911 calls for emergency medical services in heart failure: A descriptive qualitative study

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Abstract

Background: Heart failure (HF) is a common condition leading to activation of emergency medical services (EMS).

Objective: To describe reasons given by persons with HF, family members, or other caregivers for requesting EMS activation during 911 calls.

Methods: In this descriptive qualitative study, a content analysis was performed on transcribed audio files of 383 EMS requests involving 383 persons with HF in the community.

Results: One hundred forty-seven (38.4%) calls were placed by family members, 75 (19.6%) by the patients, 56 (14.6%) by healthcare workers or personnel from living facilities, and the rest of the calls (27.4%) were placed by others (e.g., friends, neighbors, officers). Three broad categories of symptoms, signs, and events were identified as the reasons for an EMS request. Frequently reported symptoms were breathing issues (55.4%), chest pain (18.3%), and other pain (e.g., head, extremities) (16.7%). Signs included decreased consciousness (15.4%), swelling (5.7%), and bleeding (5.0%). The reported events involved falls (8.1%), heart attack (6.3%), hypoxic episodes (6.0%), stroke (5.2%) and post-hospital discharge complications (4.7%). In most calls (74.9%) multiple reasons were reported and a combination of symptoms, signs, and events. HF diagnosis was mentioned in fewer than 10% of the calls.

Conclusions: Overall, symptoms and signs of HF exacerbation were common reasons to activate 911 calls, with falls frequently reported. Under the duress of the emergent situations surrounding the 911 call, callers rarely mentioned the existence of HF.

Interventions are needed to guide patients with HF and their family members to better respond to emergency situations.

Introduction

Heart failure (HF) is a tremendous burden on public health affecting 6.2 million adults in the United States.[1] The healthcare cost for HF continues to rise and is estimated to increase to $69.8 billion by 2030 from $30.7 billion (2010 dollars).[1] Heart disease including HF is the most costly condition greater than cancer or stroke with frequent hospitalizations.[1] Episodes of acute decompensation of HF often lead to hospital readmissions and mortality. In fact, 83% of patients with HF in Olmsted County from 1987 through 2007 were hospitalized at least once and 43% hospitalized at least 4 times after being diagnosed with HF.[1,2] After hospitalization, case fatality rates are high for these patients. In one study the fatality rates for HF were 10.4% at 30 days, 22.0% at 1 year, and 42.3% at 5 years after first HF hospitalization.[3]

Many hospitalizations for HF are made via the emergency department,[4,5] of which patients with HF are frequent users.[6] Of the approximately 22 million emergency medical services (EMS) activations reported in the United States in 2018,[7] a large number involves patients with HF. From 2006 to 2010 there was an average of 958,167 visits to emergency department made by patients with acute decompensated HF.[8] One study showed that 62% of all EMS patients had a history of chronic HF.[9]

In the Acute Study of Clinical Effectiveness of Nesiritide and Decompensated Heart Failure (ASCEND-HF) trial in Canada (N=1,068), 27% of the clinic patients arrived at hospital by ambulance and 52% of the registry patients arrived by ambulance.[10] EMS use was associated with higher mortality among patients with acute decompensated HF. Specifically, HF patients who were transported to the emergency department by

EMS had a two-fold increased risk of 30-day mortality compared with the patients who presented to the emergency department on their own.[10]

There is limited data regarding experiences of patients with HF and their family members resulting in 911 calls during the prehospital phase of care. The prehospital phase is a critical window for treatment to improve clinical outcomes.[11] However, there is a lack of data on the health issues (i.e., symptoms, signs, and events) that trigger EMS activation among patients with HF in the prehospital phase.[12] In the study of this analysis using EMS electronic health records (N=6,582 community-dwelling patients with HF), there were 28 chief complaints reported during EMS transports and the frequent chief complaints were respiratory issues, feeling sick, and chest pain.[12] Although, the study provided new insights on chief complaints and treatments received during the transports, our understanding of the emergency experiences among patients with HF is still limited because the analysis was around the chief complaints and less focused on other presenting conditions. If such data were available, they could reveal more thorough understanding of the emergency experiences that could guide the development of interventions to prevent the triggers for EMS activation. Furthermore, understanding communication during emergency situations may help to identify areas of future research, clinical improvements or new interventions provided at clinics, hospitals, and communities. Thus, in an effort to address the need, we conducted a study to identify and describe reasons given by persons with HF, family members, or other caregivers for requesting EMS activation during 911 calls.

