

Reasons for seeking acute care in chronic heart failure

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Abstract

Background: Patients with chronic heart failure (CHF) have frequent episodes of exacerbation leading to recurrent hospitalization.

Aims: To explore factors related to patients seeking care for worsening CHF.

Methods: Eighty-eight patients diagnosed with a deteriorating CHF condition were interviewed. Data were analysed using content analysis.

Results: Overall, 51 (58%) patients sought emergency care because of their symptoms while 37 (42%) were either sent by relatives or referred from outpatient clinics. Delay in seeking care was explained by 62 (71%) patients as a “wait and see” strategy, 9 (10%) were reluctant to use the health care system and 10 (11%) felt that it was futile to seek care. Fifty percent of the patients were uncertain about their current deteriorating status. Only 4 patients reported their symptoms to be related to heart failure.

Conclusions: Although symptoms were the dominant reason for seeking emergency care, only a few patients related their symptoms to worsening CHF, which might be an important factor for not seeking emergency care earlier. Patient education programs should make efforts to improve understanding of symptom recognition.

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1. Introduction

Patients with chronic heart failure (CHF) have frequent episodes of exacerbation leading to recurrent hospitalisation [1]. Three- to six-month readmission rates in severe cases are estimated to be as high as 27–47% in patients over 70 years of age [2]. About 50% of these re-hospitalisations may be prevented because they are related to such behavioural factors as diet, non-adherence to medication or failure to recognise the significance of early signs and symptoms of deterioration [3].

CHF is associated with various symptoms, including dyspnoea, lack of energy, pain and anxiety, loss of appetite, depression and sleeping difficulties [4–7]. Symptoms and signs (such as shortness of breath, fatigue and leg oedema) are

hallmarks of the condition [1]. Symptoms are clearly an important aspect of CHF and therefore frequently evaluated in research. The New York Heart Association (NYHA) functional classification system has been used for over three decades as a measure for categorising the clinicians' impression of symptoms in patients with CHF [8]. However, in practice, classifications are based not only on functional limitation because of symptoms but also influenced by knowledge of the severity of cardiac dysfunction, prior medical history and judgements regarding likely prognosis [8,9]. The clinicians' task is difficult to assess correctly because symptoms are subjective. Studies consistently show discrepancies between patient-assessed functional status and clinicians' NYHA classifications [10,11]. Another complicating factor is that the most prevalent symptoms of CHF may not be the most distressing ones from the patient's perspective. For instance, Zambroski et al. [4] found that some patients reported a number of relatively rare symptoms that the patients found particularly burdensome, including numbness,

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itching, changes in food taste and lack of appetite. Consequently, it is not clear what symptoms, either typical or atypical of heart failure (HF), induce patients with deteriorating CHF to seek prompt emergency care.

With the development of outpatient heart failure clinics, patients have increased access to information, counselling and support [12]. Obviously, it is essential to investigate whether this information flow has influenced symptom interpretation and response in patients with worsening CHF.

Although delay in seeking treatment has been studied in patients with CHF [13], the reasons as to why and when individuals seek emergency care have yet to be addressed. By eliciting descriptions of the patients' experiences in their own words, a better understanding of their needs is likely to be developed and anticipated. Hence, this study was designed to explore reasons to why patients with deteriorating CHF seek acute care at an emergency department (ED).

2. Method and theoretical frame of reference

Data were collected face-to-face by a trained interviewer using a semi-structured, open-ended interview guide on seeking care at an ED. The interview guide was based on three components from the symptom experience dimension of the Symptom Management Model (SMM): symptom perception, symptom evaluation and symptom response [14]. Symptom perception concerns how patients perceive the severity, frequency or disabling aspects of their symptoms. Symptom evaluation refers to past experiences, thresholds, knowledge, cognitive function, co-morbidities and social support. The third component, symptom response, pertains to how and when patients make their decision to seek care.

2.1. Sample and setting

The study was conducted at Sahlgrenska University Hospital/Östra Hospital, a hospital serving 250 000 inhabitants in Göteborg, Sweden. Patients who sought care for deterioration of CHF were identified either at the ED or within the first 72 h after hospital admission. The sole inclusion criterion was exacerbation of CHF. Dementia, inability to talk and unwillingness to participate in the study were exclusion criteria. Initially, 117 patients were approached of which 6 declined to participate and 23 others were excluded

