

Symptom Management and Hospital Readmission in Heart Failure Patients

A Qualitative Study From Portugal

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This article reports a study aimed at identifying the factors that result in hospital readmissions for patients with heart failure. The high rates of readmission are often due to a lack of knowledge about symptoms and signs of disease progression, and these Portuguese nurses believed that readmissions could be decreased through disease management programs in which patients assumed a more active role in self-care. A study was designed to identify broad categories of problems that lead Portuguese patients with heart failure to be readmitted to hospital. Semistructured interviews were conducted, recorded, and submitted for content analysis, revealing 3 main categories for targeting: health management, behavioral management, and psychological support. This study revealed that patients with heart failure seem to struggle with management of multiple treatment regimens during the long course of their chronic illness. Based on these interviews, authors conclude that a disease management program be tailored expressly for the Portuguese culture and their lifestyle. **Key words:** *disease management, heart failure, hospital readmission, self-care behavior*

HEART FAILURE (HF) is considered a major public health problem worldwide^{1,2} and is expected to continue to increase in coming years.^{1,3} HF is a life-threatening event with fast onset,³ characterized by fatigue, breathlessness at rest or

on exertion, and fluid retention occurring mostly in the legs, ankles, and lungs.^{3,4} Furthermore, it is associated with frequent hospital readmission, poor quality of life, high mortality, and financial problems.⁵⁻⁸

It has been previously reported that about 50% of the population in industrialized countries is at risk of being hospitalized with HF.⁹ In addition, these same patients are likely to be readmitted to the health system within 6 months after discharge,⁹ leading to a health system burden.¹⁰ Some of the main causes for readmission include premature discharge and educational and follow-up inefficacy, suggesting that about half of these readmissions could potentially be prevented.^{6,9,11} However, it is also possible that because of the overwhelming level of responsibility regarding disease management (eg, medication management, exercise, resting of the legs, and eating habits) and difficulty in coping with the multiple lifestyle changes required by HF, it is difficult for them to engage in recommended self-care behaviors.¹¹

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Self-care can have different meanings, depending on the underlying theory.^{4,12} According to Riegel et al,⁴ self-care is the decision-making process through which patients adopt specific behaviors to maintain physical stability (eg, monitoring HF symptoms and therapeutic adherence) and promptly react when symptoms are first detected. In the context of HF, these self-care behaviors include adherence to the treatment regimen, symptom monitoring, and prevention of heart deterioration.^{6,9,11,13,14} In patients with HF, self-care behaviors include detection of initial symptoms of the disease, which allows them to make appropriate decisions about the best course of action regarding the implementation of proper treatment strategies.^{4,11} Riegel and colleagues¹¹ further subdivided self-care into 2 additional subtypes relevant to HF: self-care maintenance (which involves the choice of behaviors that tend to maintain physiologic stability) and self-care management (which includes a response to symptoms when they first occur). Based on these 2 types of self-care for HF management, patients may benefit from a 2-stage disease management program (DMP). In this DMP, patients (1) would be able to start a decision-making process and (2) would learn about the disease to identify health problems and implement strategies to solve them.¹⁵ According to the European Society of Cardiology guidelines for HF, such a program should be provided in specialized HF clinics with health professionals (eg, nurses, physicians, pharmacists, and physical therapists) who are experts in this disease, with the goal of developing specific HF care and better outcomes.^{16,17}

Although a previous study described the main categories of problems for a sample of patients from the United States,¹⁸ it is not clear whether the same categories are present in patients with HF from a southern European country. In this study, the aim was to identify broad categories of problems that lead Portuguese patients with HF to be readmitted to hospital, through analyses of semistructured interviews with patients with HF, car-

diologists, and expert nurses in a cardiology ward. Based on these interviews, the first intent was to determine why patients with HF do not contact their doctors or nurses when symptoms first start (eg, weight gain, body edema, or tiredness) and second, what health care providers can do to meet patients' needs to engage them and change their behaviors.

METHODS

Design

This study was based on the framework of complex interventions proposed by the Medical Research Council (MRC),¹⁹ which involves 4 phases: development, feasibility/piloting, evaluation, and implementation.^{19,20} This study represents primary research, which is part of phase I (development) of the MRC framework, using qualitative methodology. According to the MRC,¹⁹ complex interventions allow a clear and detailed description of all the components of the experimental and control interventions, providing a better understanding of the feasibility and effectiveness, as well as optimizing dissemination and implementation of the experimental intervention. This initial qualitative study allowed identification of themes to be developed based on interviews with participants. In combination with a systematic literature review, these themes form the basis of a complex intervention to be later implemented in a DMP. Therefore, this study was designed to ensure that the future choice of intervention would be based on participants' needs, rather than on the researcher's opinion or preference. In short, the present study constitutes phase I of a larger study that will be later evaluated in a DMP for patients with HF.^{19,20}

Sample

For this study, a convenience sample was composed of 5 patients (Pt) hospitalized for primary HF, 2 cardiologist physicians (C), and 3 nurses (N) who were experts in HF, from a cardiology ward in Centro Hospitalar e

Universitário de Coimbra, Portugal. Inclusion criteria for patients were being older than 18 years, admitted into an HF cardiac ward, and consented to be interviewed for this study. Patients were not currently involved in a structured DMP; thus, they were receiving little information about what to do if an escalation of symptoms was detected.