Methods

This study was approved by the Institutional Review Board at Indiana University.

Design

A qualitative description approach was used as described by Sandelowski.[13,14] This approach is used when researchers seek a low-interpretive summary of narrative data. Rather than providing an abstract or conceptual rendering of data as in common to other qualitative methods, qualitative description provides an end product that is a straightforward and comprehensive presentation of information contained in the narratives. Data is re-presented in a way that remains close to the everyday words of the participants. Qualitative content analysis is often used in qualitative description studies to organize informational content into categories and to count participant responses that fall into each category. These counts reflect patterns in the surface words of the participants. Because our aim was to describe reasons given by persons requesting EMS activation, a qualitative descriptive approach was deemed to be the most appropriate and providing the surface words used by the callers were critical.

Data Source

The data were retrieved as part of a parent study conducted to characterize prehospital clinical status of adults with reported HF and evaluate predictors of EMS transports to an acute care hospital.[12] Data were retrieved from a large urban EMS system in the Midwest recorded between 2009 and 2017. The database and the methods used for retrieving the data are described in more details elsewhere.[12] Inclusion criteria for the data retrieval in the parent study were: (1) having HF as a medical condition during the EMS transports by the emergency medical responders; (2) adult (age 21 years and older); and (3) transported to one of the three acute-care hospitals in the city. There was a total of 16,905 EMS transports for 6,582 adults with

HF between 2009 and 2017. Among the 6,582 index transports (their first transport during the period), 400 were randomly selected to retrieve the 911 calls for this study.

The 400 digitally recorded audio files of 911 calls were professionally transcribed verbatim into document files using a transcription service with a secure server. The transcript files were analyzed by study team members. Identifiable information was redacted from the audio files (i.e., names and addresses) during transcription. Seventeen calls were excluded from analysis because of lack of information (e.g., missing demographic data or poor quality of the audio file). The final sample included 383 individual calls for 383 patients. The characteristics of the 383 patients with HF are presented in Table 1.

Data Analysis

Descriptive statistics (e.g., frequency, mean, and standard deviation) were used to describe the sample. This analysis was completed with IBM SPSS Statistics software (Version 26; Armonk, NY).

Content analysis, as described by Miles, Huberman, and Saldaña,[15] was used to describe reasons given for requesting EMS activation. The data were analyzed by three research team members who had expertise in HF and cardiovascular nursing. These team members had experience in conducting qualitative research. In addition, the team was advised by a senior nurse researcher with extensive experience in qualitative description. The data analysis occurred in six steps. First, the first two authors read the transcripts to gain a familiarity with the overall tenor of the calls (e.g., urgent) and the amount and type of information presented as well as to note if the diagnosis of HF was mentioned. Memos were kept for the initial readings of the transcripts and summarized.

Second, the first two authors extracted segments of text (referred to as text units) from the transcripts that reflected any reason callers gave for the EMS call. Text units, which served as the unit of analysis, were typically a few words or phrases but could be complete sentences. Each text unit was given a brief label with a code that reflected the essence of the text unit. Third, the team met to discuss the codes, through discussion and consensus, and grouped them into categories. Because the analysis was at a low-level of interpretation and focused on the surface words of the callers, disagreements about the categories or placements of codes in categories were few and easily resolved through team dialogue and reexamination of the data. Fourth, the number of callers whose codes contributed to each category were counted. The counts represented that total number of persons with HF, family members, or other caregivers who the same reason for the EMS call. Fifth, a narrative description of each category was prepared by the first author. Lastly, each narrative description was validated by the other research team member.

