão: precisamos ouvir e escutar o paciente, para tornar nosso cuidado de enfermagem adequado as suas necessidades reais. Descriptores: Insuficiência Cardiaca; Doenças Cardiovasculares; Percepção; Enfermagem.

ABSTRACT

Objective: to analyze the patients’ perception, with diagnosis of chronic heart failure, in its daily life. Method: exploratory, descriptive, qualitative study, developed with 15 patients in follow-up ambulatory, approval in the Ethical Committee, CAAE 0005.0.258.000-33. The data collection occurred from March to July of 2011, through recorded interview, analyzed according to Bardin. Results: five categories were established: 1. Initiating a new life with chronic heart failure diagnosis; 2. Living with chronic heart failure and its present repercussion; 3. Changes caused by the chronic heart failure in the life of its bearer (subcategories: economic changes, social changes, emotional changes); 4. The physical modifications due to the chronic heart failure; 5. Limitations imposed by the chronic heart failure. Conclusion: as nurses we need to hear and listen to the patient; to turn our nursing care adequate to the real needs. Descriptors: Heart Failure; Cardiovascular Diseases; Perception; Nursing.
INTRODUCTION

In Brazil, the cardiovascular diseases are the main cause of death between men and women, corresponding to 31% of all deaths, and to 10% of hospitalizations, as well as the higher proportion of premature deaths.1

Among the cardiovascular diseases, it detaches the heart failure (HF), constituting a serious public health problem in the country as well as worldwide, being the main cause of hospitalization of patients older than 65 years in the SUS. And that, according to estimate, the Brazil in 2025, will have the sixth biggest elder population in the world, about thirty million people, or 15% of the total population, having the IC as the main cause of death from cardiovascular disease. 2

It’s a complex clinical syndrome of systemic nature, defined as cardiac dysfunction that causes inadequate blood supply to meet tissue metabolic needs, in the presence of normal venous return, or do it only with high blood pressure filling. 3

The diagnosis of a serious, chronic and progressive disease, as the heart failure, can bring frustration and psychological perturbations to the patient life and family.4 The daily tasks are hampered by physical repercussions imposed by the disease and treatment.4 And the alterations in the life style that are necessary due to the disease represent a threatening normally enclosed by anxiety, distress, fear and doubts, requiring knowledge and psychosocial interventions by health professionals.3 And, in this perspective, each individual possesses a different self-perception on the disease process, and in general this view is associated with the sudden disease installation, giving rise to the most different feelings.3

The nurse’s intervention becomes significant as this professional can provide necessary information about the pathology and of the patient’s state of health, of its prognosis, help him to understand the disease process, incentive the self-care, and when viable, adequate the therapeutic schemes to the client’s life style.3

So, the objective of this study is to analyze the patients’ perception, with diagnosis of chronic heart failure in their daily life.

METHOD

Qualitative, exploratory, descriptive study developed in the Clinic of Heart Failure, of the Hospital Universitário Antônio Pedro, Niterói/RJ/Brazil. Of the group of 167 patients registered in the clinic, a non-probability sample was constituted, of intentional type with 15 patients under follow-up.

Patients of both of sexes, minimal age of 18 years, hemodynamically stable, without cognitive deficit and that agreed to participate in the research, signing the Free and Informed Consent Term, according to the Resolution 196/96 were included in the study. The data collection occurred in the months of March to July of 2011, using a semi-structured interview, developed by the researches and supported by theoretical questions. The statements lasted about 30 minutes, being recorded through of a MP3 and further transcribed. To maintain anonymous the research subjects, the same were identified by pseudonyms.

The data collected were categorized, described and further submitted to the content analysis, according to Bardin.6

This study was approved under protocol N. 026 A/2011/CAAE 005.258.00.33, by the Ethics Committee of the Faculty of Medicine, of the Universidade Federal Fluminense (UFF).

RESULTS AND DISCUSSION

Seeking to characterize the population it was identified that 73. 3 % are female, with age between 46 to 88 years, and for the male of 53 to 71 years.

As for the social aspects, 53.4% are married, 20% of the women are widow, 60 % are retired, 80% has incomplete fundamental teaching, and all the participants have great expression about faith and religiosity.

We still identified presence of comorbidities as systemic arterial hypertension in 80%; dyslipidemia in 53.3%; Diabetes Mellitus in 33.3%; coronary artery disease, in 26.7%, and acute myocardial infarction, in 6.7%. And that the heart failure average time of the medical diagnosis among the subjects was 8.7 years.

