

A Qualitative Study of Symptom Experiences of Women With Acute Coronary Syndrome

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Abstract:

Background: Most studies show that women with symptoms of acute coronary syndrome (ACS) delay seeking care longer than men do. Contributing factors include women being more likely to experience diverse symptoms, to experience symptoms that do not match preexisting symptom expectations, to interpret symptoms as noncardiac, and to minimize symptoms until they become incapacitating.

Objective: The aim of the study is to identify factors influencing women's ability to recognize and accurately interpret symptoms of suspected ACS.

Methods: This qualitative study used in-depth interviews with 18 women diagnosed with ACS to determine how they recognized, interpreted, and acted on symptoms. An interview guide developed from the author's initial research was used to provide structure for the process.

Results: All of the women went through a process of recognizing and interpreting their symptoms. Eight women had symptoms arise abruptly. Most of these women recognized a change immediately, "knew" to go for treatment, and did so quickly. Three women had vague symptoms that started slowly, converting unexpectedly to intense symptoms prompting them to seek care urgently. The remaining 7 women had evolving symptoms, were more likely to interpret symptoms as unrelated to their heart, and avoided disclosing symptoms to others. Despite recognizing that the situation may be serious, women with evolving symptoms adopted a wait-and-see approach.

Conclusion: Women with less severe, intermittent, or evolving symptoms are at increased risk for delayed presentation, diagnosis, and treatment for ACS. These women should be targeted for educational and behavioral interventions.

Keywords: acute coronary syndrome | myocardial infarction | symptoms | treatment delay | women

Article:

Background

Early recognition and accurate interpretation of symptoms of an acute coronary syndrome (ACS) event are essential for patients to receive time-sensitive therapies to minimize myocardial ischemia. Mortality and morbidity increase if there is a delay in diagnosis and treatment for these patients.¹ Despite the fact that survival rates after myocardial infarction improve if treatment begins within 1 hour, most wait 2.5 to 3 hours to seek care.¹ Quality care initiatives to improve patient outcomes have recently focused on reducing total ischemic time (time of symptom onset to inflation of the balloon to restore coronary artery blood flow) as a performance metric for patients with ST-elevation MI (STEMI), 1 type of ACS.²⁻⁴ Total ischemic time correlates better with infarct size and mortality compared to door-to-balloon time (time of hospital arrival to inflation of the balloon to restore coronary artery blood flow) for STEMI patients.^{3,4} Furthermore, total ischemic time includes the time for patients to recognize, interpret, and act on symptoms, which accounts for the largest portion of total ischemic time.^{3,4}

Studies indicate that women delay longer than men do when deciding to seek medical attention for ACS symptoms.⁵⁻⁸ One reason for their delayed care seeking is that the symptom experiences of women differ from those of men. In a systematic review of symptom presentations related to age and sex, authors reported that women with ACS were more likely than men to present with symptoms other than chest pain or discomfort (42% vs 30.7%; $P < .001$, respectively).⁹ Furthermore, findings from a multicenter study of 1064 patients admitted to the emergency department for symptoms suggestive of ACS revealed that women with ACS were less likely than men to report chest pain as their chief complaint.¹⁰ Studies have also shown that women are more likely to report a greater number of symptoms and more diverse symptoms at presentation.⁹⁻¹⁶ In fact, women are more likely than men to have back/neck/jaw or arm pain, shortness of breath, cough, or paroxysmal nocturnal dyspnea, nausea/vomiting/indigestion or lack of appetite, weakness, fatigue, dizziness, syncope, palpitations, and/or a sense of dread with their ACS event.^{9,11-20} Furthermore, many women have ACS symptoms that are intermittent, often evolving over hours, days, or weeks.^{16-18,21,22}

One possible explanation for symptom differences is that women with ACS tend to be older than men (mean age, 72.0 vs 65.1 years).¹ In addition, women have more comorbidities at the time of their ACS event, including a higher prevalence of diabetes, hypertension, heart failure, atrial fibrillation, chronic kidney disease, peripheral arterial disease, and depression.^{1,23} Women are also more likely to have a non-STEMI (NSTEMI) and nonobstructive coronary artery disease when they present with ACS.²⁴ These differences may influence the timeliness of symptom recognition and interpretation and their decision whether to seek care. Through better

understanding of how the symptom experiences of women influence care-seeking behavior, targets for interventions to decrease hospital delay can be identified.