Results

General Description of the EMS Calls

The 911 calls lasted between 30 seconds and 7 minutes and 21 seconds. Of the 383 calls, 147 (38.4%) were placed by family members, 75 (19.6%) by the person with HF, 56 (14.6%) by healthcare workers or personnel from living facilities (e.g., skilled nursing facility, nursing home). The rest of the calls (n = 105, 27.4%) were placed by others including friends, medical alarm company, security officers, neighbors, and bystanders.

Memos of the initial readings of the transcripts revealed that the tenor of the calls ranged from non-urgent to highly urgent. For example, whereas some callers seemed to relay information in a matter-of-fact manner, some were highly distraught. A few callers (n = 5) were instructed to initiate cardiopulmonary resuscitation for the person with HF. Some callers provided a good deal of information about the preexisting and current health concerns of the person with HF, whereas other callers gave very few details about the person's overall health. In some cases, the dispatcher had to probe the caller for information needed to activate the EMS, whereas other dispatchers asked pointed questions to focus the callers.

Thirty-two callers (8.4%) indicated that the person needing EMS transportation had a diagnosis of HF. Of these 32 calls, 18 were placed by family members, six by the patients themselves, five by health/living facility staff, and three by others. For the remaining 351 calls (91.6%), the HF diagnosis was not identified until the paramedics obtained the information in the ambulance during transport.

Reasons for the EMS Calls

The reasons given by callers for requesting EMS activation were divided into three broad categories: symptoms (subjective reports of health problems that a person experiences), signs (objective reports of health problems that can be observed by someone else), and events (specific accidents or episodes). In most calls, (n = 287, 74.9%) multiple reasons were reported and a combination of symptoms, signs, and events were mentioned. The symptoms, signs, and events are described below along with representative quotes from the transcripts. These findings are also presented in Table 2.

Symptoms

In 326 calls (85.1%), the callers reported one or more symptoms prompting the request for EMS activation. The symptoms reported, in order of frequency, were breathing problems, chest pain, pain in other areas of the body, and other symptoms.

In 212 calls (55.4%), breathing problems were mentioned as a reason for the EMS activation request. The callers described breathing problems in multiple ways. They indicated that the persons with HF "couldn't breathe," were "short of breath," were "gasping for air," or had a "hard time breathing." One person with HF stated, "*I can't breathe. I'm having a lot of trouble breathing. I can't get up. I can't walk two feet.*" Although breathing problems were most frequently raised by callers, they rarely mentioned breathing problems at the beginning of the calls and often acknowledged them only with prompted.

In 70 calls (18.3%), chest pain was mentioned as a reason for the EMS activation request. The callers described chest pain in multiple ways. They remarked that the persons with HF had chest "discomfort" or "tightness" or that their heart was "hurting." In some instances, they stressed that the chest pain was "getting worse." One family member stated, "*My daughter is suffering from congestion heart failure and she's having kind of a chest pain*." Often, chest pain was the first symptom reported in the call and other symptoms, such as breathing problems, were mentioned later.

In 64 calls (16.7%), other types of pain were mentioned as a reason for the EMS activation request. Callers indicated that the persons with HF were having pain in their head, abdomen, shoulders and arms, back, hips, and legs. In some instances, callers revealed that the person with HF could not clearly describe the pain and instead just

indicated that it “hurts all over” or they were having “a lot of pain.” A home health aide stated, “*My client, her stomach is hurting her real bad. She’s throwing up*.”

In 49 calls (12.8%), a variety of other symptoms were mentioned in the absence of the three frequent symptoms as the reason for the EMS call. Some callers reported gastrointestinal symptoms, remarking that the person with HF was “sick to their stomach,” vomiting, or nauseous. Others indicated that the person with HF was having mobility difficulties and could not “move” or “get up.” Yet others said that the person with HF “couldn’t talk,” had difficulty speaking, or had slurred speech. Some callers reported the person with HF had changes in sensation such as numbness, tingling, visual disturbance, hot and cold flashes, dizziness, or shakiness; had vague complaints such as “feeling bad” or “getting sick;” or were anxious, upset, or agitated. One family member reported only that “*Mother is sick*.”