From the qualitative data analysis, we established five categories, that express the patients’ feelings:

1- Starting a new life with chronic heart failure diagnosis
2- Living with the chronic heart failure and its present repercussion
3- The changes caused by the chronic heart failure in its bearer’s life (subcategories: economic, social, emotional modifications)
4- Physical modifications caused by the chronic heart failure
5- Limitations imposed by the chronic heart failure.
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- **Starting a new life with chronic heart failure diagnosis**

  In this category it was evidenced feelings and sensations lived by patients on perceiving himself as a heart ill person. The question made to the clients for the answers obtaining was: Do you remember what did you feel as soon as you knew that had heart failure? Can you describe? The most cited feelings by the interviewees were: sadness; fear of death, concern at the state of health, as are shown by the examples below:

  [...] I was worried. I remained with that concern addressed to the sadness. I felt fear of the death. (Jaspe)

  [...] I still afraid of staying alone, I feel fear of dying at home alone, I’m afraid of [...] the night, do you understand? (Safira)

  To know the death meaning for the person that experience it, helps in the understanding of the behavior (agitation, silence) manifested by the patient. Even having to worry with technical aspects involved in the assistance, it is important that the nurse considers the client’ feelings and also meets its psycho-spiritual needs, relieving its fears.⁷

  When it speaks about sadness, feelings cited by the most of the patients is difficult do not associate it with suffering, that are emotional states inherent to any subject, deprived of any personal and emotional satisfaction. There are ways of answer of the organism to confront with deep fragility state, such as, in receiving a chronic heart failure.⁸

  Not all the patients described unfavorable feelings and sensations after the disease diagnosis, some interviewees showed apparent indifference; and/or conformism regarding pathology and death risk:

  [...] I did not feel anything. I know that I will die someday in fact I know that I will die. (Agata)

  [...] no, I stayed normal. (Jade)

  Some patients attribute their disease appearance to destine things; situation in which they were destined to undergo, that shows a relative acceptance of their condition.⁹

- **Living with chronic heart failure and its present repercussion**

  In the 2⁰ category, the reports were related to changes occurred in the patient’ s perception in relation to the illness process, since the diagnosis to the interview moment, being addressed the following question: Currently, which are theirs feelings in relation to the disease? The main reports are related to the conformism associated with the faith and religiosity, as well as the follow up by the health professionals as are shown in the reports:

  [...] Then, as, you (health professionals) give us much safety, can you understand? I think that without you, I don’ t know what could happen with us. Do you want to see, you are not well, you come. Somebody speaks anything that is good to you, like this: “oh, but you will feel better. Take this medicine, because it will be better, do you understand?” All these things. Then, I think that if you were not here [...] It’s because I speak, you help us, we also must help you, do you understand? (Esmeralda)

  In understanding the difficulty of the ill body in adapting to a new reality, of living with a chronic and limiting disease, the nurse and other multidisciplinary team professionals can support; orient and evaluate the patients’ needs, guaranteeing them emotional support and safety. The nurse due to being closer the client, can stimulating it to expose its world, its thoughts and sentiments; discuss its afflictions, seeking at reducing distress and fear, helping him overcome a typical moment of its existence.⁹

  Knowing the disease is not sufficient for that the patient can manage adequately the pathology, other factors are determinants for effective control and to increase the self-care, such as the trust in the health professionals.¹⁰

  The contribution given by the health professionals is associated with the patients’ religiosity and faith is present, evidenced by the thanks and search for God present in the statements. Most people search for emotional support in what they consider divine, linked or not to a specific religion, to become stronger to overcome difficult moments.⁹

  Feelings of fragility and impotence added to uncertainty regarding death stimulate the patient in search of comfort and support in the faith and in the religiosity, as a way of lightening its fear and afflictions.⁹

  The chronic heart failure patients supported in theirs religious beliefs demonstrated certain conformism regarding the presence of the disease, according to the following examples:

  [...] If live in peaceful way today, do you understand? I have a peaceful life, I’ m already conformed, because we need to conform. There is no other way, then, thank God, God grants me strength. (Pérola)

  [...] When God want me to go, I will. (Agata)

- The changes caused by chronic heart failure in its bearer life (subcategories: economic, social, emotional modifications)
The impact of the heart failure on daily...pleasure in anything in my life. I do not leave, I do not walk [...] Do you know what means a person that has not fun? I have no fun. My sisters leave, call me, to walk with them, they travel, I don’t leave [...] (Turqueza)

The heart failure brings to the client’s life, besides the emotional impact that affects directly the stimulus to give continuity to the leisure activities, signals and symptoms that make it difficult to maintain a normal routine. The fatigue disease-related can lead the patient to abandon that brings to it pleasure and realization, due to the restrictions imposed by clinical signals.