This current study builds on a grounded theory study that explored the thoughts and behaviors of women with symptoms of ACS.²¹ The qualitative study used in-depth interviews with 9 women to elicit a basic social process of searching for the meaning of suspected ACS symptoms. The process of symptom recognition and interpretation served as the central core category, which included noticing symptoms, forming a symptom pattern, using a frame of reference, finding relief, and assigning causality. The process of symptom recognition and interpretation was embedded within the larger social context related to continuing life as usual, using others, preparing for departure, and seeking definitive care. Symptomatically, the women fell into 2 groups: those who had immediately recognizable symptoms and those who had evolving symptoms. The women with more abrupt, intense, immediately recognizable symptoms were more likely to interpret their condition as serious and potentially heart related. Women with evolving symptoms experienced uncertainty about their symptoms and delay seeking care until symptoms worsened. Although a conceptual model was developed, more research was needed with a larger sample to extend/confirm the early findings. Therefore, the aim of this study is to identify factors influencing women's ability to recognize and accurately interpret symptoms of suspected ACS.

Methods

This qualitative study used directed content analysis to explore how women experiencing symptoms of ACS recognized, interpreted, and acted upon their symptoms. The goal of directed content analysis is to use existing theory or prior research to extend or refine previous work.²⁵ Congruent with this methodology, previous findings shaped the interview guide and initial coding scheme, which subsequently drove the analysis.²⁵ Thus, data for this study were collected through in-depth semistructured face-to-face interviews using an interview guide developed in earlier research.²¹ The interview began with a broad, open-ended question that introduced the topic inviting the participant to tell her story. Follow-up questions and targeted probing questions were used to gather more information about the symptom experience as the interview progressed (Table 1).

Participants were recruited from 2 inpatient cardiac units in a not-for-profit, 803-bed state-owned academic medical center in the southeastern United States. This site provided a heterogeneous sample in terms of age, race, ethnicity, and socio-economic status. Women 35 years or older who had been hospitalized with a definitive diagnosis of ACS were eligible. Diagnosis of ACS was determined through having symptoms of cardiac ischemia combined with 1 or more of the following: positive cardiac biomarkers, 12-lead electrocardiogram changes (ST-elevation, ST-depression, and/or T-wave inversion in 2 contiguous leads), and/or significant cardiac disease as noted by a cardiac catheterization during their index hospitalization. Women were excluded if they had hemodynamic instability (eg, cardiogenic shock, altered cognition, or life-threatening arrhythmias) or were unable to understand spoken English.

Institutional review board approval was obtained for the study and a limited waiver of Health Insurance Portability and Accountability Act authorization was provided to allow access to

medical record to review eligibility criteria and contact potential subjects. If a woman qualified for the study, the author confirmed with the nurse that she was hemodynamically stable and pain free before inviting her to participate.

TABLE 1 Outline for Semistructured Interview

<p>Broad open-ended statement to invite participants to start the interview</p> <p>I would like to understand more about what happens when women experience cardiac symptoms and what they do when symptoms occur – especially in terms of seeking care.</p> <p>Tell me the story about when you first thought you might be having symptoms of a heart attack and how you thought about managing the other things in your life.</p> <p>Topical outline for additional questions</p> <p>Definability of symptoms</p> <ul style="list-style-type: none">• Quality of symptoms• Number of symptoms• Symptom course (onset and continuation/duration of symptoms)• Timing, frequency, location, and intensity of symptoms• Level of distress related to symptoms• Thoughts about causality• Thoughts about seriousness• Thoughts about anticipated outcomes <p>Situational influences related to symptoms:</p> <ul style="list-style-type: none">• First time versus a recurrent event• Acuteness of disruption• Personal knowledge of heart attack symptoms• Perceived susceptibility to heart disease <p>Life events going on at the time of symptoms:</p> <ul style="list-style-type: none">• Activities at the time of symptoms• Disclosure to others about symptoms• Complexity of activities during the symptom experience• Ease of exiting responsibilities <p>Decision about seeking care</p> <ul style="list-style-type: none">• Decision to go to hospital• Pros/cons about going to the hospital• Others involved in the decision• Decision about mode of transport to the hospital <p>Final thoughts</p> <ul style="list-style-type: none">• In hindsight would anything be done differently and why?