Signs

In 165 calls (43.1%), the caller reported one or more signs prompting the request for EMS activation. The signs reported, in order of frequency, were decreased level of consciousness, swelling, bleeding or signs of bleeding, and other health issues observed by the caller.

In 59 calls (15.4%), decreased level of consciousness was mentioned as the reason for the activation of the EMS call. The callers described decreased alertness, confusion, and unconsciousness. Some indicated that the person with HF “can barely stay awake” or they are “in and out of consciousness.” Others described the person with HF as could not respond to the caller or “doesn’t know where he/she’s at or nothing.” A nurse at an assisted living facility said, “*She’s [person with HF] is just having decreased*

cognition, increased lethargy. Her face is really puffy. Something's not right. She's a full code. The on-call physician wants her to be evaluated."

In 22 calls (5.7%), swelling was mentioned as a reason for the activation of the EMS call. Swelling was often reported in conjunction with breathing issues and pain. Callers who reported swelling mentioned swollen lower extremities, remarking that the persons' "feet are swollen up real big," and their "legs are swollen and [they] can't walk." Some callers mentioned specifically that the "fluid built upon his (the patient's) knee." Other callers did not report the swelling linked to specific areas of the body. For example, one caller said the person with HF was "swollen all over" or "got fluid on her body." One person with HF called reported "*I've on a breathing machine. Every time I move, any time I walk, I can't breathe. I'm on one right now, and I'm still having difficult problems. My feet are swollen up. I mean, I am chopped up right now*."

In 19 (5.0%) calls, bleeding or signs of bleeding (e.g., bruises, hematuria) were mentioned as the reason for the activation of the EMS call. In the 911 calls the body parts associated with bleeding or bleeding signs were diverse, including head, abdomen, rectum, extremities (legs, toe, fistula site), and vagina. Some callers described the patient as having "bruises everywhere," "peeing blood," or having "tarry stools." The origins of bleeding or signs of bleeding were less likely associated with HF, but more likely associated with accidents (e.g., a fall, motor vehicle accident, and surgeries) or other health conditions. The callers reported diverse intensity of bleeding from having bruises to active and massive bleeding such as "throwing up lots of blood" or "bleeding from rectum and won't stop."

In 71 calls (18.5%), a variety of other signs were mentioned in the absence of the frequent signs as the reason for the EMS activation. Callers reported injuries such as concussion, broken bones or lacerations. One person with HF said, "*Please hurry… I cut the side of my head. I had a fall outside*." Callers also described changes in the vital signs. One family member said "*My wife's blood pressure has dropped… 67 over 35. I need to go to [the hospital name] now*." A healthcare center staff member said "*respirations are between 30 and 40 with weakness.*" Callers also reported decreased level of oxygen saturation. Some provided specific details such as the "[oxygen saturation is] *"in the '60's while receiving an oxygen therapy," "95% with room air,"* or *"dropping between 75 and 93 percent."* Callers noted changes in the skin color by stating that the skin of the person with HF was "very pale" or the person's 'lips are starting to turn blue.' Callers reported sweatiness and/or clamminess by remarking the person with HF was "sweaty all over" "sweating profusely" or "very clammy." Some callers remarked that the person with HF had "collapsed" suggesting syncope.

Events

In 163 (42.6%) calls, the callers reported events prompting the request for EMS activation. The events were often reported to provide the background of the symptoms and signs that the persons with HF were experiencing. The events reported, in order of frequency, were falls, heart attacks, hypoxic episodes, strokes, and other health-related episodes or accidents.