However, in the spite of the disease complexity, the individuals must seek leisure moments, situations that offer distraction and occupy their time, as in these conditions the adaptation to the disease will be less frustrating and traumatic. 12

- Emotional modifications: frequently, all disease, be acute or chronic, results in disturbing feelings related to the sight that every one has about the phenomenon of becoming ill and the treatment. Therefore, the nurse must pay attention to the patients’ psychosocial answers that many times are neglected by clinical manifestations. The professional must incorporate the idea that the human being is a whole, and to ensure that the adjustment be reached all parts should be in harmony. 13

At that moment of the interview the patients pointed out which were the emotional impacts brought by the disease. The main alterations registered were: increase of the sensibility and the sadness, as are explained by the registers above:

 […] I am very emotive. I became more sensitive. (Jaspe)

 [...]ah, yes. I am very sad. I have no more will to live. I remain sad, sometimes at the edge. Sometimes I feel like crying. Sometimes I’ m crying without knowing why. (Pérola)

The suffering can be associated with many daily events of the persons, including to the rise of a disease, especially, if it is of chronic nature, as it can be understood as a stressful factor, whose impact rises spontaneously is of permanent nature altering the process of being healthy of the person. The chronic disease can represent an aggression for its bearer, a barrier, uncertain future, loss of liberty, among others, that leads to the appearance of negative sentiments and sensations related to the pathology and its consequences. 13

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This category evidences the main life alterations caused by heart failure in the view of its bearers. Three subcategories were created in order to evidence the economic, emotional and social modifications. In that moment it was addressed the following question: Mr (Mrs), can you describe the economic, social or emotional changes that occurred in your life after the appearance of the disease?

- Economic modifications: the chronic disease, such as heart failure, poses patient at need for financial reprogramming in a permanent form, altering not only the patient’s routine, but also possibly of whole family, affecting its life quality and resulting in implications for adherence to the treatment, as is shown below:

 […]you had not this spending which appeared. The visits to the hospital, medicine which you have to take correctly. You must take care with the nutrition because you must not eat anything, ok? You should be aware of it. (Diamante)

 […] then, I spent before, but I could not because of my sons, otherwise it could lack for then. […] (Aguia Marinha)

There are several factors for the non-adhesion to the treatment, including the lack of patients’ access to the medicines. The high cost medicines is related to failures in the treatment and was evidenced by study that showed that the monthly cost of the adhesion ´ medicines were lower than the not-adhesion. 10

The identification of the barriers in the therapeutic adhesion of each patient is important for the guarantee of a safe assistance; compromised and less frustrating for the health professional. Every patient has a unique form of following the prescriptions influenced for habits acquired throughout life.

- Social modifications: in this subcategory the patients registered alterations caused by the disease in its social life. The main complaints involve the distance from the living with family and friends. The followed examples can illustrate:

 […]ah, a lot of things changed, a lot of things, no longer. I, mainly, I don’t leave my house. Previously I got out, I have not missed any birthday of 15 years, and do you understand? I liked to go to a “pagode” with my daughter, my wife, I don’t go any more. […] It is because, it is tiredness, it is some much tiredness, it is very tiredness. I was very, very tired, then, it means, at present I just not make this. (Topázio)

 […]my daughter, after happening it to me, I became a very angry person; I have no...
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- The physical modifications brought by the chronic heart failure

In the 4th category the patients were asked for the main physical alterations perceived by them due to the appearance of the disease.

The question done was: Which alterations in your body that was noticed by you? The main statements are related to the rise of weight and edema in lower limbs, evidenced by the statements below:

[…] I think that I gained weight. I gained with any edema. If the weather is hot I swell a little, I become swollen. (Diamante)

[…] I think that I swelled. I think that I became more swollen, I have no swelling in the legs, in the finger, and I am[…] it means, with less mobility. […] (Jaspe)

The heart failure is a complex, systemic syndrome, where occurs a cardiac dysfunction that leads to an inadequate blood supply to attend the organism metabolic needs, or makes it only with high filling pressures. Usually, the hemodynamic alterations related to the pathology are associated with an inadequate response of the cardiac output and rise in pulmonary and venous systemic pressures.3

Heart failure bearers present important and progressive clinical manifestations that affect not only the physical dimension, as well the psychological. The signs and symptoms interfere in the daily activities and in the self stem of the clients too, affecting directly the life quality.

- The limitations imposed by the chronic heart failure

In the 5th category there were evidenced the main life modifications brought by the heart failure related to an inability to carry out certain activities. The following question was done: What did you do before, and what do you do more frequently after the disease diagnosis?

