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Factors associated with patient delay in seeking care after worsening symptoms in heart failure patients.

Short title: Patient delay in Heart failure patients

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Abstract

Background

To receive optimal treatment and care, it is essential that heart failure (HF) patients react adequately to worsening symptoms and contact a health care provider early. This specific 'patient delay' is an important part of the total delay time. The purpose of this study was to assess patient delay and its associated variables in HF patients.

Methods and Results

In this cross-sectional study, data of 911 hospitalized HF patients from 17 Dutch hospitals (mean age 71 ± 12 years; 62% male; LVEF $34\pm 15\%$) were analyzed. During the index hospitalization, patient delay and HF symptoms were assessed by interview. Patients completed questionnaires on depressive symptoms, knowledge and compliance. Clinical and demographic data were collected from medical charts and interviews by an independent data collector. Logistic regression analysis was performed to examine independent associations with patient delay.

Median patient delay was 48 hours; 296 patients reported short delay (<12 hours) and 341 long delay (≥ 168 hours). A history of myocardial infarction (MI) (OR .49; 95%CI .34-.71) or stroke (OR .43; 95%CI .24-.76) was independently associated with short patient delay. Male gender, more HF knowledge and more HF symptoms was associated with long patient delay. No differences were found between patients with and without a history of HF.

Conclusion

Patients with a history of a life-threatening event (MI or stroke) had a shorter delay than patients without such event. Patients without a life-threatening event might need to be educated on the recognition and need for appropriate action in a different way than those with an acute threatening previous experience.

Introduction

Heart failure (HF) is one of the main causes of hospitalization in the adult population.¹ Adequate self-care behaviour is an important factor reducing the risk of readmissions due to worsening of HF.² Along with compliance with medication, diet and exercise, self-care behavior consists of adequate recognition of deterioration and taking relevant actions in case of worsening HF symptoms.³ The early recognition of symptoms of HF is important, since they might be warning signs of further deterioration.¹ Long pre-hospital delay after onset of acute coronary syndrome (ACS), negatively affects the patients' prognosis.^{4,5} In HF patients, many admissions could have been prevented if patients had sought medical care in an earlier stage of worsening symptoms.^{2,6-9} However, long pre-hospital delay times are common in HF patients.^{6,7,10}

In studying delay in cardiovascular patients, it is important to distinguish between 'patient delay' (time from worsening symptoms to actually contacting a health care provider) and 'transportation delay' (time from contacting a health care provider to arrival at the hospital). Pre-hospital delay therefore can be defined as the composition of patient- and transportation delay (Figure 1).¹¹ The importance of timely seeking care in the ACS population is recognized and, therefore, delay in this population has been well established.^{4,5,11-14} In ACS, symptoms such as angina is often sudden and interpreted by patients as threatening, resulting in seeking medical care early.^{5,11} In contrast, the most common symptoms of worsening HF (dyspnea and fatigue)^{2,6,8,15} often have a gradual pattern of worsening. Therefore many HF patients do not seek medical care but wait for a decline in symptoms^{10,15} Patient delay can be due to a failure to routinely monitor symptoms or to the inability to recognize and interpret symptoms when they occur.¹⁶ Elderly patients may neglect early symptoms such as fatigue and dyspnea by attributing them to aging or other illnesses, thereby interpreting them as less threatening and non-acute¹⁷, which can result in a longer delay.

Although delay in HF patients has been studied previously⁶⁻¹⁰, these studies actually assessed pre-hospital delay (Figure 1). However, little is known on patient delay as we defined earlier as the

time from worsening symptoms to actually contacting a health care provider, which reflects the patients' own action in seeking care. More insight in this process can help to identify those who are at risk for long patient delay. The relationship between a history of HF and delay was assessed in other studies,⁶⁻¹⁰ however, factors related to delay in those patients has not been studied previously. Therefore, the aims of the present study were (1) to examine patient delay time in HF patients, (2) to assess which variables are associated with patient delay in HF patients and (3) to assess which variables are associated with patient delay in patients with a history of HF.