In 31 calls (8.1%), falls were mentioned as the reason for the activation of the EMS call. Most of these calls were placed by family members and bystanders. The calls revealed that the falls had occurred at the home of the person with HF when they were

getting out of bed or off the toilet or when they were on their porch, at the nursing home where they were staying, or in other spaces such as the sidewalk or a neighbor's home. Callers reported injuries caused by the fall such as *"cut(ting) side of my head*," "*bleeding in head*," or having "*left eye shut due to swelling*." A family member said, "*She [her grandmother] was just was trying to get to the bed, and she fell. Her legs got weak."* Callers indicated that a few of the falls were associated with other health conditions such as seizure or stroke.

In 24 calls (6.3%), possible heart attacks were mentioned as the reason for the activation of the EMS call. Callers typically gave this information at the beginning of the call. One person with HF stated, "*I think I'm having a heart attack. I can't breathe.*" A family member reported "*I think my wife just had a heart attack or is having one.*" One caller was uncertain if the person with HF was having a heart attack or a stroke.

In 23 calls (6.0%), hypoxic episodes or episodes related to chronic hypoxic status requiring oxygen therapy were mentioned as the reason for the activation of the EMS call. Callers described the patients who had shortness of breath, breathing difficulty, or low oxygen saturation levels. One family member said "*Yes she [her sister] is breathing but I believe her oxygen level, she's on oxygen, I believe is probably pretty low*." A reported "…*She [grandmother] said even on her oxygen, she's still having a hard time breathing. …You've got to come pick her up*."

In 20 calls (5.2%), a possible stroke as mentioned as a reason for EMS activation. Some callers reported indications of a stroke such as the person with HF had "left-sided weakness" or could "hardly speak or see" and others mentioned a stroke at the onset of the call. One family member stated, "*I think my mother-in-law may have*

probably had, possibly another stroke." One medical alarm service staff said, "*I've got a client who pushed her medical button and she indicates she's having a stroke*."

In 18 calls (4.7%), health issues after a recent hospital discharge were mentioned as the reasons for EMS activation. These health issues occurred from a few hours to a few days post-hospital discharge. The hospitalizations had been for HF as well as other health problems such hip surgery, fistula surgery, and abdominal surgery. Callers reported that the person with HF "*couldn't breathe*," was "*full of blood from (the) nose*," and was having chest pain. Some callers had contacted the hospital where the person with HF had been treated first and then were advised to call 911. One family member said, "*She [my mother] recently got out of the hospital where she had been in respiratory failure and heart failure…She said her chest is hurting and I called the nurse and the nurse said for me to have her come to the ER.*" One person with HF stated he had followed post-operation instructions when he noticed "trouble getting air in" and was getting weaker with a headache.

In 53 calls (13.8%), a variety of other events were mentioned in the absence of the frequent events as the reason for the activation of 911 calls. Some callers reported events caused by medication problems such as the persons with HF had not had taken their medications or was 'choking' on a pill. Some callers were reported diabetic episodes, some of which were serious. For example, a medical company staff member reported "*The medical button was pressed…It looks like she's going into a diabetic coma*." Other callers reported the person with HF was 'having a seizure,' 'asthma attack,' the cold or the flu. A family member reported, "*She [grandmother] has a real bad cold, a lot of inflammation, and … She was coughing and leaning over, and she lost*

consciousness." A caller reported an event in which persons with HF in hospice had high levels of ammonia and confusion. Other callers reported assaults and pedestrian accidents.

Discussion

This qualitative descriptive study identifies and describes the reasons given by persons with HF, family members, or other caregivers for requesting EMS transports for 383 persons with HF. Audio files of the 911 calls were analyzed using qualitative content analysis and the reasons were divided in the broad categories of symptoms, signs, and events.

As would be expected, reasons for calling 911 were often related to cardiac-related health conditions. Breathing problems, chest pain, and other body pain (symptoms), decreased level of consciousness, swelling in lower extremities, and sweatiness (signs), and possible heart attacks (events) are consistent with new cardiac events (e.g., acute coronary syndrome) or acute exacerbations of HF.[12,16-18] Helping the patients and family members to recognize these health conditions (symptoms, signs, and risks of the events) early in their occurrence may prevent the frightening experiences as they become more severe.

