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Delayed Hospital Presentation in Acute Decompensated Heart Failure: Clinical and Patient Reported Factors

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Abstract

Background—Patients with acute decompensated heart failure (ADHF) often wait a considerable amount of time before going to the hospital. Prior studies have examined the reasons why such delays may occur, but additional studies are needed to identify modifiable factors contributing to these delays.

Purpose—To describe care-seeking delay times, factors associated with prolonged delay, and patient's thoughts and actions in adult men and women hospitalized with ADHF.

Methods—We surveyed 1,271 patients hospitalized with ADHF at 8 urban medical centers between 2007 and 2010.

Results—The average age of our study population was 73 years, 47% were female, and 72% had prior heart failure. The median duration of pre-hospital delay prior to hospital presentation was 5.3 hours. Patients who delayed longer than the median were older, more likely to have diabetes, peripheral edema, to have symptoms that began in the afternoon, and to have contacted their medical provider(s) about their symptoms. Prolonged care seekers were less likely to have attributed their symptoms to ADHF, less likely to want to have bothered their doctor or family, and were more likely to be concerned about missing work due to their illness (all p values < 0.05).

Conclusions—Care-seeking delays are common among patients with ADHF. A variety of factors contribute to these delays which in some cases may represent efforts to manage ADHF symptoms at home. More research is needed to better understand the detrimental effects of these delays and how best to encourage timely care-seeking behavior in the setting of ADHF.

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Keywords

heart failure; care seeking behavior

Introduction

More than 5 million Americans have been diagnosed with heart failure (HF) and upwards of 700,000 new cases of HF occur annually in the U.S.¹ Hospitalizations related to acute decompensated HF (ADHF) have increased over the past several decades, and ADHF is now a leading cause of hospital admissions in the elderly.² Significant efforts have been devoted to developing HF management programs and patient educational tools that may decrease HF related hospitalizations and readmissions.³⁻⁷ A major focus of these programs is early detection of ADHF, thereby facilitating an earlier intervention. Timing of intervention is important in such scenarios because it has been established that patients may wait a considerable amount of time before seeking medical attention for HF symptoms.⁸⁻¹⁰

Prior studies have found that patients with ADHF wait several days on average before presenting for medical treatment.¹¹ The reasons why patients with ADHF may delay their presentation to the hospital have been found to be multifactorial. Some of the more common factors that have been shown to be associated with prolonged pre-hospital delay include symptoms such as edema, dyspnea, male gender, older age, absence of a history of HF, and lack of appropriate sensing of symptoms of ADHF.⁸⁻¹⁴ Factors that have been shown to decrease delay include chest pain, a prior history of HF, and using an ambulance to arrive at the hospital.^{8,10,15} Irrespective of the cause, delays in treatment may increase morbidity and result in a more severe case of ADHF when inpatient admission is ultimately required.

Most of the prior studies that have examined pre-hospital delay in patients seeking medical care for ADHF have been conducted in single hospital centers or have included relatively small numbers of patients, thus limiting the conclusions one can draw.^{8,11,14,16} Moreover, additional details regarding the thoughts and actions of these patients relating to delay may further inform efforts to mitigate such delays. The objectives of the present study were to characterize the distribution of pre-hospital delay times, elucidate the factors associated with delay in seeking medical care, to determine if delay adversely impacts outcome, and describe some of the thoughts and actions of each study subject following the onset of acute HF symptoms, in a large multicenter population of individuals hospitalized with ADHF.

Methods

Study Design and Setting

Data for this investigation were derived from a cross sectional, observational study that enrolled and surveyed patients admitted with ADHF. The final study sample consisted of 1,271 patients hospitalized for ADHF at 8 medical centers between July, 2007 and June, 2010; 3 of the study hospitals were located in Worcester (MA), 1 in Burlington (MA), 2 in Providence (RI), and the other 2 in Hamilton, Ontario. The average size of these medical centers was 391 beds with a range from 319 beds to 719 beds. The study was approved by each institution's Committee for the Protection of Human Subjects in Research.