A purposive sample of 18 women who met the eligibility criteria were recruited for the study. Women with all 3 types of ACS (STEMI, NSTEMI, and unstable angina) were included. However, women with STEMI were targeted for more in-depth exploration of their symptom experience because the initial research study primarily included women with NSTEMI and unstable angina. Sampling ended when saturation was achieved (new data did not reveal further insights).

Initial interviews were conducted in the hospital or within 2 weeks of hospital discharge in participants' homes. Interviews lasted about 1 hour (mean [SD], 59.6 [12.47] minutes). Ten were conducted in the hospital; the remainder in participants' homes. The median time from hospital admission to interview was 4 days. One woman was contacted a second time to clarify the timeline of her symptom experience.

After the interview, demographic data were collected and participants completed a Response to Symptoms Questionnaire to triangulate the responses generated from the in-depth interviews. The instrument, with previously reported content validity, is useful for description to assess the context in which ACS symptoms occurred, including the patients' affective, behavioral, and cognitive responses to symptoms; symptom appraisal; and social factors related to care seeking.²⁶⁻²⁸ The 21-item instrument contains fill-in-the-blank, multiple-choice, and Likert-type questions.

Interviews were audio-recorded and transcribed verbatim. Congruent with directed content analysis, coding began immediately after the interview data became available using codes predetermined in an earlier study.²¹ Any text not categorized with the predetermined codes was highlighted and used to refine/extend earlier findings. Visual models were created, including timelines for each participant's symptom experience to enhance analysis. Alonzo's validated method of pinpointing the time of symptom onset was used during the interview when asking participants to recount the events of the hours surrounding the event.²⁹

Trustworthiness was addressed as follows: Credibility was maintained by starting the interview with open-ended questions, transcribing the data verbatim, verifying accuracy of transcripts, and retaining the digital audio recording until after the analysis was completed. Dependability was optimized by discussing cases and timelines using a constant-comparative method with senior researchers and methodological mentors to validate findings which offered support from the preliminary research study and those not present in the initial study. Memos were used to track explanations for how data were generated and analyzed which served as an audit trail.

Results

Two-thirds of the women enrolled had a confirmed MI; majority were STEMIs ($n = 8$). The remaining 6 were diagnosed with unstable angina. Women's ages ranged from 46 to 84 years (mean [SD], 65.56 [10.91] years). Four were African American and 14 were white. See Table 2 for sociodemographic and clinical data.

All 18 women interviewed went through a process of recognizing, interpreting, and acting on their symptoms. Symptomatically, participants fell into 3 groups: an immediately recognizable symptom group, an evolving/abrupt conversion symptom group, and an evolving symptom group (Table 3). How symptoms began influenced how quickly the women recognized a change in their body, whether they accurately interpreted the symptoms, and their timeliness in seeking care.

Group 1: The Immediately Recognizable Symptom Group

The 8 women in the immediately recognizable symptom group had abrupt symptoms, and most could pinpoint the exact time of symptom onset, frequently to the minute. Nearly all of the women sensed almost immediately that the situation was serious, and 6 of the 8 interpreted the likely cause of the symptoms as cardiac. One participant, with no history of heart disease, described her symptom experience:

It woke me slam right up. It was abrupt, heavy chest pain that radiated down my arm and neck. I knew instantly that I was having a problem; that it was my heart. There was no doubt.