The results in the current study resonate with the results of the parent study which examined chief complaints in persons with HF assessed during EMS transports (N=16,905) and recorded in the EMS electronic health records.[12] In the parent study, respiratory problems were the most frequent chief complaint (26.6%).[12] Similarly, in the study reported here, breathing problems were the most frequent symptom mentioned during the 911 calls (55.4%). The difference suggests that breathing problems are

particularly common among persons with HF who requested for EMS activation. Chest pain was frequently reported in both the parent and the current studies at similar rates (17% in parent study[12] and 18.3% respectively).

The reasons for requesting EMS transport in 911 calls were not limited to cardiac-related health conditions. For example, callers reported symptoms of stroke or stroke events, which is not surprising as patients with HF have a higher risk for stroke.[19] National guidelines on how to cope with stroke symptoms are based on the F.A.S.T. acronym (Face drooping, Arm weakness, Speech difficulty, Time to call 911)[20-22] and provide action item with observable manifestations of stroke. Similarly, there is a guideline for heart attack and cardiac arrest published by American Heart Association to improve recognition of the events. However, in the guideline, the manifestations of heart attack are vague (i.e., chest discomfort, discomfort in other areas of the upper body, shortness of breath, and other signs).[23] Moreover, unlike stroke national guidelines, there are no action items, such as when to call 911. Although the lack of action items can be derived from the different nature between the health events, more effort is needed for greater clarity and actionable guidance for patients and families to better respond to emergency situations.

Among the non-cardiac reasons, falls were the most frequent event prompting EMS activation among patients with HF in this study. The patients in this study were older adults with chronic HF, both of which are associated with higher risk of falls. Falls occurred both at the patients' residence (e.g., house, living facility) and public places. Some falls resulted in bleeding and decreased level of consciousness. In previous studies patients with HF were shown to be slower in gait and more likely to have falls.[24-

[26] Whether the falls in these studies were serious enough to activate EMS transports, however, is unknown. The fact that falls are the most frequent event leading to EMS transport is important to recognize. Injuries from these events lead to higher healthcare cost,[27] but are preventable.

Post-hospital discharge concerns (both cardiac and non-cardiac such as hip and abdominal surgeries) were noted as a frequent reason resulting in EMS activation. This post-discharge period of time was previously identified as a vulnerable phase of HF and associated with increased risk of readmissions and mortality.[28] Post-discharge stage emergencies may be challenging to prevent, but can be managed more appropriately by identifying high risk patients and preparing well-crafted hospital discharge plans. For example, one patient in our study followed the post-discharge instruction for possible emergencies, while four patients contacted the hospital first and then were re-directed to 911.

Some of the callers did not clearly report if the condition was associated with cardiac or non-cardiac origin, for example, ‘feeling sick’ in general and ‘hurt all over.’ This is a consistent but less frequent finding in current study compared with our previous study where ‘feeling sick’ was the second most frequent chief complaint recorded in the EMS electronic health records for patients with HF (23% of the 16,905 transports).[12] These unclear reports of their conditions may be contributed by their decrease cognitive function due to lowered cerebral blood flow in HF, which interfere the symptom recognition and interpretation.[29] The relationships between the failure of recognizing and interpreting the health conditions and health outcomes (e.g., hospitalizations, mortality) may need to be investigated in future studies.