Study Procedures

To identify potential research subjects, nurse or physician interviewers completed daily reviews of computerized data of inpatients with an admission diagnosis of possible HF (International Classification of Disease-9 code 428) at our participating sites. Patients admitted with less specific diagnoses (e.g., shortness of breath, leg swelling), or other

diagnoses in which HF was possible (e.g., pneumonia, COPD exacerbation), were also screened for study inclusion. Subsequently, the interviewers performed a review of each potentially eligible patient's medical record to determine if the patient's admission data satisfied the Framingham criteria for HF¹⁷ which was our diagnostic criterion. The Framingham criteria for HF are satisfied when there are two major criteria, or 1 major and 2 minor criteria, identified. Major criteria include rales, acute pulmonary edema, and an S3 gallop among other clinical findings, and minor criteria include such findings as bilateral ankle edema, pleural effusion, and dyspnea on ordinary exertion. Patients were excluded if their HF occurred in the setting of a myocardial infarction, after an invasive procedure (e.g., coronary artery bypass surgery), or due to iatrogenic volume loading. Patients who developed HF secondary to admission for another disease, those with dementia documented in their medical chart, those who screened positive for delirium using a standardized assessment method (Confusion Assessment Method¹⁸), and those who spoke languages other than English were also excluded.

Each patient satisfying the Framingham criteria for HF was approached by trained nurse or physician interviewers within 72 hours of their hospital admission. The interviewers described the study in detail and assessed each patient's ability to provide informed consent. Consenting patients were asked to complete a structured 30-minute interview during their hospital admission. The interview was based entirely on the standardized 24 page survey questionnaire and included a history of the patient's chief complaint(s) and additional presenting symptoms. The presence or absence of a symptom was assessed by the interviewer by directly questioning the patient and determined by a dichotomous (yes/no) response. If the symptom was reported to be present, the patient was then queried as to the time the symptom began and if it worsened at any point. The interviewer recorded all patient responses directly on the survey document. We focused on symptoms (14 in total) that are most often associated with an episode of ADHF. These symptoms included shortness of breath, orthopnea, chest pain/discomfort, fatigue, nausea, edema, paroxysmal nocturnal dyspnea, palpitations, abdominal pain, loss of appetite, cough, anxiety, impending doom, and bloating. To better understand patient actions, the interviewers asked whether they had contacted family, friends, or their physician prior to presenting to the hospital.

A series of questions about specific reasons for delaying going to the hospital, despite having ADHF symptoms, were also asked of patients by our trained interviewers. Questions pertaining to patient's heart related symptoms, severity and seriousness of their symptoms, ability to treat oneself, dislike of hospitals, not wanting to bother either their personal physician, family, or friends, embarrassment about calling an ambulance, lack of health insurance, concerns about the cost of hospitalization and missing time from work, and either difficulty they had in contacting their physician or nurse, or that they had a regularly scheduled appointment in a few days and preferred to wait, were asked of patients directly by our interviewers. Additional information was collected from hospital charts about each patient's demographic characteristics, medical history, clinical characteristics, duration of hospitalization, treatment approaches, and hospital survival status.

Study Variables

The extent of delay preceding hospital presentation was based on the date and time that each patient became aware of a symptom consistent with ADHF. Duration of prehospital delay was calculated as the time interval between symptom onset time and arrival at each of the respective hospital's emergency departments (ED); this variable was calculated separately for both an 'acute' delay time and a 'premonitory' delay time. For calculating acute delay times, an acute symptom was defined as the last symptom that a patient reported experiencing prior to presenting to the hospital for evaluation and admission. This could represent either the worsening of a pre-existing symptom or the onset of a new complaint

and could include any of the 14 symptoms included in the survey. Our definition of ‘acute’ delay was based on the last symptom reported before hospital presentation rather than on the experience of specific symptoms that may be considered more ‘severe’ (e.g., chest pain). We chose this definition for the following reasons: First, patients may experience a wide range of symptoms in the days and weeks prior to presenting to the hospital with ADHF. Secondly, these symptoms may wax and wane over time, and our definition removes much of the ambiguity with trying to identify the exact onset of ADHF considering all the symptoms (and varying symptom severity) these patients experience. Although this definition has limitations, it should allow for the study of delay times based on symptoms that are most likely attributable to ADHF. Since HF can exhibit a gradual pattern of worsening, and patients may delay seeking medical care until these symptoms increase in severity, or a new symptom arises, we also obtained pre-hospital delay times in reference to ‘premonitory’ symptoms. A premonitory symptom was defined as a symptom that represented the first or earliest change in each patient's usual health status. Any of the 14 symptoms surveyed could be considered a premonitory symptom.

