



SYMPOSIUM PROCEEDINGS

NEW INFORMATION TECHNOLOGY
AND THE NATIONAL HEART
ATTACK ALERT PROGRAM:
SETTING A 5-YEAR AGENDA

APRIL 14–15, 1998
LISTER HILL CENTER,
NATIONAL LIBRARY OF MEDICINE,
BETHESDA, MARYLAND

SYMPOSIUM PROCEEDINGS

NEW INFORMATION TECHNOLOGY
AND THE NATIONAL HEART
ATTACK ALERT PROGRAM:
SETTING A 5-YEAR AGENDA



*Cosponsored by:
National Heart, Lung,
and Blood Institute;
National Library
of Medicine; Agency
for Health Care Policy
and Research*

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*National Institutes of Health
National Heart, Lung,
and Blood Institute*

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SYMPOSIUM PROCEEDINGS OVERVIEW

This book contains the proceedings for the symposium, *New Information Technology and the National Heart Attack Alert Program: Setting a 5-Year Agenda*, which took place on April 14 and 15, 1998, in Bethesda, Maryland.

The symposium was cosponsored by the National Heart, Lung, and Blood Institute; the National Library of Medicine; and the Agency for Health Care Policy and Research. The goal of the symposium was to develop an agenda of innovative ways in which the domain of information technology and medical informatics can be used to help fulfill the mission of the National Heart Attack Alert Program (NHAAP), a program of the National Heart, Lung, and Blood Institute of the National Institutes of Health. The mission of the NHAAP is to reduce morbidity and mortality from heart attack through early recognition and treatment.

Symposium attendees comprised NHAAP coordinating committee members; representatives from the National Library of Medicine; from the National Heart, Lung, and Blood Institute; and from the Agency for Health Care Policy and Research; content experts in the field of information technology; and health professionals in emergency medicine, cardiology, nursing, and emergency medical services. A list of participants can be found in the appendix.

The symposium was divided into two sections:

1. A series of tutorial presentations on medical informatics content and NHAAP background to lay the foundation for understanding the proposals presented on the second day of the symposium
2. A series of presentations organized into one of five informatics content areas—telehealth; education of the public, patients, and health care providers; medical records access; diagnostic and treatment decision support; and large-scale database access and mining—that constitute specific ideas and proposals for the application of new information technology to the NHAAP.

The abstracts of the presentations are structured in a common format: a delineation of the core content of the proposal, a review of what has already been done in the area, a discussion of how the proposal specifically serves the mission of the NHAAP, a statement of perceived obstacles to successful implementation of the proposal, and recommendations for next steps to be taken.

SYMPOSIUM PROGRAM

TUESDAY, APRIL 14, 1998

Tutorial Presentations on New Information Technology and the National Heart Attack Alert Program: Setting a 5-Year Agenda

Lister Hill Center
National Library of Medicine
Bethesda, Maryland
1:30-5:00 p.m.

1:30 p.m. Welcome and Overview

Mark S. Smith, M.D.
Symposium Program Chair
Chairman, Department of Emergency
Medicine
Washington Hospital Center
Clinical Professor of Emergency Medicine
The George Washington University School of
Medicine and Health Sciences
Washington, DC

1:40 p.m. The National Heart Attack Alert Program: Its Mission and Its Accomplishments

James M. Atkins, M.D., F.A.C.C.
Medical Director
Emergency Medicine Education
Professor of Internal Medicine
Division of Cardiology
University of Texas, Southwestern Medical
Center at Dallas
Dallas, TX

2:10 p.m. Telecommunications and the Next Generation Internet

Craig Feied, M.D.
Director of Informatics
Department of Emergency Medicine
Washington Hospital Center
Associate Clinical Professor
of Emergency Medicine
The George Washington University School of
Medicine and Health Sciences
Washington, DC

2:40 p.m. Confidentiality and Medical Information

Paul Clayton, Ph.D.
Professor and Chair
Department of Medical Informatics
Columbia University
Director of Clinical Information Services
Columbia Presbyterian Medical Center
New York, NY