Methods

This descriptive, cross-sectional study on patient delay is a secondary analysis of the COACH (Coordinating study evaluating Outcomes of Advising and Counselling in Heart failure) study. COACH was a randomized, multi-centre, controlled study in which 1023 hospitalized HF patients were included between November 2002 and February 2005 (registered at <http://trialregister.nl>, reg. no NTC98675639).^{18,19} Patients were included in the study during an admission for HF (New York Heart Association [NYHA] functional class II-IV), with HF as the primary diagnosis which was confirmed by the cardiologist and at least 18 years of age. Exclusion criteria were participation in another study, a planned or recent invasive cardiac intervention, or inability to complete questionnaires. The main objective of the COACH study was to evaluate the effect of education and counselling by a HF nurse on clinical outcome. The study complied with the Declaration of Helsinki and the Medical Ethics Committee granted approval for the protocol. All patients provided written informed consent and were examined during a fixed period of 18 months after discharge from the hospital. In the current study, patients were excluded from analyses when they had a patient delay time of 0 hours and, at the same time, were in NYHA-class IV during admission. These patients had an acute episode of HF, resulting in calling a health care provider immediately (i.e. patient delay 0 hours) due to this very serious condition. Not calling a health care provider in this situation is

unimaginable and since the focus of this study was on determinants of patient delay, these specific patients were excluded.

Patient delay, HF symptoms and HF experience

Patient delay in this study was defined as the time between worsening HF symptoms and calling a health care provider. Patients were asked to indicate the time from worsening HF symptoms as experienced by the patients themselves to the moment they contacted a health care provider (i.e. general practitioner, HF nurse or emergency department) as accurate as possible in days, hours and minutes. To differentiate between patients who called a health care provider in an early stage ('short delay') and patients who waited for a substantial time to seek care ('long delay'), cut-off scores were formulated, based on the 33rd and 66th percentiles of the patient delay time; patients with a short patient delay contacted a health care provider within 12 hours, while patients with a long patient delay waited 168 hours (= 1 week) or more.

In addition, patients were asked whether they had the following 10 symptoms of HF during the past 4 weeks before hospitalization; swollen ankles/legs (after waking up or during the day), sleeping problems, loss of appetite, fatigue, dyspnea (at rest, lying flat or on exertion), cough and dry cough. Data on patient delay time and HF symptoms were collected by a well-trained independent data-collector during the index hospitalization.

Patients were defined as 'patients with a history of HF' when they had a history of one or more previous HF admissions and had HF symptoms for at least 6 months.

Compliance, self-care behaviour and knowledge

Compliance with the HF regimen was measured with the Revised Heart Failure Compliance Scale.²⁰ Internal consistency of the instrument was tested using Cronbach's α (.68). For the Dutch version of the scale, two HF nurses experienced in the field of compliance assessed face validity.

Compliance was measured on a 5-point scale (0 = never; 1 = seldom; 2 = half of the time; 3 = mostly; 4 = always). Patients were asked to rate their compliance the last week (medication, sodium-restricted diet, fluid restriction and exercise), the last month (daily weighing), or the last 3 months (appointment keeping) before index hospitalization. Patients were defined as compliant when they followed the recommendation ‘always’ or ‘mostly’. Regarding daily weighing, patients were compliant when they weighted daily or at least three times a week. Patients were considered ‘overall compliant’ when they were compliant with at least four of the six recommendations.

Self-care behavior was measured with the 12-item European Heart Failure Self-care Behavior Scale (EHFScB), which is found to be a reliable and valid scale to measure self-care behavior.³ The items are rated on a 5-point scale between 1 (completely agree) and 5 (completely disagree), with lower scores indicating that patients perform more self-care behavior. The EHFScB can be reduced to 9 items (EHFScB-9)²¹, representing 2 subscales; ‘consulting behavior’ and ‘adherence to regimen’. The total score of both subscales was also used for analysis.