Measures and Data Analysis

To distinguish early from late responders to acute symptom onset we used our median overall delay time of 5.3 hours; this cut-point was selected based on the distribution of delay times in our study sample and on the basis of prior studies that also utilized median delay times.¹¹ Differences in the distribution of selected demographic and clinical characteristics between patients with varying durations of pre-hospital delay were examined using chi square and t-tests where appropriate. Multivariable adjusted logistic regression models were constructed to examine the association between a variety of possible predisposing factors and duration of pre-hospital delay with accompanying odds ratios (ORs) and 95% confidence intervals (CI). Patients thoughts related to rapidity of seeking care in groups stratified around the median delay time were compared by chi square.

Results

Study Sample Characteristics

A total of 1,271 men and women were interviewed in the hospital after being admitted for ADHF. The average age of this patient population was approximately 73 years, 53% were men, 91% were white, and 72% had been previously diagnosed with HF (Table 1). These patients experienced a range of HF related symptoms. Overall, the 4 most common symptom complaints (irrespective of acute and premonitory designation) were dyspnea (92%), edema (58%), fatigue (53%), and orthopnea (50%) (Table 1). Three-quarters of patients recalled a point in time when their dyspnea worsened, nearly half experienced a worsening of their edema and orthopnea, and a third developed a worsening of their fatigue prior to admission (data not shown).

Delay Times

The average overall delay time based on the onset of an acute symptom was 50.0 hours with a median of 5.3 hours (25th percentile 1.8 hours; 75th percentile 23.4 hours). When delay was calculated based on the onset of the earliest or premonitory symptom of potential ADHF, much longer delays were observed with a mean of 31.9 days and a median of 12.9 days (25th percentile 3.3 days; 75th percentile 30.2 days).

Characteristics Associated with Time to Hospital Presentation after Acute Symptom Onset

Univariate analysis demonstrated that patients who delayed longer than the median delay time we found (5.3 hours) after acute symptom onset were more likely to be older, white, or

to be married or living with someone. They were also more likely to complain of peripheral edema or 'bloating'. Several acute symptoms were significantly associated with shorter delays (<5.3 hours) including chest pain, anxiety, dyspnea, palpitations, and a feeling of 'impending doom'. Delays were also shorter in patients with hypertension, in those who contacted friends or family prior to going to the hospital, and in those who used ambulance transportation (Table 1).

A multivariable logistic regression analysis was performed to examine which factors were independently associated with delays in seeking medical care after the onset of acute symptoms onset (Table 2). Advanced age, a history of diabetes, presence of edema, development of acute symptoms between 12:00 p.m. and 5:59 p.m., and attempting to contact a healthcare practitioner were independently associated with prolonged delay. Similar to the results of the univariate analysis, several factors were found to predict a shorter pre-hospital delay including the symptoms of chest pain, anxiety, and dyspnea, among others, having a history of hypertension, contacting a family member or friend, and being transported by ambulance (as opposed to private car or other means) to the hospital (Table 2).

When patients were asked to explain some of their thoughts regarding their care-seeking behavior, those that delayed longer than the median were more likely to report that they did not think their symptoms were heart related, that they did not want to bother their family or their doctor, and that they did not want to miss work, among other reasons (Table 3).

Hospital Outcomes

In order to determine if the observed delays in seeking medical care might have had a detrimental effect on short-term clinical outcomes, we examined differences in inpatient length of stay and hospital case-fatality rates in patients with symptoms of ADHF who delayed less than or greater than the median acute delay time of 5.3 hours. Length of inpatient stay was similar in the two groups and averaged 5.7 days versus 5.2 days ($p=0.10$) in those delaying longer than the median compared to those with shorter delays. In-hospital case-fatality rates were also relatively similar (2.2% versus 1.3% ($p=0.19$)) in patients with longer as compared to those with shorter durations of pre-hospital delay.