from data analyses because of discharge diagnoses other than CHF exacerbation. Of the 23 excluded patients, one patient had HF on the basis of hypertension, which was verified only one month before study enrolment. Three patients were not eligible because they had no previously verified diagnosis of CHF. The remaining excluded patients ($n=19$) had primary discharge diagnoses other than CHF, which made them ineligible for data analysis. All presented with symptoms (e.g., dyspnoea) and were classified into primary discharge diagnoses such as pneumonia, unstable angina, myocardial infarction, urinary infection, anaemia, atrial fibrillation, COPD, bronchitis, alveolar hypertension and acute myocarditis. Reasons given by the six patients who declined participation included; feeling too ill to take part in the interview, feeling decrepit and old and concerns of relatives that the patient would be overly burdened by research participation. The diagnosis of CHF was validated according to ESC guidelines [1] and verified from electronic medical records. Discrepancies were reviewed and resolved by a senior cardiologist. The study was conducted between April 2004 and January 2006.

2.2. Procedure

All patients were approached in a consecutive manner and informed orally and in writing about the study. The face-to-face, semi-structured interviews were conducted only after obtaining written consent. The interviews lasted approximately 15–30 min and took place either at the ED or in the ward, where information about aetiology, NYHA class, age and sex was collected. Data about co-morbidities, previous hospitalisations related to HF and HF nurse specialist clinic utilization was obtained from the patient's medical record. The following open-ended questions were used: "Could you please explain why you sought care at the ED today?" "Did you consider seeking care at an earlier time?" "Did you have any idea what your condition was?" The patients' responses were written down verbatim.

2.3. Data analysis

The interview analysis was inspired by Krippendorff's content analysis technique [15]. Krippendorff defined content analysis as, a research technique for making replicable and valid inferences from data to their context. This technique

Table 1
Illustration of the data analysis process using the content analysis technique

Unit of analysis	Code	Category
Feeling horrible. Worried about breathing. Felt like seeking emergency care. Hard to breathe; it is hard to describe. Tired and worried. My wife wanted me to seek care, but I wanted to avoid it. I think it is unnecessary to be stuck with a needle. It hurts and in the end you become a 'pincushion'. I might have managed by seeking care at an earlier time, but no one likes going to the hospital. I want to be healthy and never want to be hospitalised (Patient 18).	Difficulty breathing, feeling bad, anxious, tired Wife's worry Fear of injections, patient wanted to seek care earlier but avoids hospital	Symptom recognition Caregivers/relatives' concerns Reluctance to use the health care system

Table 2
Sociodemographic characteristics of the sample ($n=88$)

Patient characteristics	Number (%)
Age	$N=88$ Mean 77.7 SD 9.5
Sex	
Male	54 (61%)
Female	34 (39%)
NYHA	
II	12 (14%)
III	70 (80%)
IV	6 (6%)
Aetiology	
Ischaemic heart disease	46 (57%)
Valvular	8 (10%)
Cardiomyopathy	6 (7%)
Hypertension	7 (9%)
Other	14 (17%)
Co-morbidity	
Ischaemic heart disease	54 (62%)
Post-myocardial infarction	43 (49%)
Asthma/COPD	18 (21%)
Atrial fibrillation	52 (60%)
Hypertension	36 (41%)
Diabetes	35 (40%)
Number of patients under local heart failure nurse specialist service	19 (22%)
Time in days since last hospitalisation and study enrolment for patients	Range (0–2531)
–	Mean \pm SD
Under HF nurse specialist service	192 \pm 298 (median 113) days
–Patients NOT under HF nurse specialist service	267 \pm 418 (median 91) days
Number of hospitalisations before study enrolment:	Range (0–15)
Patient under HF nurse specialist service	3 \pm 1 (median 3)
Patient NOT under HF specialist service	3 \pm 3 (median 2)

was found to be suitable because it is unobtrusive, accepts unstructured material and is context sensitive and thus able to process symbolic forms.

Statements that were observed in the text were coded into units. Similar coding units were then classified into content categories according to the patients' answers to the open-ended questions. An example of the analysis process is shown in Table 1. One of the co-authors (IE) read one third of the interview text and validated this process by coding independently. Because the narratives were short, disagreements in coding were rare, and when they did occur, they were discussed until consensus was reached. The categories were counted using SPSS version 12.0.1 for windows (SPSS Inc., Chicago, ILL, USA). Descriptive statistics, i.e. frequency, percentages, medians, means and SDs were calculated.

The study was approved by the Regional Ethical Review Board in Göteborg and the investigation conforms to the principles outlined in the Declaration of Helsinki. The questions posed to patients were routine questions that are typically asked in this kind of context and thus were not considered an additional burden on the patients.