Knowledge on HF and the regimen was measured with the Dutch HF Knowledge Scale, which consists of 15 multiple choice items (range 0-15). This scale is a reliable and valid instrument to measure knowledge on HF in general, symptom recognition, and HF treatment.²² All questionnaires were completed at baseline during the index hospitalization.

Clinical and demographic variables

At baseline, clinical variables (e.g. medical history, comorbid conditions such as myocardial infarction [MI] or stroke) were assessed from the patients’ medical record; demographic variables were collected using interviews by an independent data collector. The Centre for Epidemiology Surveys-Depression scale (CES-D) was used to measure depressive symptoms.²³ This scale consists of 20 items and measures the presence of depressive feelings and behaviors ranging from 0 (‘rarely

or none of the time') to 3 ('most or all of the time'). The total score ranges from 0 to 60 and a score of ≥ 16 is an indication for the presence of depressive symptoms.

Statistical analysis

Descriptive statistics were used to characterize the study population. Differences between patients with short and long patient delay were tested with Chi-square tests or Fisher's exact tests for dichotomous variables and Mann-Whitney tests for continuous variables. A P -value < 0.05 (two-tailed) was considered as statistical significant. Logistic regression analysis was performed to assess which characteristics and clinical variables were independently associated with patient delay. Long patient delay (≥ 1 week) was used as the dependent variable. Based on theoretical assumptions and an univariable P -value < 0.05 , the following variables were inserted in the regression model, using backward methods: age, gender, NYHA-class at admission, depressive symptoms, history of MI, diabetes, stroke, HF knowledge, all HF symptoms except **from** (dry) cough, and the total amount of symptoms.

Patients with a history of HF were diagnosed with HF before the index hospitalization, assuming that these specific patients were already treated according to guidelines (including advices on the HF regimen, e.g. sodium restriction, fluid restriction, daily weighing). Therefore, differences in compliance and self-care behavior were only assessed in those patients with a history of HF.

Logistic regression analysis was performed to assess which variables were independently associated with long patient delay in patients who were experienced with HF. Based on theoretical assumptions and an univariable P -value < 0.05 , the following variables were inserted in the regression model: age, gender, educational level, diabetes, HF knowledge, swollen ankles (after waking up and during the day), loss of appetite, fatigue, dyspnea at rest and total amount of symptoms. SPSS 16.0 statistical software (SPSS Inc, Chicago, IL) was used for statistical analyses.

Results

Characteristics of the study population

A total of 1023 patients participated in the COACH study. Of these patients, 112 had a patient delay time of 0 hours and, at the same time, were in NYHA-class IV at admission and were therefore excluded from analyses. These patients did not significantly differ in age, gender and LVEF, compared to the 911 patients included in this substudy. The mean age of the study population ($n = 911$) was 71 ± 12 years and 62% was male. The mean length of HF symptoms was 32 ± 54 months and the mean LVEF was $34 \pm 15\%$. Most patients were in NYHA-class III (57%) or IV (37%) during admission and 40% of the patients had depressive symptoms (Table 1). Based on the 33rd and 66th percentiles of patient delay time, 296 (33%) had a patient delay time less than 12 hours, 341 patients (37%) waited for 1 week or longer before they contacted a health care provider. In this study, both patients with preserved ($n = 279$) and reduced ($n = 552$) ejection fraction were included. However, no significant difference in delay time was found between the 2 groups. The two most reported HF symptoms in the study population were dyspnea on exertion (92%) and fatigue (88%).

Patient delay and associated variables

The median patient delay time was 48 hours in the study population. Patients with a short delay more often had a history of MI, diabetes and stroke. Patients with a long patient delay were significantly younger, were more often male, had a higher educational level and more often reported depressive symptoms compared to those with short patient delay. These patients were also more often classified as NYHA-class IV at admission and had more HF knowledge and reported more HF symptoms than those with short patient delay time (Table 1). Except from (dry) cough, HF symptoms significantly occurred more often in patients with a long patient delay.