Procedure

All participants were interviewed and approached face-to-face by the primary researcher (J.P.S.), a registered nurse in this setting, in a separate room of the cardiology ward of Centro Universitário e Hospitalar de Coimbra. The cardiologist physicians and nurses who participated were coworkers of the primary researcher. The patients interviewed had been admitted with chronic HF, had an acute escalation in their symptoms, were available at the time of the interview, and consented to be interviewed for this study. At the time of the interview, the primary researcher and the patients did not have an existing relationship. The interviews took place during a 2-month period and lasted approximately 30 minutes each. The semistructured interviews were recorded and followed by verbatim transcription.

Analysis

Content analysis was conducted using the NVivo 10 program for qualitative data, by the

primary researcher. After transcription, key terms were identified, and themes emerged. The coding process was reanalyzed 3 times, wherein the main categories were narrowed down from 4 to 3. Key terms were then reanalyzed to track variability of themes. Lastly, key terms were grouped into main categories.

Ethical considerations

All participants provided written informed consent for the interviews. The Committee for Ethics of Centro Hospitalar e Universitário de Coimbra approved this study. This investigation also followed the principles defined in the Declaration of Helsinki.²¹

RESULTS

Analysis of the semistructured interviews revealed 3 main categories: *health management*, *behavior management*, and *support received*, which can be seen in the Table.

Health management

The category *health management* was related to patients' knowledge about HF signs and symptoms. It also included the ability to follow the therapeutic regimen as specified by health care providers (eg, prescriptions), the ability to adopt a specific lifestyle, and knowledge about when to contact the physician. Examples of this include the following: "I know I must walk a little bit every day.

Table. Emergent Themes From Semistructured Interviews

Emergent Themes	Subthemes	Participants
Health management	Contact doctor when feeling worse	Patients (Pt1, Pt2, Pt3, and Pt4) Cardiologist physician (C1)
	Follow providers' prescriptions (eg, exercise and diet)	
	Knowledge about heart failure signs and symptoms	
Behavior management	Lack of knowledge	Patients (Pt1, Pt2, Pt3, Pt4, and Pt5) Cardiologist physician (C1 and C2) Nurses (N1, N2, and N3)
	Consciousness of lifestyle errors	
	Therapeutic noncompliance	
Support received	Longer and regular clinic visits	Patients (Pt3, Pt4, and Pt5) Cardiologist physician (C1 and C2) Nurses (N1, N2, and N3)
	Home visits	
	Family and patient education	
	Telephone follow-up	

I should drink about a liter of water (...) and not eat salty food and avoid sugars" (Pt1), and "Yes, I am careful at home, with the amount of water and food" (Pt2). During interviews, it was found that, of 5 patients, 4 mentioned information related to symptom identification (such as symptoms indicative of a worsening health condition). For example, "I am here because of shortness of breath and swollen legs" (Pt4) or "I walked two or three steps and became distressed" (Pt1). Most importantly, these patients were not only able to identify these signs and symptoms but also able to decide when they should contact their physician. For example, "then, I telephoned my cardiologist" (Pt1). In contrast, health professionals generally did not mention these symptoms in their interviews. Only one physician—an exception to this trend—mentioned the following: "to seek medical advice and contact the medical and nursing teams when there is a worsening of symptoms, for example, daily weight (if there is weight gain) or starting to become tired or short of breath" (C1). However, neither the other physician nor the nurses mentioned these symptoms in their interviews (see the Table).

Behavior management

This theme showed a general lack of knowledge of the signs and symptoms of the disease. For example, patients mentioned that "at medical consultation, the physician told me to stay and be admitted to hospital because of my health complaints (tiredness and fatigue)" (Pt3) and that "I came to the hospital only when I couldn't sleep anymore, I slept sitting with several pillows under my back. My legs were swollen ..." (Pt3). In addition, patients also mentioned being self-aware of not complying with the required lifestyle. For example, one patient mentioned, "In reality, I should fulfill the water restriction, but I drink much more than is recommended. I struggle meeting this kind of guideline because I have had this problem for so long" (Pt3). Meanwhile, another patient mentioned that despite having the intent to

follow the health worker's suggestions, working far from home made it difficult to change behaviors related to self-care: "I have been working abroad for 24 years and it is really hard to follow any kind of guideline because I have lunch in restaurants and at night I eat whatever I have. I come home every two weeks" (Pt3). One patient also mentioned not obeying health care instructions, despite being aware that this would most likely lead him to hospital readmission: "sometimes I drink wine that I should not drink. Also [I drink] beer and should be more careful with the food [I eat]" (Pt5).