TABLE 2 Sociodemographic and Clinical Characteristics of the Sample

	Mean \pm SD or n (%)
Sociodemographic variables	
Age, y	65.56 \pm 10.91
Years of education	13.67 \pm 2.91
Race	
White	14 (77.8)
African American	4 (22.2)
Marital status	
Married	8 (44.4)
Divorced/separated/widowed	7 (38.9)
Single	3 (16.7)
Employment status	
Employed	5 (27.8)
Unemployed, disabled	5 (27.8)
Unemployed, retired	8 (44.4)
Annual household income	
<\$20 000	3 (16.7)
\$20 000-\$39 999	3 (16.7)
\$40 000-\$59 999	3 (16.7)
>\$60 000	3 (16.7)
No data	6 (33.3)
Number in household (in addition to self)	1.4 \pm 1.7
Insurance status	
Medicare primary	13 (72.2)
Private insurance	3 (16.7)
Medicaid primary	2 (11.1)
Clinical variables	
Cardiac biomarkers (+)	12 (66.7)
12-Lead ECG changes (+)	
ST \uparrow w/ reciprocal changes (STEMI)	8 (44.4)
ST \downarrow /T wave inversion (non-STEMI)	1 (5.6)
Q waves	4 (22.2)
No acute ischemic changes	4 (22.2)
Paced rhythm	1 (5.6)

Abbreviations: ECG, electrocardiogram; NSTEMI, non-ST elevation myocardial infarction; STEMI, ST elevation myocardial infarction.

TABLE 3 CAN BE FOUND AT THE END OF THE ARTICLE

Most of the women in this group “knew” to go for treatment and did so sooner than the other symptom groups (median time from symptom onset to hospital arrival, 1.74 hours). Five women called emergency medical services versus private transportation to the emergency department, primarily because of the abruptness of symptoms. Family members of 2 women offered to take them to the emergency department, but emergency medical services was used because of “seriousness of the situation.” As 1 woman said:

Pain in the chest, arm cramping, and sweats woke me up. Surprised me. It didn’t hurt as bad as I thought a heart attack would hurt. It was pretty serious and we needed to go to the hospital. I woke my husband up and said you need to call 911 right now.

However, despite interpreting symptoms as serious, 2 of the women in this group delayed telling others about their symptoms. Although symptoms woke them up, they waited until the next morning to notify others. One of these women, who was 73 years old, waited until her doctor’s office opened to make “sure” she should go to the emergency department. Although she felt confident that her symptoms were heart related, she did not want to risk being “wrong again,” as in her last 3 visits to the emergency department. However, this time was different; she had been told a few days before that her stress test result was positive. The other woman delayed seeking care despite interpreting her symptoms as serious because her work obligations took priority over her symptoms. She was the primary provider for her family, and as she put it, despite knowing something was “really wrong,” she did not want to face it for fear of not being able to work and pay her bills. Thus, for 2 of the women in this group, correct interpretation of symptoms was not enough to get them to seek care immediately.

Group 2: The Evolving/Abrupt Conversion Symptom Group

For the 3 women in the second group, symptoms started slowly, which dramatically changed. These women had less intense, often vague symptoms that evolved over hours or days; however, at some point, their symptoms converted abruptly. All 3 continued with their activities, although at times scaling back, until the symptoms intensified. Once symptoms converted, all 3 interpreted their condition as serious, potentially related to their heart and made the decision to seek care (median time from conversion to hospital arrival, 2.52 hours). Because their symptoms evolved more slowly, the women did not make the decision to seek care until things changed for the worst. Only 1 of the 3 women used emergency medical services as a means of transportation to the hospital.

Group 3: The Evolving Symptoms Group

For the remaining 7 women, the evolving symptom group, symptoms were often vague, nonspecific, and intermittent. Five of these women were unable to form a symptom pattern; as a result, they did not interpret their symptoms as serious and delayed seeking care. One woman described symptoms as something she had never experienced before. As she put it:

It didn't occur to me that it could be my heart. I took a couple of Tums thinking that's going to take care of it, but it didn't. I felt good for 10–15 minutes, then it came back. Same thing, exactly in the same place, same severity, everything. It was strange, coming and going. Even when I was laying down or at the grocery store. It was off and on the entire day. It wouldn't stay away long enough to forget it.