3. Results

Of the 88 patients (54 males and 34 females), 12 (13%) were classified as NYHA II, 70 (80%) as NYHA III and 6 (7%) as NYHA IV. Patients ranged in age from 46 to 95 years, with a mean age of 77.7 ± 9.5 years. Sociodemographic data are shown in Table 2.

3.1. Reasons for seeking emergency care

Fifty-eight percent of the patients reported that they had sought emergency care because they had experienced symptoms associated with CHF. A majority of the patients mentioned that they had experienced some symptoms, but they did not necessarily associate them with deterioration of CHF.

3.1.1. Symptoms

The most frequent symptoms patients reported were dyspnoea ($n=76$, 86%) and fatigue ($n=47$, 53%). Clusters of other symptoms ($n=62$, 70%), including dizziness/syncope, cough and swollenness of the body ($n=38$, 43%) were also reported. Thirty-three (38%) patients reported pain. The most prevalent symptom clusters are illustrated in Fig. 1. The mean number of reported symptoms was 3.0 ± 1.5 (range 0–6). Patients responded to more than one cluster of symptoms and therefore the number of responses is greater than the number of patients. Smaller groups comprising very few symptoms were subsequently collapsed into one cluster.

The dominating reason for seeking acute care was shortness of breath (e.g., while lying down or when speaking). These breathing difficulties had lasted from one night up to

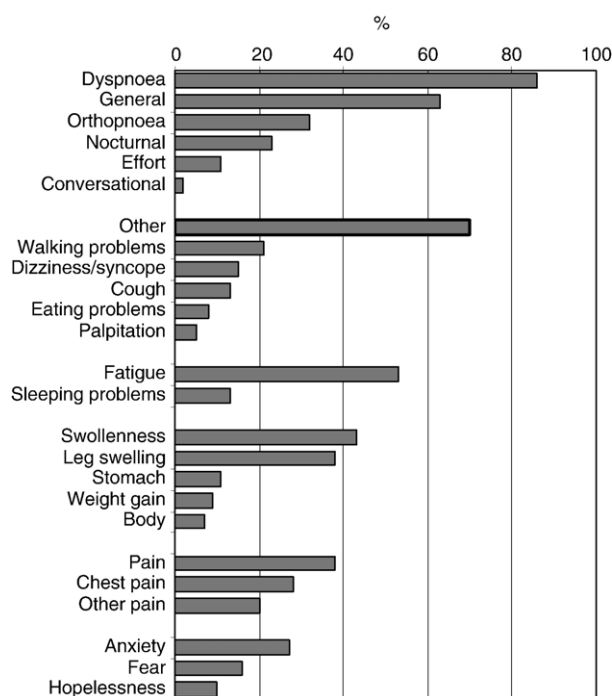


Fig. 1. The most prevalent symptom clusters.

two years. The patients often described breathlessness as difficulty to fill the lungs with air; as tight, heavy and effortful breathing and as suffocating sensations. Patients metaphorically expressed their breathing problems in the following terms: “breathing was sturdy and it felt like my lungs were going to explode”, “blowing like a whale”, “gasping for air”, “puffing like bellows”, “words were stuck in my mouth” and “a heavy mist was lying over my chest”. Some patients reported feeling restless, shaky and fearful of losing control over their breathing.

Other symptoms included palpitation, hot flushes, diaphoresis, dry mouth, lightheadedness or dizziness, syncope, cough, lip cyanosis and freezing. The patients also reported vertigo, fainting and dizziness, which they likened to rolling down blinds. Eating problems were associated with feelings of nausea, vomiting and diarrhoea as well as poor appetite combined with feelings of tightness of the stomach. Walking problems were related to dizziness, swollen legs, shortness of breath, feebleness, sore stomach, chest pains, shakiness, irritating feelings while walking and problems with balance.

The patients described fatigue as tiredness, feebleness, lack of stamina, infirmity, extreme tiredness, lack of strength, hard to sit up, unable to carry on with daily activities and as a desire to sleep all day and night. Sleeping problems were related to orthopnea, nocturnal dyspnoea, fear of not getting air, anxiety and nervousness about not being able to sleep.

Swollenness was experienced in the stomach, legs and body. It was also associated with weight gain, which was described as water retention in the body, as well as stiffness of the legs, imbalance when walking and legs feeling as “heavy as logs”. Eight (9%) patients specifically mentioned weight gain.

The pain cluster included chest pain, described as pain occurring during deep breathing, heaviness in the chest, epigastric pain, a feeling of tightness or pressure in the chest, thorax or epigastrium during conversation and in the lungs during coughing. Bodily pain included pain in the neck area, arms and explosive pain in the legs, as well as leg cramps and muscle stiffness of the body, back and stomach.