As the audio files were analyzed, one impression that surfaced was the frightening situations with which the patients with HF and family members had to cope during emergencies. It is known that patients and their family members experience stress when managing HF symptoms, but the use of these digital recordings collected at the point of emergency 911 care provided a more personal and detailed window into just how stressful and frightening the situations were. For example, patients were experiencing crushing chest pain, caregivers were being instructed to initiate CPR, and severe hemorrhaging of blood occurred that were reasons for EMS transport. The influence of experiencing these crisis situations on the patients and their caregivers has not been a major focus of research. Future studies are needed to better understand how patients and family members can be prepared for emergency situations and how nurses and physicians can assist them after these events. Similarities and differences of the experiences between the callers (e.g., patients with HF vs. family members) may need to be investigated. Novel interventions may need to be tested and ultimately integrated into existing plans of care for patients and family caregivers to manage stress and fear and improve survival and health-related quality of life. One exemplar would be providing CPR training with social support to both the patients and their family members which shown to lead to better psychosocial and emotional adjustment.[30]

Another surprising impression was the lack of communication regarding the pre-existing HF diagnosis. Less than 10% of the callers in this study disclosed that the patients had a HF diagnosis when they requested EMS transportation. Given that over half of the patients experienced breathing issues, this is an unexpected pattern to be identified. This lack of communication in 911 calls about their existing serious chronic

condition may be originated from the emergency situation that the callers tend to attend the immediate needs or manifestations of the changes in the patients' conditions rather than thinking of the impact of existing health issues. The result indicates that important clinical information is not acknowledged by 911 callers and the need was found to improve communications between the patients, families or significant others with the EMS system.

This study is unique in its analysis of 911 calls that activated EMS transports. Previous studies used data from emergency departments that include both EMS transported patients as well as 'walk-in (self-presented)' patients.[5,10] Although the investigators found that the patients with HF who presented via EMS had worse outcomes,[10] those studies were almost exclusively on acute HF.[5,10] This current study aimed to fill the gap and provides important knowledge by understanding the reasons prompting EMS transports to emergency departments more holistically. In addition, using 911 calls provided the opportunity to capture the emergency experiences of requesting EMS activation for patients with HF precisely at the moment and thus provides more complete data in addition to patient surveys, which can be biased because they involve recall of the event. Using 911 calls has benefits over using electronic medical data at emergency departments that may focus on chief complaints rather than accurately and holistically capturing the emergency experiences of the patients and their family members.

However, this study does have several limitations. First, no detailed information was available about HF diagnostic test results and severity because the EMS data storage system did not include it. The patients in this study are living in the community,

and the clinical diagnostic data were part of the EMS data storage system. Second, the 911 calls were short in terms of length due to the nature of emergency situation. It may be that not all experiences were captured in the calls. In order to deepen the understanding of the emergency experiences and increase trustworthiness of the findings, future studies may utilize interviewing the patients with HF and family members. Third, the EMS data were retrieved from one metropolitan area in the Midwest and only included calls that resulted in EMS transportation successfully which would limit generalizability. Last, severity of the health conditions in each 911 call was not analyzed. Although all of the 911 calls in this study activated EMS transports, distinguishing true emergency situations may need to be evaluated from the urgent situations requiring medical attention but not do not EMS transports.

Conclusions

The common reasons 911 callers requested EMS activation were consistent with exacerbation of HF symptoms and signs, with the exception of events, such as falls. Recognizing alternations in mobility and exacerbations of HF symptoms should be included in discharge planning and assessment for community dwelling people with HF. Education and tools are needed for people with HF and their families to promote communication about chronic diseases such as HF. Creating guidelines for 911 calls for people with HF and their families including the report of HF presence at the beginning of their 911 calls may help the communication of the emergency.