In a multivariable analysis, a history of MI (OR .49; 95% CI .34-.71) and stroke (OR .43; 95% CI .24-.76) were inversely associated with long patient delay time, indicating that patients with

a MI or stroke contacted a health care provider in an earlier stage. Male gender (OR 1.58; 95% CI 1.09-2.29) and more HF knowledge (OR 1.10; 95% CI 1.01-1.18) were also independently associated with long patient delay. The following HF symptoms were associated with long patient delay: swollen ankles (OR 1.50; 95% CI 1.05-2.15), loss of appetite (OR 1.77; 95% CI 1.23-2.56), fatigue (OR 2.93; 95% CI 1.60-5.38) and dyspnea at rest (OR 1.58; 95% CI 1.09-2.30) and dyspnea during exercise (OR 2.58; 95% CI 1.19-5.57) (Table 2).

Patient delay in patients with a history of HF and associated variables

To specifically examine the role of experience with chronic HF and earlier HF readmissions on patient delay, the same uni- and multivariable analyses were conducted in a subgroup of patients with a history of HF (i.e. HF symptoms > 6 months and a previous HF admission). To assess the additional role of self-care behavior and compliance, these variables were added in the univariable analysis with 267 (29%) patients with a history of HF.

Patients with a history of HF had the same median patient delay. Also a comparable percentage of these patients (34%, $n = 94$) had short patient delay (< 12 hours); 31% ($n = 83$) waited for 1 week or more with calling a health care provider.

The same univariable differences were found for age, gender, educational level, diabetes, HF knowledge and HF symptoms as reported for the total group. In contrast with data of the total group, in patients with a history of HF, no differences between patients with short vs. long delay in MI, stroke, NYHA-class and depressive symptoms were found (Table 3).

No differences were found in self-care behavior between patients with a history of HF with short and long patient delay. Regarding the care-seeking behavior scale, patients with long delay reported that they would contact a health care provider in case of worsening symptoms with the same magnitude of patients with a short delay (8.5 vs. 8.7, *ns*). No differences in compliance between patients with a short and long patient delay were found, neither in 'overall compliance' (~75% in

both groups), nor in compliance with the separate components of the HF regimen. Compliance with daily weighing, a component of the HF regimen related to symptom monitoring, was low in both groups (32% and 34%).

In a multivariable analysis, it was found that patients with a history of HF with more HF knowledge (OR 1.17; 95% CI 1.01-1.36) and those who were male (OR 2.22; 95% CI 1.11-4.44) were more likely to delay. Furthermore, the total amount of HF symptoms was independently associated with long patient delay, indicating that patients with a history of HF, who delayed long in seeking care, were presented with more HF symptoms at the hospital, compared to those with a short patient delay.

Discussion

Although delay in HF patients was assessed in previous studies, these studies assessed the time from worsening symptoms to arrival at the hospital. The scope of this study was on patient delay, reflecting the time from worsening symptoms to actually contacting a health care provider. Most important findings of this study were that a history of MI or stroke was independently associated with short patient delay. Furthermore, we also found that male gender, more HF knowledge and the presence of swollen ankles, loss of appetite fatigue and dyspnea were independently associated with long patient delay.

Patients with a history of MI or stroke had a shorter patient delay time than those without these events, which was also found in studies on delay in patients with ACS.^{13,14} Since patient delay reflects the patient's own decision process, a previous cardiovascular, life-threatening event might have led to a higher symptom awareness, more adequate symptom evaluation and quicker decision making. However, this relationship was not found in a study of Goldberg et al.⁹ This can be due to a different definition of delay, the retrospective study design or the large amount of missing data (56%) in the study sample. Furthermore, a history of a previous HF

admission was not associated with short patient delay in our study, indicating that patients do not seem to benefit from their earlier experience with HF.⁷

HF knowledge has an association with better self-care behaviors, such as compliance with the regimen.^{24,25} In this study, a longer patient delay was independently associated with more HF knowledge in all patients, as well as in those with a history of HF. This result is quite remarkable, since one could expect that patients with more HF knowledge, including knowledge on HF symptoms, should seek care earlier.²⁵ Patients with more HF knowledge might try to manage the worsening symptoms themselves by, for example, taking extra diuretics or adjusting their fluid or salt intake⁸, instead of calling a health care provider. However, it is worrisome that performing self-care behaviors is often challenging in HF patients; besides adequate self-care behaviors, also insufficient or counterproductive behaviors, such as drinking more water or taking medications other than prescribed, are performed.² This stresses the importance of providing education and information on adequate self-care behaviors in case of worsening symptoms.