Anxiety included thoughts about death and fear of suffocating and other problems when trying to lie down in the evening. The patients were also fearful of feelings of shortness of breath and chest pains. Many of the patients felt depressed and confused.

3.1.2. Relatives and Caregivers' concern for the patient

Thirteen (15%) patients were sent to hospital by their spouses, children or home carers. A few of the patients admitted that although they had dreaded evenings because of their breathing difficulties, they never wanted to trouble their relatives or seek care. Relatives insisted that the patients seek hospital care when they noticed that something was seriously wrong, despite strong denials from the patients.

Twenty-four (27%) of the patients were referred to the ED from outpatient clinics. These patients often felt that their symptoms did not warrant emergency care, “...he [the attend-

ing physician] wanted to send me in, although I never felt anything wrong. But the doctor insisted”. Many of the patients had experienced symptoms for more than 10 days without attributing them to their worsening condition. Although some patients could barely talk because of shortness of breath, they still intended to wait until their regularly scheduled appointment with their GP, or HF outpatient clinic or other specialist clinic.

3.2. Reasons for not seeking treatment earlier

Fifty (57%) of the patients put off seeking care because they did not think that their symptoms warranted treatment; instead, they attributed their symptoms to, for example, constipation, high or low blood pressure or simply a consequence of overwork and stress.

Eight (9%) of the patients were uncertain whether they needed care at an earlier time, mainly because they had periodically felt feeble over a long period. Several patients attributed their symptoms to old age or recent hospitalisation. Thirty (34%) patients reported that although they had wanted to seek care earlier, they had simply not done so. Patient's reasons for not seeking care earlier are summarised below:

3.2.1. A waiting strategy

Sixty-two (71%) patients explained that they waited to seek care because (1) the problem was not serious and would go away, (2) they were unsuccessful in their attempts to make an appointment at the primary health care centre and therefore decided to wait for their scheduled follow-up visit or (3) they had no one to accompany them to the ED.

3.2.2. Reluctance to use the health care system

Nine (10%) patients reported that they avoided hospital care because of previous unpleasant experiences with ED care. Examples of such experiences were: “long waiting hours”, “don't want to be a pincushion” and “fear of being rejected by ED personnel”.

3.2.3. Feelings of hopelessness

Ten (11%) patients postponed seeking medical care because they felt that their situation was hopeless: “it's no use ... there's still no cure for me”.

3.3. Reasons for a changing state of health

Sixty-five (74%) patients claimed that they knew the factors responsible for their deterioration, whereas 23 (26%) were uncertain.

3.3.1. Heart–lung related

Of all patients, 44 (50%) thought that their symptoms were associated with problems of the heart or lungs (e.g., valve leakage, bad lungs, atrial fibrillation, heart attack, angina pectoris, water in the lungs, walking problems associated with a failing heart, side effects of medication, asthma, COPD and

impaired heart capacity). One of the patients reported that HF was something that comes and goes. Only 4 (4%) patients directly related their symptoms to deteriorating CHF.

3.3.2. Uncertainty

Forty-four (50%) of the patients that claimed they knew why they were deteriorated had difficulties explaining reasons for their current decline in health. A few of these patients offered several proposals to account for their illness: “*the water in my lungs is because of poor pumping capacity and not because of heart failure*” and “*I have heart and lung problems, but not heart failure*”. Some of the patients linked their symptoms to external factors such as new medicines, hot weather, a draft from an open balcony and strong odours.

4. Discussion

The present data reveal that patients with CHF seek emergency care mainly because of their symptoms. Fifty-eight percent of the patients initiated their visit to the emergency care facility for one or more symptoms, whereas 42% were brought in by relatives or referred by caregivers. Decisions about whether to seek care were affected by a variety of factors, as well as by varying beliefs about the patients’ exacerbating condition. From a clinical perspective, the most important findings in this study were as follows: (a) despite considerable advances in information provision and attention to self-care education, about half of the patients had no idea what had caused their deterioration; (b) only 4% of the patients related their current deterioration to heart failure; and (c) 34% of the patients reported that they had wanted to seek care earlier, but for various reasons did not.

The present findings show that most of the patients sought acute care for symptoms such as dyspnoea and fatigue. Chest pain, or pressure or heaviness in the chest and dyspnoea are common symptoms in ischaemic heart disease (IHD). The most common aetiology underlying CHF in this cohort was IHD, which might explain why the patients reported chest pains when they sought acute care. Patients also reported pain in various parts of the body. Pain in the neck, back and arm regions may be related to referred pain from myocardial ischaemia, but symptoms such as headache and bodily pain are difficult to explain. Most of the patients in the current study were in NYHA class III and IV, indicating a serious affliction of HF. It is noteworthy that the patients reported a total of 45 symptoms. In a recent study on symptom prevalence in patients recruited from an HF outpatient clinic, 32 symptoms were described (mean 15.1 ± 8.0) during the previous seven days [4]. We found the mean number of symptoms in our study to be 3.0 ± 1.5 . This discrepancy may be due to difficulties patients have in verbalising specific symptoms in the acute situation.

