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Development of Systems of Care for ST-Elevation Myocardial Infarction Patients The Patient and Public Perspective

George A. Mensah, MD, FAHA, Co-Chair; Mary M. Hand, MSPH, RN, FAHA, Co-Chair;
Elliott M. Antman, MD, FAHA; Thomas J. Ryan, Jr, MD, FAHA;
Robert Schriever; Sidney C. Smith, Jr, MD, FAHA

A major objective for creating an ideal system of care is to be able to do “the right thing, at the right time, in the right way, for the right person—and having the best results possible.”¹ Critical to this endeavor are patients’ beliefs, values, wishes, fears, expectations, perceptions of symptoms, and cognitive and emotional processes. All of these factors play important roles in determining if, when, and how they access these systems of care.²

Creating an ideal system of care to address the care for patients with ST-elevation myocardial infarction (STEMI) is complex from both the system’s and patient/family’s perspectives. In general, this care is unlike most other hospital care. It typically involves very fast and complex decision making and, often, sudden transportation to another facility for percutaneous coronary intervention (PCI). All of this occurs with a potentially critically ill patient and at a time when the family is often not immediately available. In this report, we address key perspectives from the patient and public point of view of the current system of care for STEMI patients and highlight the barriers and gaps that must be addressed by an ideal system of care (Table 1).

Perspectives on the Current System of Care for STEMI Patients

The biggest challenge to developing an ideal system of care for STEMI patients is the inadequate recognition, by patients and bystanders in the community, of the full spectrum of acute myocardial infarction (MI) symptoms and the urgency

of activating the emergency medical services (EMS) system by calling 9-1-1.³ The problem of delay in the setting of symptoms has been recognized for decades,⁴ but it gained greater urgency with the new treatment paradigm created by fibrinolytic therapy. In surveys and focus groups, heart attack patients, family members, and the public reported that they thought presenting symptoms were less dramatic than expected, they perceived these symptoms as not serious or as transient and therefore took a “wait and see” approach until they were more certain of their significance, and they attributed their symptoms to other chronic conditions or common illnesses. Respondents also cited fear of embarrassment for “false alarms,” reluctance to “bother” physicians or EMS providers unless they were “really sick” or had received permission from others to take rapid action, and existing stereotypes of who is at risk for a heart attack as reasons for delay.² They often did not perceive women or men under a physician’s care for risk factors as persons at risk.⁵ They were also unaware of the benefits of rapid action, calling 9-1-1, and reperfusion treatment.

In the current system of care, when and how patients and/or those around them recognize and respond to STEMI symptoms influences which parts of the healthcare system are accessed and can impact the resultant treatment and outcome. The Figure illustrates the time windows and reperfusion scenarios recommended by the American College of Cardiology/American Heart Association (AHA) guidelines. Two EMS options are suggested depending on

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TABLE 1. Perspectives on the Current System of Care for STEMI Patients

Community knowledge
Inadequate recognition of wide range of MI symptoms
Inadequate awareness of reperfusion treatment and the importance of time to artery-opening intervention
Suboptimal use of EMS
EMS system
Inadequate enhanced 9-1-1 coverage
EMS: availability, response time, costs, heterogeneity
Prehospital triage and related issues
Patients' choice, transparency of decisions, patients' desires (living will)
PCI
Variable quality of STEMI care delivered
Challenges in patient involvement in consent and decision making
Delays in diagnosis and treatment in the ED, in interhospital transfer (if done), and in activation of the PCI team (if patient receives PCI)
After PCI
Suboptimal coordination of care and postdischarge instructions: secondary prevention, cost of treatment

whether the patient accesses EMS and is taken to a non-PCI-capable hospital or a PCI-capable hospital (or self-transport to one). The current recommended time-to-treatment system goals start with contact with the medical system (either EMS arrival or presentation at the emergency department [ED]) but acknowledge the critical total ischemic time of 120 minutes (and the ideal of the “golden hour” of 60 minutes).⁶