Analysis of physicians' interviews suggested that changing self-care behaviors might be hard for patients. One physician mentioned that "there are people for which the intervention is not effective, even with regular information sessions. This is either because they do not have any nearby family, or they live alone, or they are alcoholics" (C1). This physician concluded that "the biggest cause of heart failure decompensation is non-compliance." The interviews with these physicians also suggested that "patients do not comply with the pharmacological regimen and fluid restriction" (C2). These patients also were not following a proper "diet, not exercising, in other words, not living a lifestyle adjusted to his chronic disease" (C1).

Analysis of nurses' interviews revealed that behavior management also included "therapeutic non-compliance" (N2), and "not being careful with food regimen and fluid and alcohol intake" (N3). For nurses, the main factor in "getting worse is the failure in fluid intake" (N1). They mention that, even though patients received information about their illness and about decisions to make when first signs of complications were detected, "after a week or two they start to forget the education received, if not recalled" (N1). Other nurses mentioned that patients "have the notion that they should not drink large amounts of liquids, should not drink alcohol, and should not smoke. However, they are not yet motivated. There is some reason why they keep engaging in inappropriate behaviors" (N1). In addition,

these nurses also mentioned that some patients may think that because they are “taking the medication, they are controlled and make food mistakes,” apparently, due to “lack of knowledge” (N2).

Support received

In this category, both patients and health care providers mentioned the importance of having regular visits. For example, one of the patients explicitly mentioned, “Instead of making one annual visit to the physician (in the clinic), these should take place more regularly. I am willing to come to the hospital more often and be assessed by a nurse” (Pt5). In the interviews, both physicians and nurses suggested that, if a regular visit to the clinic was not feasible, a telephone follow-up should take place. According to the physicians and nurses, health professionals should be able to “periodically (...) telephone our patients to determine if they are following the therapeutic regimen or not, and how their weight is evolving. This is a way to detect heart failure decompensation” (C2); or as a nurse put it, “if they do not remember (...) I think there should be an effort from us (healthcare providers), with a telephone call, because eventually all the information taught will be forgotten. Then there will be the temptation (of increasing fluid intake...), they will start to decompensate,” (N3) and eventually end up being admitted to emergency care or the intensive care unit.

As a possible solution for health and behavior management, physicians and nurses suggested implementing a structured educational program. According to one nurse, patients should receive “several educational sessions, which are fundamental; we should implement educational sessions in all clinic visits, because they (patients) need this kind of education” (N2). These sessions should include reminding the patient about illness progression and necessary lifestyle changes. As one physician put it, “first of all, the concept of heart failure as a disease must be well clarified. This includes why a patient

has heart failure and what he/she can do to adjust his/her daily life” (C1). In addition, knowing when to take specific actions was also considered a key feature, as mentioned by a nurse: “If a patient starts to feel shortness of breath or tiredness, this patient should not stay at home, because staying at home will probably worsen the health problem, and the patient will eventually arrive (at hospital) in a deteriorated condition” (N3).

During these interviews, it was also noticed that some patients knew they should adhere to health care providers’ prescriptions to avoid hospital admissions: “what counts is to meet the most guidelines” (Pt5); however, unfortunately, patients tend to forget if not reminded.

DISCUSSION

Self-care is a decision process through which the patient has the ability to choose between different health-influencing behaviors.^{2,3} This process helps patients maintain an adequate physical status (monitoring signs and symptoms and therapeutic regimen adherence), and prompts an early and adequate response when necessary.^{4,11} In HF, self-care is believed to be relevant because previous studies have demonstrated that DMPs run by a multidisciplinary team can lead to improvements in self-care, which are followed by improvements in overall disease management.²² Specifically, explaining pathology in nontechnical terms and training patients to identify early signs and symptoms of the disease have been associated with fewer hospital readmissions or shorter stays.²³ Although education seems to play a key role in disease management, a previous systematic review on HF education and self-management²⁴ described a gap between the information given to patients and actual performance of self-care in patients with HF. Thus, even if information is given to a patient, this does not necessarily mean that he/she will be able to use it appropriately at a later time. During this study, interviews seemed to support these previous findings,