Another explanation is that these patients do have enough general HF knowledge, but lack the specific knowledge to recognize or to anticipate adequately to worsening HF symptoms. Patients often have insufficient information about recognition, causes, symptoms, management and consequences of HF; therefore they are not fully prepared to self-manage. Furthermore, it is often difficult for chronic HF patients to differentiate between baseline symptoms and signs of deterioration.²⁶

Gender was independently associated with patient delay, which has also been reported in another study⁹; male patients were more likely to delay in seeking care. This result was found for all patients, as well for patients with a history of HF. This was not found in 2 other studies on delay in HF patients.^{6,8} In contrast, from the ACS population it is known that female patients more often had long delay in case of onset of MI, compared to males.¹⁴ Most important explanations for longer delay in women with ACS were older age, perceiving atypical symptoms, living alone and additional

comorbidities.¹⁴ We did not find these differences in HF patients. Further research on the specific role of gender in delay in HF patients is needed.

In this study, in patients with a history of HF, no differences in self-care behavior and compliance between patients with a short- and long delay were found. Although patients reported that they would contact a health care provider in case of worsening symptoms, many patients delay in seeking care when those symptoms actually occur. Three quarters of the patients with a history of HF were overall compliant with the regimen; however, compliance with daily weighing was low (~35%). It is known that many patients are failing to monitor their weight or are unaware of the importance of this self-care behavior.²⁷ Although it is suggested that compliance with recommendations on daily weighing may lead to detecting worsening symptoms in an earlier stage²⁸, this aspect of the non-pharmacological regimen did not affect patient delay time in our study.

Depressive symptoms have a negative effect on clinical outcome in HF patients²⁹ and are associated with low self-care behavior.³⁰ It was also found that patients with depressive symptoms do not benefit in terms of mortality and readmission from a disease management program directed at education and counseling.³¹ In this study, depressive symptoms were not associated with long patient delay. In contrast, in one of our previous studies which was also based on the COACH-data, we found an association between depressive symptoms and long delay in HF patients.³² However, in line with other studies on delay in HF, this previous study also actually assessed pre-hospital delay, which may be one of the explanations for the differences in results regarding the relation between depressive symptoms and delay. Another explanation may be the use of different formulations of cut-off points to differentiate between short and long delay (median versus 33rd and 66th percentiles of the delay time).

In this study, HF symptoms were independently associated with patient delay. However, from these data it is not clear whether a long delay resulted in more HF symptoms or that some HF symptoms resulted in a longer patient delay. On the one hand, it might be reasonable to assume that

early undetected HF symptoms may develop into more severe symptom manifestation. On the other hand, symptoms like swollen ankles, loss of appetite or fatigue often have a gradual pattern of worsening and can be perceived as not important or non-threatening, thus resulting in a longer patient delay as was also suggested in other studies.^{10, 15}

One of the limitations of the study is the use of arbitrary cut-off scores based on the 33rd and 66th percentiles to differentiate between patients with short and long patient delay. However, in the existing literature no standard criterion on short or long delay time has been formulated. Another limitation is that there were no data on the behavior of the patients during the time from worsening symptoms to calling a health care provider. Further research is needed to assess the patients' own actions and coping strategies in case of worsening symptoms. A final limitation is the cross-sectional design of the study; a prospective design would have been preferable in case of establishing direction of causality.

Conclusion and implications

Patients with a history of a serious, life-threatening event, such as MI or stroke, contacted a health care provider earlier in case of worsening HF symptoms, compared to those without such event.