Finally, the current system of care is characterized by marked disparities in access to care and significant variations in the quality of care delivered to those who have access. The most recent National Health Care Quality and Disparities Reports, sponsored by the Agency for Healthcare Research and Quality, document that although many Americans have good access to health care, many others face barriers that make the acquisition of even basic

essential health services difficult.^{7,8} Racial and ethnic minorities, persons of low socioeconomic status or educational attainment, those without health insurance, those who live in rural areas, and poor persons are disproportionately represented among those with access problems.^{7,8} In fact, in Asian/Pacific Islanders and American Indians/Alaska Natives, the quality of care for acute MI is not only worse than that for whites, but the disparity is getting worse rather than better (comparing the most recent and oldest years of data available).⁸

The current system of care often places a much higher value on technical competence than on “patient centeredness,” although the evidence suggests that patient-centered care not only improves patient satisfaction but can enhance safety.⁹ Meeting the needs and expectations of patients and their families is not typically seen as a priority,¹⁰ nor is cultural competence or the provision of education and support that patients need to make decisions and participate in their own care, especially after hospital discharge.

Current Barriers and Gaps That Must Be Addressed by an Ideal System

Access to timely primary PCI hinges on the patient’s/ bystander’s ability to expeditiously recognize STEMI symptoms and activate the EMS system. Current barriers and gaps in knowledge that must be addressed by an ideal system of care exist: in the community and among patients, about STEMI symptoms, the importance of time to artery-opening treatment, the need to access EMS, and how hospitals differ in their capabilities to perform PCI; and among providers, about why patients fail to take appropriate action and the need to deliver systematic, evidence-based education to their patients about appropriate recognition and response to heart attack symptoms and about the advisability of accessing EMS, and gaps in demonstrated effective communication/ educational interventions.

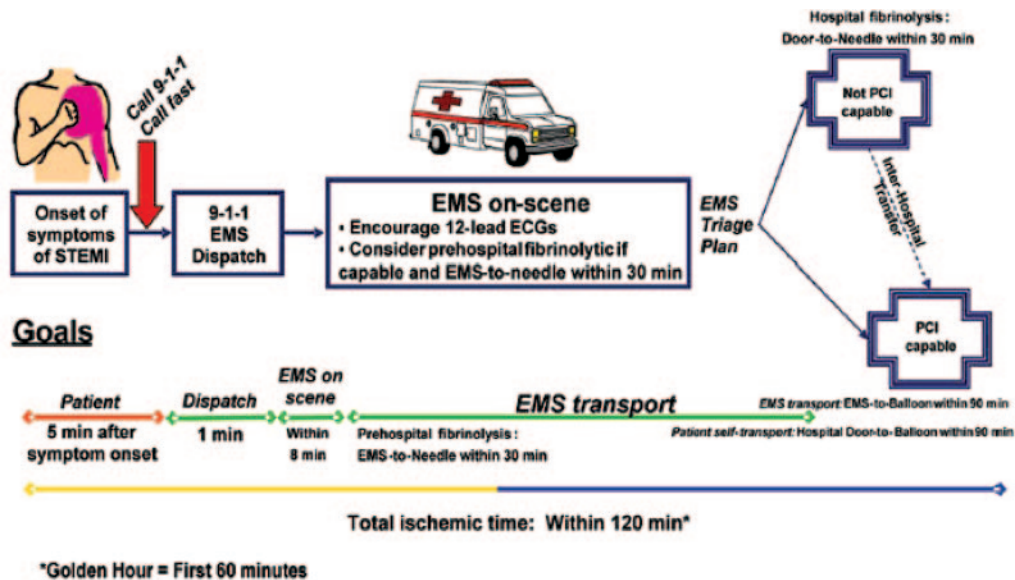


Figure. Options for transportation of STEMI patients and initial reperfusion treatment: patient transported by EMS after calling 9-1-1. Reprinted, with permission, from Antman et al.⁶

TABLE 2. Recommendations for Needed Research, Programs, and Policies: Patient Perspectives Work Group**Research**

Patient, family, and community knowledge

Invest in targeted research on perspectives of informed patients and their family members, especially those with direct experience with the care for STEMI, as consumers and beneficiaries of health care.