Discussion

The results of this large observational cross sectional study suggest that patients who are hospitalized for ADHF exhibit significant delays in seeking inpatient medical care. Several demographic and clinical factors were found to be associated with longer delays in seeking medical care that may inform providers with regard to efforts to hasten patient's actions in response to worsening symptoms of ADHF. Interestingly, we found that contact with a healthcare provider was associated with longer pre-hospital delay times, and that patients had a wide range of thoughts about their symptoms of ADHF that influenced the urgency with which they sought hospital-based care.

Duration of Delay After Onset of ADHF Related Symptoms

Previous studies examining the extent of pre-hospital delay prior to admission for ADHF have reported a wide range of delay times ranging from a few hours to several weeks after symptom onset.^{8-10,16,19} These wide variations in delay likely reflect different study methods, the number and characteristics of patients studied, and the manner in which acute symptom onset and the seeking of medical care was determined or defined. The current investigation adds important information to the literature by collecting data through structured inpatient interviews in a large sample of patients admitted with ADHF. The few

other interview-based studies in this area have been considerably smaller and have examined different aspects of delay.^{16,19} For example, a study of 83 patients who were interviewed shortly after hospital admission for ADHF examined delays from the perspective of specific symptoms (e.g., edema, dyspnea) and found delays prior to admission ranging from 8 to 12 days depending on the specific symptom.¹⁶

Despite the relatively large number of studies that have documented delayed care-seeking behavior of patients with HF,^{8-11, 19} data regarding adverse outcomes associated with these delays are limited. In the present investigation we did not find significant differences in either the average length of hospital stay or short-term death rates between patients with longer pre-hospital delays compared to patients who sought care in a timelier manner. Additional studies in larger and more diverse patient populations of the adverse effects associated with delayed medical care are needed. In addition, there may be other important outcomes that may be adversely impacted by patients not seeking care earlier after the onset of symptoms of ADHF, and documenting these adverse effects is crucial before governmental bodies can recommend widespread efforts to mitigate these delays.

Factors Associated with Delay

Previous studies of patients with decompensated HF have identified several factors that are associated with delays in hospital presentation following the development of symptoms of ADHF.¹⁰⁻¹⁴ These factors include patient demographics, clinical variables, psychosocial factors, and cognitive impairment. Similar to our prior study on delayed HF presentations,¹⁰ in the present study we found that older patients exhibited longer pre-hospital delays than younger patients. Older age as a factor mediating delay has been noted in other studies as well,^{9,14} and may be related to an inadequate cognitive and emotional response to the symptoms of ADHF¹⁴ and may be exacerbated by confounding symptoms due to the presence of multiple comorbidities. We also found that delays in seeking medical care were greatest when symptoms began in the afternoon which may reflect the greater inconvenience associated with going to the hospital at these times and by a reluctance to use ambulance transport. The association of diabetes with delay is not wholly unexpected since it is widely accepted that diabetes can alter the perception of symptoms during myocardial ischemia,²⁰

A novel aspect of the present study was the information we obtained on patient's thoughts about their reasons for their delays in seeking medical care. Our findings revealed that patients had difficulty recognizing their symptoms as being HF related. Difficulties with the recognition of ADHF symptoms have been reported in other studies where approximately one third of patients attributed their symptoms to something other than ADHF.¹⁴ This same study also found that half of the patients with ADHF reported that they did not want to bother others when they were ill,¹⁴ a finding which we also noted in our study population. Our results suggest that patients need assistance in recognizing the importance of new signs and symptoms of ADHF.

Knowledge of the factors related to care-seeking behavior may assist nurses and other healthcare providers in identifying groups at higher risk for delay and may help focus outpatient educational efforts aimed at helping patients recognize and respond appropriately to acute changes in their health status. Nurses involved in hospital discharge planning should discuss with patients and their close family members or caregivers the particular factors that each patient may have that could represent a barrier to the timely receipt of effective medical care. In particular, patients with previously diagnosed ADHF need to be educated about the potential benefits of using ambulance transport in response to future HF symptoms where the more effective treatment or acute complications of ADHF may be addressed in the pre-hospital setting. However, despite the knowledge gained from the present study, as well as others, implementing strategies to mitigate delays in hospital presentation for these patients

is likely to be difficult and costly. Patients will have to be motivated and able to exercise effective self-care, providers will have to follow them closely, and hospitals will have to provide high quality discharge planning and instructions. Further research in how best to implement these strategies is needed.