More HF knowledge, male gender and more HF symptoms were also independently associated with long patient delay in all patients, as well in those with a history of HF. Although these results might suggest a profile of HF patients vulnerable to long delay in seeking care after worsening symptoms, further research is needed to obtain more insights on symptom recognition and performed actions from time to worsening symptoms to actually calling a health care provider. In order to reduce patient delay, patients should be educated on the importance and recognition of worsening symptoms, and the importance of care seeking in case of deteriorating HF. Education of patients should stress the importance of recognizing relevant symptoms and taking appropriate action, even if symptoms do not seem acute or life-threatening to them.

Disclosures

Conflict of interest: none declared

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Figure 1 *Time schedule of patient-, transportation- and pre-hospital delay*

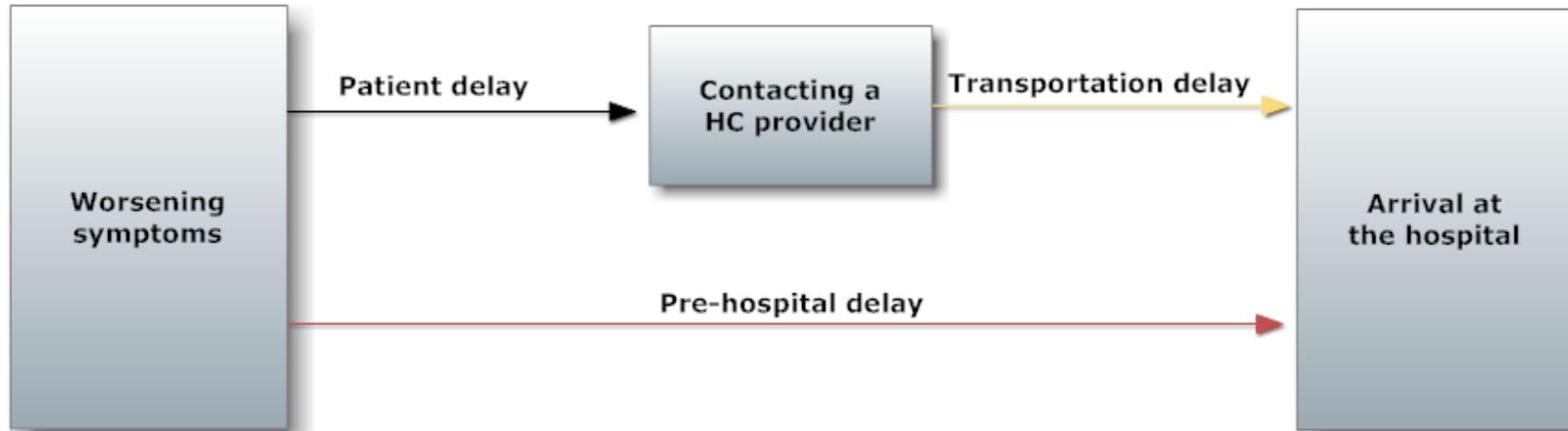


Table 1 Characteristics of the study population and differences between patients with short and long patient delay

	All patients (n = 911)	Delay <12 hrs (n = 296)	Delay ≥1 week (n = 341)	P-Value
Demographics				
Age, years ± SD	71 ± 12	73 ± 11	70 ± 11	<0.01
Gender, male	62% (565)	57% (169)	67% (227)	0.01
Living with a partner	61% (550)	56% (162)	63% (215)	0.07
Educational level, high	10% (90)	8% (23)	13% (44)	0.04
Clinical variables				
LVEF % ± SD	34 ± 15	35 ± 15	34 ± 14	0.55
NYHA (Admission)				<0.01
II	6% (52)	4% (12)	6% (20)	
III	57% (517)	67% (196)	54% (182)	
IV	37% (333)	29% (85)	40% (135)	
Length of HF, months	32 ± 54	31 ± 47	29 ± 52	0.41
Previous HF-admission	32% (291)	33% (98)	27% (92)	0.09
Depressive symptoms	40% (345)	35% (95)	45% (144)	0.01