with health professionals indicating that, in follow-up visits, patients did not know which strategies they should adopt to improve their health status or in which situations they should contact health professionals. These findings generally support the notion that giving information to patients is no guarantee of future adequate self-care. Instead, these results indicate that, in addition to the information given, health care professionals should ensure that patients with HF have actually understood the message and are able to identify early signs and symptoms of the disease. Lack of knowledge has been reported to be the cause of patients not recognizing signs and symptoms, leading to delays in searching for specialized help.^{25,26} In addition, as found in previous studies,⁵ all of those interviewed in our study (patients, nurses, and physicians) considered management of signs and symptoms to be a major problem that should be addressed in a DMP. According to them, this could be achieved if the education program was followed by telephone reminder calls.

These findings indicate that educational programs for patients with HF should focus on self-care behavior, mostly in terms of self-care maintenance and self-care management.²⁷ Self-care maintenance requires counseling (by health care providers) on therapeutic adherence, low-sodium diet, physical exercise, preventive behaviors, and an active monitoring of signs and symptoms by the patient.^{2,3} Self-care management focuses on patient decision-making, response to signs and symptoms of illness, recognition and evaluation of body changes (eg, edema of some body parts), implementing treatment strategies (eg, taking an extra pill when necessary), and evaluating the response to this process.^{4,11} In HF, self-care is mostly related to self-care maintenance, in which patients try to maintain physiological stability for a longer period.⁷ As HF is a chronic disease, achieving self-care will most likely require a change in a patient's behaviors and habits and patients will have to continuously decide what is best for their health.²⁸

Our interviews showed that some patients contacted health care providers as soon as the first symptoms and signs appeared, while others went straight to the hospital emergency department. These results suggest that there may be 2 different types of patients with HF: those who understand relevant information and contact health care providers, and those who do not understand the necessary information and may need additional reinforcement or further learning periods.²⁹ As mentioned earlier, self-care can be subdivided into self-care maintenance (ie, behaviors that maintain physiologic stability) and self-care management (ie, response to symptoms).¹¹ Previous results and this study suggest that, although both types should be targeted in a DMP for HF, self-care management seems to be particularly relevant.⁶

The present study interviewed patients who were in a cardiology ward and were not yet stable (ie, acute HF condition). In a previous study conducted with a larger number of stabilized patients with HF,¹⁸ similar interviews revealed 4 components/categories: *symptom recognition*, *symptom evaluation*, *treatment implementation*, and *treatment evaluation*. Several variables could account for the differences in categories between the previous study and this one. For example, it is possible that cultural differences, the number of interviews (higher in Dickson et al¹⁸), interviewing patients in different disease stages (stable in Dickson et al¹⁸ and acute in this study), or a combination of factors may have an influence. However, despite these differences, it is noteworthy that the sequence of *disease management/symptom identification/taking immediate adequate action* is common to both studies. This means that despite cultural and methodological differences of these studies, in both cases, the prompt identification of disease-worsening situations and taking appropriate actions was considered to be a fundamental issue. Thus, the results from this and the previous study indicate that an important effort should be made to ensure that HF DMPs improve patients with HF ability to detect symptoms and respond

appropriately. Further support for this comes from Ahmad et al,³⁰ who found that distress symptoms and illness were patients' main reasons for hospitalization, while patients' behaviors such as diet and medication adherence were identified by physicians as the main reason for hospital admission.³⁰ Note that, in the study reported here, these reasons (ie, distress symptoms, illness, and patient's behaviors) were grouped in the common theme "behavior management." Thus, therapeutic noncompliance and lack of knowledge (about symptom escalation and the disease itself) seem to be the main motive for hospital admission in our study, in Dickson et al,¹⁸ and in Ahmad et al.³⁰

Study limitations

The major limitations of this study are the small sample size and lack of generalizability. Even though it took place in a university hospital, the ward into which patients with HF were admitted had only 5 intensive care unit beds and 5 intermediate beds. In addition, hospital stays were usually long, preventing more participants to be included in this qualitative research. In future research, it is important to increase the sample size and settings

to encompass more patients and health care providers to support these findings.

Implications

- HF is a chronic condition that requires symptom recognition by patients.
- It is important to teach/learn about HF symptoms to manage early signs of decompensation and contact health care providers as soon as possible to avoid hospital admissions.
- Focusing on a step-by-step intervention can be a useful strategy to improve self-care management in patients with HF.

CONCLUSION

Overall, the results of this study support previous findings, and suggest the need to implement an educational program for patients with HF. This program should, according to our results, focus on 3 main categories of self-management: health management, behavior management, and support received. In addition, this and other studies indicate that a DMP for HF should ensure that patients can identify and act accordingly when changes first occur in their health status.

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