Conduct research on patient and family preferences regarding transfer to a PCI-capable hospital, ie, outside of their community.

Determine the most effective communication methods to bring about changes in patient/bystander action (decreased delay and appropriate system access).

Assess the role of decision support and information technology in the home and its impact on patient/bystander delay and EMS utilization.

Study the psychological, medical, logistical, social, and financial impacts on patients and families of transfer out of their community to a PCI-capable hospital either directly by EMS or via interhospital transfer.

Examine how patient/family awareness of the unique issues associated with a PCI-oriented system of care affect patient delay and use of EMS in response to symptoms.

Quantify the characteristics, frequency, natural history, and effectiveness of interventions with patients who have early prodromal symptoms of an MI.

Collect and make available data on patient-centeredness, safety, effectiveness, and timeliness in the delivery of care for STEMI, as well as data on patient outcomes, including health status, after discharge.

Invest in further research and application of information technology to facilitate access to early recognition of symptoms/diagnosis/treatment.

EMS system

Invest in a formal evaluation of the proposed ideal system of care for STEMI from the perspective of patients and their use of EMS.

Evaluate alternate options to EMS; for example, does calling a gatekeeper about symptoms (available 24 hours per day/7 days per week) result in less time delay than calling EMS?

PCI/after PCI

Conduct patient/family surveys about ways to improve management for STEMI before, during, and after PCI for the acute event.

Full spectrum of care for patients with MI

Identify the economic impact of a primary PCI system of care for STEMI on patients and their community providers.

Identify aspects of a system of care based on access to primary PCI that have an impact on patient satisfaction.

Obtain input from STEMI survivors to inform future program and system development.

Examine how the tools of information technology (telehealth; diagnosis and treatment decision support; large-scale databases; medical records access; and education of the public, patients, and healthcare providers) affect access to timely primary PCI.

Explore outcomes of patients seen for early assessment of prodromal (eg, intermittent, stuttering) symptoms.

Programs

Patient, family, and community knowledge

Develop and test effectiveness of educational campaigns to decrease patient delay and increase use of EMS based on access to a primary PCI-capable hospital destination (ideally building on current campaigns), including education about hospital capability for PCI and the implications for the management patients will receive if they access care for symptoms.

Implement prospective education with patients and families about the system of care they will access when seeking evaluation of MI symptoms in a regional system of care (based on access to primary PCI for STEMI).

Address what communities should tell patients about where they will be taken (ie, PCI-capable hospital vs non-PCI-capable hospital), including the rationale for transport/transfer and logistical issues associated with the transport/transfer.

Convey to patients/families the ramifications of self-transport in a PCI-based hospital system of care.

EMS system

Provide educational and concrete logistical information (eg, directions to PCI-capable hospital; parking; where to find the patient in the hospital) to family members of patients being transferred out of their community to a PCI-capable hospital (ie, direct transfer if EMS was accessed or interhospital transfer).

PCI/after PCI

Provide educational and concrete logistical information (eg, directions to PCI-capable hospital; parking; where to find the patient in the hospital) to family members of patients being transferred out of their community to a PCI-capable hospital (ie, direct transfer if EMS was accessed or interhospital transfer) [also under EMS].

Educate patients at discharge (and those "ruled out" in the ED) about recognizing MI symptoms and accessing the EMS system.

Full spectrum of care for patients with MI

Develop novel and expedited methods of patient consent and medical information transfer.

Include patient education and outreach as part of community/regional hospital and system strategies to increase the number of STEMI patients who receive timely reperfusion.