History of MI	42% (378)	50% (148)	33% (114)	<0.01
HF-symptoms, mean \pm SD	6.5 \pm 2.2	5.6 \pm 2.3	6.9 \pm 1.9	<0.01
Smoking	16% (140)	16% (44)	16% (54)	0.89
Alcohol, units/day	.7 \pm 1.4	.7 \pm 1.3	.8 \pm 1.4	0.17
Aetiology of HF				
CAD	43% (387)	50% (147)	35% (119)	<0.01
Hypertension	14% (125)	15% (45)	15% (51)	0.93
Cardiomyopathy	24% (217)	19% (55)	28% (94)	<0.01
Co-morbidities				
Diabetes	28% (252)	30% (89)	23% (77)	0.03
COPD	26% (238)	26% (78)	26% (89)	0.94
Stroke	10% (93)	15% (44)	8% (27)	<0.01
HF knowledge				
Total score	11.6 \pm 2.3	10.7 \pm 2.3	11.2 \pm 2.3	<0.01

CAD -Coronary Artery Disease; COPD -Chronic Obstructive Pulmonary Disease; HF -Heart Failure; LVEF -Left Ventricle Ejection Fraction;

MI -Myocardial Infarction; NYHA -New York Heart Association

Table 2 Variables independently associated with long patient delay in HF patients (n = 598)

Variable	Odds ratio	95% CI	P-value
Gender, male	1.58	1.09-2.29	0.02
MI	.49	.34-.71	<0.01
Stroke	.43	.24-.76	<0.01
HF Knowledge	1.09	1.01-1.18	0.03
Swollen ankles (after waking up)	1.50	1.05-2.15	0.03
Loss of appetite	1.77	1.23-2.56	<0.01
Fatigue	2.93	1.60-5.38	<0.01
Dyspnea at rest	1.58	1.09-2.30	0.02
Dyspnea on exertion	2.58	1.19-5.57	0.02

HF -Heart Failure; MI -Myocardial Infarction

Table 3 Differences between patients with a history of HF with short and long patient delay

	Delay <12 hrs (n = 92)	Delay ≥1 week (n = 83)	P-Value
Demographics			
Age, years ± SD	74 ± 11	71 ± 10	<0.01
Gender, male	52% (48)	71% (59)	0.01
Living with a partner	55% (47)	60% (49)	0.50
Educational level, high	7% (6)	18% (15)	0.02
Clinical variables			
LVEF % ± SD	36 ± 15	36 ± 14	0.86
NYHA (Admission)			0.10
II	8% (7)	7% (6)	
III	66% (60)	54% (44)	
IV	26% (24)	38% (31)	
Length of HF, months	60 ± 45	76 ± 70	0.17
Mean Prev. HF-admissions	1.6 ± 1.0	1.8 ± 1.5	0.62
Depressive symptoms	43% (36)	44% (35)	0.96
History of MI	57% (52)	45% (37)	0.12

HF-symptoms, mean \pm SD	5.8 \pm 2.4	7.0 \pm 1.9	0.03
Smoking	15% (13)	12% (10)	0.60
Alcohol, units/day	.6 \pm 1.6	.8 \pm 1.5	0.36
Aetiology of HF			
CAD	53% (49)	51% (42)	0.73
Hypertension	10% (9)	11% (9)	0.82
Cardiomyopathy	20% (18)	25% (21)	0.36
Co-morbidities			
Diabetes	41% (38)	24% (20)	0.02
COPD	37% (34)	33% (27)	0.54
Stroke	16% (15)	10% (8)	0.19
HF knowledge			
Total score	10.5 \pm 2.3	11.4 \pm 2.2	0.01

CAD - Coronary Artery Disease; COPD - Chronic Obstructive Pulmonary Disease; HF -Heart Failure;

LVEF -Left Ventricle Ejection Fraction; MI –Myocardial Infarction