All of the women in this group avoided disclosing to others that they were having symptoms, primarily, as they put it, because symptoms “weren't bad enough to worry others.” As 1 woman who waited for hours before telling her spouse about her intermittent symptoms said:

I don't like to complain about every little ache and pain. I want to make sure it's “something” before I tell him. If I complain, it's “something” because I don't complain much.

However, 3 of the women in this group who suspected their symptoms were cardiac early on still delayed seeking care for various reasons. For these women, interpreting symptoms as heart related was not enough to seek care quickly. All of the women in this group continued with activities until symptoms became incapacitating, resulting in longer prehospital delays compared with the other 2 groups (median time from symptom onset to hospital arrival, 11.45 hours). None of these women used emergency medical services to go to the hospital.

Discussion

These findings reveal that the type of symptoms women experience during their ACS event influences symptom recognition and interpretation, which informs their decision to seek care. The experiences of the women in the immediately recognizable symptom group support findings from the initial grounded theory study.²¹ Women who had intense, abrupt symptoms recognized a somatic change in their body almost immediately and interpreted symptoms as possible cardiac in origin. Although the median time from symptom onset to decision to seek care was shorter than that in the other 2 groups, it was longer than the 5 minutes recommended by the American Heart Association.³⁰ In addition, much of their prehospital delay time was related to the time required for emergency medical services to get to/from their house and/or time to administer treatment on site. Features of this group's experiences also support findings of other qualitative studies.^{17,31,32} Rosenfeld and colleagues³¹ dichotomized 6 common patterns of behavioral responses of women who had MI symptoms into a “knowing” group versus a “managing” group. As in this study, women in the “knowing” group quickly recognized symptoms, thought something was seriously wrong, and sought care quicker than the “waiting” group. The findings also support 2 distinct symptom presentations described by O'Donnell and colleagues^{17,32} whereby persons with “fast-onset myocardial infarction” were more likely to interpret symptoms as cardiac and sought care sooner than those with “slow-onset myocardial infarction”.

Women in the current study with less intense, intermittent symptoms had greater difficulty recognizing and interpreting symptoms as a potentially serious. For the 2 groups of women who initially had evolving symptoms, much of the delay time was caused by incorrect symptom interpretation. As in other studies, women with evolving symptoms delayed longer because of a

mismatch of expected versus experienced symptoms.^{17,21,32} As with the “managing” group described by Rosenfeld and colleagues,³¹ women with evolving symptoms were more likely to minimize symptoms adopting a wait-and-see approach.

A unique perspective in the current findings is that the evolving/abrupt conversion symptom group is considered a distinct group from the evolving symptom group. For the women in this group, the dramatic conversion of symptoms was the trigger that stimulated reappraisal of symptoms prompting care-seeking. The behavior of this group differed from the women in the evolving symptom group, who experienced the longest prehospital delay. Despite interpreting symptoms as heart related, the less intense symptoms allowed them to continue activities.

As noted in the 2016 American Heart Association scientific statement on women and acute myocardial infarction, there is a need to identify effective interventions to decrease treatment delay.²⁴ Development of personalized education and skill building interventions for women with suspected ACS symptoms will help fill the gap. Educational messages should emphasize the complex nature of the ACS symptom experience, as there is no “one” universal symptom experience.³³ Women need to know that although symptoms may be less intense or intermittent, they still could be having heart symptoms and should seek care immediately.³⁰ Also, further research is needed to explore the association between diagnosis and symptoms. The findings from this study suggest that more STEMI patients had prehospital delays times of less than 1 hour. However, caution should be taken because a sample size of 18 women is too small to conduct inferential statistical analysis.

Limitations

These data were collected retrospective to the symptom experience which risks recall bias. However, every attempt was made to provide ample time for the women to “tell their story” as soon after the event as possible. There may have been an unintended selection bias related to patients who did not seek care, who died before being offered participation in the study, and who were hemodynamically unstable during screening. However, findings from these in-depth face-to-face interviews provide insight into how symptom experiences inform behavior.