Counsel high-risk patients and their families in advance about recognizing and responding to MI symptoms, including patients seen in the ED and "ruled out" for MI, and at discharge for patients admitted to the hospital with a diagnosis of MI.

Clarify the difference in presentation between a "heart attack" (eg, with symptoms) and a cardiac arrest in communications with patients/public.

Develop programs for seamless interface with patients and their local primary care providers.

TABLE 2. Continued

Policies

Patient, family, and community knowledge

Ensure appropriateness and consistency of instructions that health plans and providers give patients regarding definitions of emergencies and accessing EMS.

Ensure commitment from lead national agencies (eg, AHA; National Heart, Lung, and Blood Institute; Centers for Disease Control and Prevention) to regularly update the current educational campaign messages/materials on recognizing and responding to an acute MI as the science and the field evolve.

EMS system

Ensure that care for patients who are determined not to have STEMI, including EMS transport/transfer, is adequately reimbursed without penalty.

Ensure timely ambulance availability to all STEMI patients for initial access and interhospital transfer.

Full spectrum of care for patients with MI

Ensure alignment of reimbursement policies to encourage providers to participate in a patient-centered integrated system.

Broaden the AHA's efforts in health information technology to include the capture of quality and outcomes data to permit assessment of data that address the consumers' perspectives on healthcare needs.

Assess current state legislation and local policies that have an impact on the system of care for STEMI patients.

Include representatives of patients and families in community coalitions to plan the local/regional system of care for timely access and optimal care of patients with STEMI symptoms.

Include the optimum way to time the onset of symptoms, because this is the initial critical measure to capture the overarching biologically important time interval of symptom onset to artery opening for quality improvement programs.

Collect individual- and population-level data as part of quality improvement efforts (ie, quality of care for the patients treated and quality of care of all eligible patients or the population served by the system).

Help standardize training and protocols around management of patients who call or walk-in/present to physicians' offices/clinics with possible heart attack symptoms.

Partner with managed-care plans to help develop explicit language for their patients about what symptoms constitute an "emergency" that requires activation of EMS without preapproval.

Community/Patient Barriers and Gaps

People who experience a heart attack generally do so in their communities, outside of the hospital, such that the community effectively becomes the "ultimate coronary care unit."¹¹ Prompt patient presentation to the EMS system and ED is the linchpin to successful coronary reperfusion. Reductions in patient delay in the United States have not been seen over time or as an outcome of intervention studies.^{12,13} Such delays compromise the likelihood of patients receiving timely reperfusion treatment.¹³ Despite the benefits of accessing EMS in the setting of STEMI (eg, earlier prehospital diagnosis, prehospital triage, and decreased time to fibrinolytic therapy),¹⁴ rates of EMS use by patients experiencing MI symptoms range from 10% to 56%.^{12,15} Most persons with MI are driven to the ED by someone else (60.4%) or drive themselves to the hospital (15.6%).^{15,16} Literacy level, socioeconomic factors, insurance status, and the prepayment systems and preapproval policies of patients' health plans can impact prompt activation and use of EMS.¹⁶

Provider Barriers and Gaps

EMS utilization is influenced by instructions provided by primary care physicians and health plan policies. Rates of EMS use are less among patients who contact their physicians than among those who do not.¹⁵ Physicians may prefer that their patients call them before calling 9-1-1 so that they can provide tailored advice to their patients whose histories are known to them.⁵ However, few patients report they ever discuss symptoms, responses, or actions for a heart attack in advance with their providers (or their families).⁵ Also, there is variability in how much explicit guidance health plans give

enrollees in defining an emergency, in particular, listing the key MI symptoms and linking these to calling EMS.¹⁷