The most statements involved the activities rhythm reduction and locomotion difficulty related to the extreme tiredness. The patients need to adapt again to the new life style, and it many times involve the work abandon and no realization of the domestic activities as the statements show below:

[…] I used to do everything before, so, in a unique day[...] I used to clean the house, and I used to do everything in a unique day. […]

Now no, I have to do everything slowly, each day I do anything. (Água Marinha)

[…] I do everything, but slowly. In the past, I used to do more quickly, and took the plunge in everything that I would do, because I could do. Nowadays I no longer do this. Nowadays, I see my backyard full of wood and I can no weed, I can not get a hoe, then, there are things that require effort, and it is the effort that just harm, that makes me feel tired. (Diamante)

Heart failure patients present fatigue and dypnea mainly during the physical exercise these symptoms cause functional limitations that can compromise socially and psychologically the bearer. The fatigue is directly related to the difficulty of maintenance of a life style desirable by the common sense.14

The life style is completely readapted due to physical limitations imposed by the heart failure. It means since the loss of independence for the daily activities to the need of a caregiver.3

Patients still register the food restriction imposed by the disease and difficulties to keep an adequate sleep.

[…] Oh, to eat, ok, those good things. Fatty food. Those good things that we like, do you understand? Feeding more. (Esmeralda)

There is the present consensus of that the HF bearers should be oriented to not put salt in food just prepared and avoid the consumption of processed and canned food, due to the high sodium.15

Due to the sodium restriction, these patients need to reorganize theirs feed habits, a posture that is many times, hampered by economic factors and well consolidated cultures.

In relation to the sleep disturbance, some patients registered orthopnea and the need to sleep with more than one pillow or even seated as consequence of the dypnea that occurs during the night while they are lying down, as specified below:

[…] lately, I have not awaked with lack of air, because I took a medicine again. But, fifteen years ago, I awaked with lack of air in which I seated in the bed and remained inactive. Then, I lie down again, and came back. (Topázio)

Approximately 60% of HF patients receive the diagnosis of sleep apnea, being 40% of central origin and 20% of obstructive type.16

The poor quality sleep can affect the cognition and interfere in the daily activities and self care, contributing for a fall of the life quality and the rise of not planned hospitalizations.4

Alterations in the sexual activity have also registered by some patients, which show the importance of this commitment in the chronic HF bearers’ daily, as well as the relevance of the health professionals’ discussion with the
same about the aspects related to this subject:

[…] and it forces a bar it almost dies. Sometimes I want, but I avoid. Oh, it will stop (patient points out to the heart and breathes deeply). No further possibility, no more. Everyone almost make it. The woman does not know what's wrong to you. Oh, breathing is difficult. I’d never seen anything like it. (Quarto)

It is known that the cardiovascular diseases implications are not uncommon in the patients’ sexual activities and it is due mainly to two factors: the psychological impact caused by the disease diagnosis, involving the appearance of feelings such as: anxiety and fear of death and also the use of drugs that can compromise the sexual function through erectile dysfunction and loss of libido.17

Although it is notable the compromising brought by the emotional component in the HF patients’ sexual life, we believe that the fatigue and dyspnea resultant from the physical effort inherent to activity is also a strong limiting factor.

It is still unclear the heart failure treatment impact in the patients’ sexual activity, but there are pharmacokinetic studies about some drugs and theirs adverse reactions. However, it is known that added to the medicines actions, the HF bearers’ sexual performance is directly related to the client and partner’s fears.3

The non-discussion of the thematic by the health teams, we believe that this is the close and particular subject of the patient or a superficial approach promoting of the same results in not well in-depth orientations addressed to clients. The multidisciplinary approach with real nursing participation is necessary not only in the clarification of the cardiovascular disease, but also in the patient’s education as for the return to the sexual practice. 18

It is essential to have a work method able to direct and organize the nursing professional care to the IC patient 19, enabling the coping of this chronic disease.

**CONCLUSIÓN**

To know the chronic heart failure patients’ perceptions and all the subjective aspects that involve the disease process, mainly when it treats of chronicity, is fundamental so that the care can be carried out in a comprehensive and effective manner for the client’s wellbeing.

By the end of the study it’s possible to notice strong impact of the chronic heart failure in the different spheres of the patients’ lives. The emotional, social and economic commitment is evident in the participants’ statements, which showed during the interviews certain dissatisfaction with the modifications that made necessary by the disease process.

The study aims to contribute to the practice of all the health professionals involved in the care to these clients, specially the nurses, those that are closer and increased possibility of approaching the thematic along with the patient. It is suggested to carry out new researches related to the theme, so that the assistance to the chronic heart failure patients may be more qualified.

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