Confirming earlier findings [9,16–19], the descriptors our patients used to express their breathing difficulties were suffocating, tight, heavy and requiring effort. The emotional effect of breathlessness was expressed as, “words got stuck in

my throat”, “feel like I’ll explode”, “heavy mist lying over my chest”, “lost control over air”, “shaky and distressing”, “sturdy breathing” and “puffing like bellows”. These descriptors, which provide an important contribution in understanding and communicating with patients seeking care at an ED, are quite distinct from those used by health care professionals in everyday clinical practice. Consistent with Edmonds and co-workers [20], we found that many patients with CHF describe breathlessness as a chronic symptom that they regard as almost a normal aspect of their lives.

Seeking health care is influenced by multiple factors, many of which have a significant impact on clinical outcome. Numerous patients did not initially wish to bother significant others, and out of concern for their relatives avoided seeking help if their symptoms occurred at night. Our study confirms research demonstrating that family members play an important role in the patient’s life by helping to recognise deteriorating health status, assessing the severity of the illness and evaluating and acting on the need for urgent help [14,21]. Although many of our patients had adult children, they did not want to inconvenience them or ask for their help, which corroborates a similar finding by Aldered and co-workers [22]. Moreover, our data are in line with the findings of Mårtensson et al. [23] who reported that women with CHF felt that they were a heavy burden on others. A review by Molloy et al. [24] identified the high level of distress and poor mental health in the family members of CHF patients. However, if family members could be involved in the care of CHF patients, health care costs might be reduced [24] and well-being increased.

Current health status and previous illness have a direct or indirect impact on the patient’s perceptions of a changing condition [14]. Jurgens [25], for instance, found that previous HF admission was associated with shorter delays for dyspnoea on exertion. Conversely, 50% of the patients in the present study were uncertain as to what their deterioration implied, even though most of them had been hospitalised earlier or treated for exacerbation of the same condition. One explanation to account for this finding is that cognitive dysfunction or memory loss may have affected their ability to recall earlier intervention strategies or that the pedagogical strategies used by caregivers when informing the patients about their condition were insufficient [26]. It has previously been reported that most patients present symptoms to the ED that they do not recognise as deteriorating heart failure until the symptoms become overwhelming and out of control [6,27,28]. We found no significant difference between those patients who were treated in an HF outpatient clinic service and those patients who were not treated in such a clinic regarding the number of days from the time the patients were hospitalised and the start of the study; however, this may be the result of the small sample size. Perception of symptoms refers to whether an individual notices a change from the way he or she usually feels [14]. Many of the elderly with CHF are afflicted with other co-morbidities that produce similar experiences. Studies on delay in seeking care for heart disease have indicated that symptom distress does not uniformly

predict timely care seeking [7,29]. Moreover, elderly patients with CHF may lack the confidence necessary to identify slow, emerging and overlapping symptoms common in multiple illnesses [30]. More research is evidently needed to clarify patients' difficulties in symptom recognition in cases of an overlapping syndrome of disorders.

5. Reliability

The patients' statements were sometimes ambiguous and thus difficult to code. Because data were obtained from individual narratives, they may have multiple meanings. Therefore, to increase reproducibility (inter-coder reliability) two coders were used to confirm a consensus on codes and categories [15]. This process provides evidence for a shared rather than individual understanding of the data. Credibility was established by continued and repeated reflection on the patients' responses in relation to the obtained findings.

6. Study limitations

A limitation of the study was that patients were not asked about their social background or about the source or amount of heart failure information they had received (i.e. from participation in heart failure education programmes, from materials distributed by HF clinics or from ward personnel during previous hospitalisations).

7. Conclusion

Patients with CHF exhibited difficulties in recognising their symptoms, even during the period when their condition worsened. Earlier symptom identification and response may reduce the number of re-hospitalisations and duration of hospital stay. Consequently, it is important to identify patient needs and provide individualised information adapted to those needs. Because relatives play an important role in identifying changes in the patients' condition, they should be encouraged to participate in such educational efforts. To promote the development of care patients should be provided with details of contact personnel or emergency telephone numbers to facilitate quick access in acute situations.

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