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Table 1. Demographic and clinical characteristics (N = 383)

Characteristics	M ± SD or N (%)
Age, years	64.92 ± 14.65 (range: 22 ~ 97)
Gender	
Female	231 (60.3)
Race	
Black	226 (59.0)
White	156 (40.7)
Other	1 (0.3)
Ethnicity	
Hispanic	1 (0.3)
Caller	
Patient self	75 (19.6)
Family members	147 (38.4)
Children/Grand children	97 (25.3)
Spouses	27 (7.0)
Parents	3 (0.8)
Relatives	20 (5.2)
Healthcare workers (including telehealth)	31 (8.1)
Living facility staff (e.g., skilled nursing facility, nursing home, assisted living)	25 (6.5)
Medical alarm company	6 (1.6)
Home care staff/personnel	5 (1.3)
Friends/neighbors	20 (5.2)
Bystander	15 (3.9)
Other (e.g., security officer)	19 (5.0)
Unidentified	36 (9.4)
Missing	4 (1.0)
Number of medications	5.74 ± 4.92 (range: 0 ~ 21, median = 5)

Table 2. Frequent reasons of EMS activations and example quotes during 911 calls (N = 383)

Category	Reason	Example Quotes
Symptoms	Breathing issues	“have short of breath” “gasping for air” “hard time breathing” “I can’t breathe. I’m having a lot of trouble breathing. I can’t get up. I can’t walk two feet.”
	Chest pain	“heart is hurting him/her” “having tightness in chest” “chest pain’s getting worse” “My daughter is suffering from congestion heart failure and she’s having kind of a chest pain.”
	Other pain (e.g., head, abdomen, legs, arms)	”hurts all-over” “my grandma is calling because she fell and she’s crying and she can’t get up and she’s hurting.” “my client, her stomach is hurting her real bad. She’s throwing up.” “I have a client here who is having severe back pain and she needs to go to the hospital.”
Signs	Change in level of consciousness	“can barely stay awake” “in and out of consciousness” “not really responding to us (the caller)” “doesn’t know where he/she’s at or nothing.” “she’s just having decreased cognition, increased lethargy. Her face is really puffy. Something’s not right. She’s a full code. The on-call physician wants her to be evaluated.”
	Swelling	“feet are swollen up real big” “legs are swollen and can’t walk” “fluid built upon his knee.” “My feet are swollen up. I mean, I am chopped up right now.”
	Bleeding/signs of bleeding	“bruises everywhere” “peeing blood” “throwing up lots of blood”

		“bleeding from rectum and won’t stop.”
Events	Falls	“fell and cut the side of my head’ “fell and can’t move” “she just was trying to get to the bed, and she fell. Her legs got weak.” “She has taken two really bad falls today. She's 90-year-old and she's complaining of her hip and her back hurting, and she's got bruises, just bruises everywhere…She was really disoriented when I got here the first time this morning… we helped get her dressed and you know, but I just don't know what else to do for her.
	Possible heart attack	“I think I’m having a heart attack. I can’t breathe” “I think my wife just had a heart attack or is having one.” “I am going to, ah, pass out, or have a heart attack, or something.” “Possible heart attack. He’s took five nitros.”
	hypoxic episodes requiring oxygen therapy	“Yes (she is breathing) but I believe her oxygen level, she’s on oxygen, I believe is probably pretty low.” “She said even on her oxygen, she’s still having a hard time breathing…. You’ve got to come pick her up.” “My brother is on oxygen. But he still can’t breathe.” “He’s sitting up in bed with his oxygen on. But, he’s kind of discolored. His face is real, real, like kind of red and purple.”
	Possible stroke	“I’ve got a client who pushed her medical button and she indicates she's having a stroke.” “… he appears to be having a stroke. He's got entirely left-sided weakness.” “I think my mother-in-law may have probably had, possibly another stroke.”
	Post-hospital discharge complications	“I just got released from the hospital Friday. I spoke to my clinic doctor, the nurse, and she said if I didn’t feel any better by Tuesday … I need to call you guys to come and get me. … I’m getting weaker and my head’s hurting more. I have a roll of toilet paper full of blood from my nose.” “….He just got out of the hospital a few hours ago….He’s trying to breathe and he can’t breathe.” “We need to transport my husband to the hospital. He just got out of rehab. He's having labored breathing…” “My mother is complaining of chest pains. She recently got out of the hospital where she had been in respiratory failure and heart failure….She said her

	chest is hurting and I called the nurse and the nurse said for me to have her come to the ER.”