Conclusion

Women with abrupt ACS symptoms or a dramatic change in symptom intensity sought care sooner than did women with evolving symptoms. Having evolving symptoms places women at risk for delayed presentation, diagnosis, and treatment; thus, these women should be targeted for educational and behavioral interventions.

What’s New and Important

- Symptom interpretation and decision making influences prehospital delay in seeking treatment for potential symptoms of ACS.
- Women with more abrupt ACS symptoms are more likely to interpret symptoms as cardiac in origin and seek care sooner than those with evolving intermittent symptoms.

- Although some women correctly interpret their symptoms as heart related almost immediately, few call emergency medical services within the recommended 5-minute time period.

TABLE 3 Symptom Attribution and Prehospital Delay Based on Symptom Group

Case Number/ Diagnosis	Symptom Attribution/ Transport Mode	Time: Sx Onset to Decision to Seek Care	Time: Decision to Hosp Arrival	Total Prehosp Delay Time	Primary Reasons for Delay
Immediately recognizable symptom group					
Case 1: NSTEMI	Cardiac/EMS	6 min	68 min	74 min	Time to/from house by EMS
Case 4: STEMI	Cardiac/EMS	15 min	50 min	65 min	Time to/from house by EMS
Case 7: STEMI	Cardiac/EMS	5 min	9 min	14 min	Time to/from house by EMS
Case 8: STEMI	Cardiac/EMS	35 min	38 min	73 min	Uncertain sx attribution at first; time to/from house by EMS
Case 11: UA	Serious/car	90 min	81 min	171 min	Waited for MD office to open; time to/from house by EMS
Case 12: STEMI	Cardiac/EMS	10 min	125 min	135 min	Life Alert equipment failure; slowed by family members
Case 13: UA	Cardiac/car	960 min (16 h)	21 min	981 min (16.4 h)	Delayed disclosure to others; poor advice by caregiver
Case 14: STEMI	Serious/car	210 min (3.5 h)	30 min	240 min (4 h)	Incorrect sx attribution at first; social reasons (cost)
Median time for group		25 min	44 min	104.5 min (1.74 h)	
Evolving/abrupt conversion symptom group					
Case 2: NSTEMI	Serious/EMS	35 min (after converted)	19 min	54 min	Delayed sx recognition until converted (then call EMS)
Case 6: UA	Cardiac/car	75 min (after converted)	77 min	197 min	Delayed sx recognition; delayed until incapacitated
Case 10: STEMI	Incorrect/car	65 min (after converted)	86 min	151 min	Incorrect Sx attribution; others moved to care
Median time for group		65 min	77 min	151 min (2.52 h)	
Evolving symptom group					
Case 3: UA	Incorrect/car	585 min (9.75 h)	39 min	624 min (10.4 h)	Incorrect sx attribution; others moved to care
Case 5: STEMI	Incorrect/car	Days; most recent sx: 208 min (3.5 h)	152 min (2.5 h)	360 min (6 h)	Incorrect sx attribution; delayed until incapacitated
Case 9: STEMI	Incorrect/car	Days; most recent sx: 868 min (14.5 h)	868 min (14.5 h)	868 min (14.5 h)	Incorrect sx attribution; others moved to care
Case 15: UA	Cardiac/car	Days; most recent sx: 240 min (4 h)	60 min	300 min (5 h)	Social reasons for delay; delayed until incapacitated
Case 16: NSTEMI	Cardiac/car	Days; most recent sx: 600 min (10 h)	87 min (1.45 h)	687 min (11.45 h)	Incorrect sx attribution; delayed until incapacitated

Case 17: NSTEMI	Incorrect/car	184.5 h (7.7 days)	212 min (3.5 h)	11,282 min (7.8 days)	Incorrect sx attribution
Case 18: UA	Cardiac/car	Days; most recent sx: 14 h	360 min (6 h)	20 h	Delayed until incapacitated; came on “own terms”
Median time for group		600 min (10 h)	152 min (2.5 h)	687 min (11.45 h)	

Abbreviations: EMS, emergency medical services; hosp, hospital; NSTEMI, non-ST elevation myocardial infarction; STEMI, ST elevation myocardial infarction; Sx, symptoms; UA, unstable angina.

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