Lastly, prior studies examining patient mediated delays of inpatient admissions have generally not examined delays that result from patient contact with medical care providers or family.¹¹ However, one large study of Veterans Administration patients with acute HF found that contact with a primary care doctor increased duration of pre-hospital delay.⁸ Similarly, we found that patients with symptoms of ADHF who sought care or advice from a medical provider had longer overall delay times. These findings have important implications because although longer wait-times in seeking medical care are generally thought to delay the institution of appropriate treatment, this may not be the case when patients carry out self-care under the direction of a medical provider.

Study Strengths and Limitations

There are several strengths of this observational study including the large, diverse, patient population studied, the inclusion of multiple study centers, the collection of data through direct patient interviews, and the detailed data collection instruments employed. By distinguishing between acute and earlier (premonitory) delay times of ADHF, our study offers a more detailed perspective on delay times. However, an important limitation of this study was our dependence on each patient's ability to accurately recall the timing of symptom onset and specific characteristics of acute HF signs and symptoms. Furthermore, because ADHF is often characterized by a group of symptoms, many of which are not specific to HF, we cannot be sure that each reported symptom was a result of ADHF. We were also unable to characterize pre-hospital delay in patients based on the severity of their ADHF or on whether they had primarily systolic or diastolic dysfunction which can alter the types of symptoms that are experienced by patients with ADHF. We also did not find a significant impact of delay on length of hospital stay or short-term death rates. However, it is likely that, despite our large sample size, this study was underpowered to detect clinically meaningful differences in these outcomes, particularly due to the low in-hospital death rates. Lastly, some non-English speaking patients were not enrolled due to the lack of an interpreter which may limit the generalizability of our results to multiethnic healthcare settings.

Conclusions

The results of the present study reinforce the notion that patients with decompensated HF often delay a considerable amount of time before presenting to the hospital for medical care even following acute symptom onset. Moreover, the median, mean, and distribution of pre-hospital delays times we observed following the onset of acute symptoms demonstrate that there are a wide range of patient responses. We also found that there were a variety of factors that contribute to delay in patients with ADHF. Further studies are needed to clarify the adverse impact of delayed care-seeking and to identify effective approaches to patient-provider communication once Male (%) 53.0 52.6 53.3 0.80 worsening symptoms of HF have been identified. Given the disconcertingly high rates of readmission attributable to decompensated HF, strategies to identify and eliminate “inappropriate” delays in seeking timely medical care remain of vital importance.

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Abbreviation List

HF	heart failure
ADHF	acute decompensated heart failure
COPD	chronic obstructive pulmonary disease
ED	emergency department
OR	odds ratio
CI	Confidence interval

Table 1
Characteristics of overall population and of patients delaying less than or greater than 5.3 hours (median) after acute symptom onset

Characteristic	Overall Population (n=1,271) %	Presenting <5.3 hours (n=636) %	Presenting >5.3 hours (n=635) %	P value*
Age (mean,yrs)	73.1	72.0	74.1	<0.01
Male (%)	53.0	52.6	53.3	0.80
White	88.0	85.1	91.0	<0.01
Married/living with someone	47.3	44.2	50.4	<0.05
Medical history				
Body Mass Index (mean)	31.0	31.2	30.8	0.47
Coronary Heart Disease	56.5	58.3	54.7	0.18
Diabetes	37.8	35.5	40.0	0.10
Heart Failure	71.7	70.9	72.5	0.54
Hypertension	80.7	83.5	78.0	<0.05
Peripheral Vascular disease	18.6	20.3	16.9	0.12
Stroke	14.6	13.5	15.6	0.30
Myocardial Infarction	32.1	34.4	29.8	0.07
HF Related Symptoms				
PND	31.7	32.1	31.3	0.78
Edema	57.8	50.3	65.4	<0.001
Fatigue	52.8	54.4	51.2	0.25
Anxiety	33.0	38.7	27.4	<0.001
Dyspnea	91.9	94.3	89.5	<0.01
Orthopnea	49.6	50.5	48.7	0.52
Palpitations	13.8	17.5	10.1	<0.01
Feeling of Impending Doom	9.8	12.1	7.6	<0.01
Nausea	15.7	17.8	13.5	<0.05
Cough	41.1	41.8	40.3	0.58
Chest pain or pressure	28.3	34.8	21.9	<0.001
Loss of Appetite	25.4	23.3	27.6	0.08
Bloating	25.0	21.9	28.2	<0.01
Abdominal pain	9.1	10.6	8.2	0.25
Time of acute symptom onset (%)				
12:00 am -5:59 am	7.7	19.5	11.7	<0.001
6:00 am -11:59 am	19.1	36.6	30.6	
12:00 pm -5:59 pm	64.0	25.0	40.5	
6:00 pm –11:59 pm	9.2	18.9	17.3	
Actions prior to admission				
Transported by ambulance	54.6	64.3	44.4	<0.001