Barriers and Gaps in Effective Communication/Educational Interventions

Although interventions to increase EMS use for MI patients to date have been only modestly successful, they must be an important part of an ideal system of care for STEMI. Most interventions have focused on reducing prehospital delay time and, to a lesser extent, increasing utilization of EMS for MI. In general, it has proven more difficult to reduce delay time than to increase EMS use. There have been 3 randomized trials conducted in the past decade in North America that have demonstrated an increased use of 9-1-1 for MI: the "Call Fast, Call 911" campaign in King County, Wash¹⁸; Rapid Early Action for Coronary Treatment (REACT) research program¹²; and the "Heart Attack Survival Kit" project.¹⁹ These intervention trials show that it is possible to increase EMS use for MI when (1) a fairly large quantity of mass media messages are disseminated throughout a community, (2) messages are targeted at high-risk audiences, (3) multi-pronged approaches are implemented that target many different stakeholders, and (4) interpersonal counseling sessions are conducted by credible sources. The results of these trials also show that it is difficult to develop an intervention that has a sustained effect over time.

Key Perspectives on the Ideal System

In light of these barriers and gaps, an ideal system of care for STEMI patients first and foremost recognizes the urgency of STEMI symptoms and the importance of time to treatment in

all community settings where patients may present.²⁰ Such a system invests in science-based education about recognition and response to MI symptoms, such as the “Act in Time to Heart Attack Signs,” launched by the National Heart, Lung, and Blood Institute, the AHA, and other partners in 2001 based on key findings from the REACT study.²¹ The ideal system invests in culturally competent and specific educational efforts. Therein, lead national organizations (ie, private, public, voluntary, and professional) periodically review and update science-based education campaigns as new research becomes available to ensure clear, consistent messages about appropriate patient recognition and actions. It streamlines patient activation of the system to eliminate any literacy, cultural, language, and precertification barriers.

In a system of care predicated on transfer for PCI, patients and family members are educated with essential information about the community’s hospitals and their capabilities for PCI (ie, thus providing the rationale for interhospital transfers and associated logistical issues) both in advance and at the time the system is accessed. The ideal system further used tested decision support tools for patients to provide early diagnostic support for patients and their families to seek care.²² Such a system would have established protocols in EDs around the processes of rapid detection, evaluation, and referral/treatment of patients²³ within a PCI system of care, incorporating quality improvement measures for ongoing monitoring and process improvement. The ideal system measures overall delay from symptom onset—including the times to presentation at both the referring hospital (“prehospital delay time 1”) and the receiving hospital (“prehospital delay time 2”)—to ultimate reperfusion, to capture process improvement needs in a regional system of care.²⁴

Furthermore, in an ideal system, neither patients nor providers would be penalized if symptoms turn out to be “false-positive.” An optimum system educates high-risk patients and their family members in advance about recognizing and responding to heart attack symptoms,²⁵ including patients seen in the ED and “ruled out” for an MI and at discharge for patients admitted to the hospital.

In addition to an expectation of high-quality care, patients and their families expect a well-coordinated care-delivery system, appropriate preparation of the patient for resumption of normal activities before discharge, and evaluation of the need for and strategies for long-term risk factor reduction. Ideal systems of care for STEMI patients should address key dimensions of healthcare experiences such as coordination of care, delivery of information and education, physical comfort, emotional support, respect for patient preferences, involvement of family and friends, and continuity and transition of care.

The ideal system looks beyond STEMI and ensures that programs are available from which patients with early prodromal symptoms of an MI can obtain prompt and appropriate evaluation and referral from a clinical setting/hospital geared to user-friendly evaluation of possible acute ischemic symptoms (eg, a chest pain center). Finally, an ideal system includes patient representatives on community coalitions that can plan the local/regional system of

care to ensure timely access and optimal care of patients with MI symptoms.

Recommendations

On the basis of perspectives from patients, their families, and the community, the writing group proposes several recommendations for research, practical programs, and public policy to address the above-mentioned gaps and barriers and facilitate the creation of an ideal system of care for STEMI and acute coronary syndrome patients (Table 2).

Disclosures

Potential conflicts of interest for members of the writing groups for all sections of these conference proceedings are provided in a disclosure table included with the Executive Summary.

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