Characteristic	Overall Population (n=1,271) %	Presenting <5.3 hours (n=636) %	Presenting >5.3 hours (n=635) %	P value [*]
Healthcare contact attempted	28.0	20.1	35.9	<0.001
Family/friend contact	45.6	57.2	34.0	
No contact attempted	26.4	22.6	30.1	
Outcomes				
Hospital stay (mean,days)	5.4	5.2	5.7	0.10
Inpatient death	1.7	1.3	2.2	0.20

* p value represents a comparison of the data from the 2nd and 3rd columns. Chi square tests were used to examine differences between the 2 primary comparison groups (columns 2 and 3) while the t test was used to examine differences in the mean age and length of hospital stay between these 2 groups.

Table 2
Factors associated with prolonged acute delay*

Characteristic	Odds Ratio	95% CI	P value
Age	1.22	1.10,1.36	<0.001
White race	1.28	0.86,1.90	0.22
Married/Living with Someone	1.13	0.88,1.45	0.35
Transported by Ambulance	0.44	0.34,0.57	<0.001
Medical History			
CHD	1.17	0.91,1.51	0.25
Diabetes	1.36	1.04,1.76	<0.05
Hypertension	0.69	0.50,0.94	<0.05
Peripheral vascular Disease	0.73	0.54,1.01	0.05
Symptoms			
Edema	1.51	1.17,1.94	<0.01
Chest Pain	0.64	0.48,0.84	<0.01
Anxiety	0.75	0.57,0.98	<0.05
Bloating	1.05	0.78,1.42	0.75
Dyspnea	0.56	0.35,0.89	<0.05
Feeling of impending doom	0.79	0.51,1.24	0.30
Palpitations	0.62	0.44,0.89	<0.05
Loss of Appetite	0.74	0.55,0.99	<0.05
Nausea	0.78	0.55,1.10	0.15
Actions prior to admission			
Healthcare contact attempted	1.42	1.02,1.98	<0.05
Family or friend contact attempted	0.62	0.46,0.84	<0.01
Symptom Onset Time			
6:00 a.m. – 11:59 a.m.	1.01	0.69,1.47	0.94
12:00 p.m. – 5:59 p.m.	1.91	1.31,2.80	<0.01
6:00 p.m. – 11:59 p.m.	1.26	0.83,1.93	0.28

* Median >5.3 hours from latest reported symptom

Table 3
Patient reported thoughts related to care seeking according to median duration of acute pre-hospital delay

Patient Reported Thoughts	Extent of Delay		P value
	<5.3 hrs	5.3 hrs	
	%	%	
Didn't think symptoms were heart Related	12.6	20.3	<0.001
Symptoms weren't that severe at first	48.1	41.3	<0.05
Didn't think symptoms were serious	31.5	32.9	0.58
Thought they could treat themselves	13.5	13.9	0.86
Do not like going to hospitals	23.7	26.5	0.26
Didn't want to bother their doctor	3.5	6.1	<0.05
Didn't want to bother or worry family	11.2	14.8	0.05
Were embarrassed to call an ambulance	2.7	4.6	0.07
Didn't have health insurance	1.3	2.1	0.27
Were concerned about cost of hospital visit	2.7	4.1	0.16
Were worried about missing work	1.9	3.9	<0.05
Had difficulty contacting provider	1.3	3.9	<0.01
Had medical appointment in a couple days	8.8	11.0	0.19

* chi square tests were used to examine differences in the frequency of these categorical variables between the 2 comparison groups.