3:10 p.m. BREAK

3:30 p.m. Diagnosis of Patients with Acute Myocardial Infarction and Other Acute Coronary Syndromes

Robert J. Zalenski, M.D., M.A.
Associate Professor
Emergency Medicine and Internal Medicine
Wayne State University
Detroit, MI

4:00 p.m. Databases and Data Standardization

Clement J. McDonald, M.D.
Distinguished Professor of Medicine
Indiana University School of Medicine
Director
Regenstrief Institute for Health Care
Indianapolis, IN

4:30 p.m. Economic, Social, and Psychological Obstacles to Achieving the National Heart Attack Alert Program's Goals

Joseph P. Ornato, M.D., F.A.C.C., F.A.C.E.P.
Professor and Chairman
Department of Emergency Medicine
Virginia Commonwealth University
Medical College of Virginia
Richmond, VA

5:00 p.m. Adjournment

Mark S. Smith, M.D.

5:00-

6:30 p.m. Reception: Lister Hill Center

Sponsored by the Friends of the
National Library of Medicine

WEDNESDAY, APRIL 15, 1998

New Information Technology and the National Heart Attack Alert Program: Setting a 5-Year Agenda

Lister Hill Center
National Library of Medicine
Bethesda, Maryland
8:00 a.m.-5:00 p.m.

8:00 a.m. Welcome and Introduction

Donald Lindberg, M.D.
Director
National Library of Medicine
National Institutes of Health
Bethesda, MD

Claude Lenfant, M.D.
Director
National Heart, Lung, and Blood Institute
National Institutes of Health
Bethesda, MD

John M. Eisenberg, M.D.
Administrator
Agency for Health Care Policy
and Research
Rockville, MD

Mark S. Smith, M.D.
Symposium Program Chair

8:30-

10:00 a.m. Telehealth

Carole Gassert, Ph.D., R.N.
Chair
Telehealth Task Force

Capt. David W. Ferguson, M.C., U.S.N.
Vice Chair
Telehealth Task Force

8:30 a.m. Telemedicine in the Department of Defense (DoD)

C. Forrest Faison III, M.D., C.D.R., M.C., U.S.N.
Director
Telemedicine Program Office
U.S. Department of Defense
Bethesda, MD

8:40 a.m. Use of Telemedicine Technology to Assist Small Rural Hospitals

Napoleon Knight, M.D.
Co-investigator
The Carle Rural Telemedicine Project
Medical Director
Department of Emergency Medicine
Carle Foundation Hospital
Carle Clinic Association
Urbana, IL

8:50 a.m. Ambulance-on-the Web: A Cellular Phone-Based, Real-Time Video-Mobile Telemedicine System for Ambulance Transport

Marian P. LaMonte, M.D., M.S.N.
Neurological Program Director
The Maryland Brain Attack Center
University of Maryland School of Medicine
Baltimore, MD

Panel on Electronic Housecalls:

Jay H. Sanders, M.D.—Moderator
President
American Telemedicine Association
Adjunct Professor of Medicine
Johns Hopkins University School of Medicine
President and CEO
The Global Telemedicine Group
McLean, VA

9:00 a.m. Behavioral Issues in Initiating Use of Telemedicine Technology

Angelo A. Alonzo, Ph.D.
Associate Professor of Sociology
The Ohio State University
Columbus, OH

9:10 a.m. Electronic Housecalls at Fort Gordon

Jack A. Horner, B.S.
Vice President
Marketing and Operations
Total Access Services, Inc.
Martinez, GA

9:20 a.m. Using Televideo To Improve Patient Outcomes

Linda L. Roman
President and CEO
H.E.L.P. Innovations, Inc.
Lawrence, KS

9:30 a.m. Operational Issues in Home Telemedicine

Charles Safran, M.D.
Director, Informatics and Advanced Technology
Beth Israel Deaconess Medical Center
Boston, MA

9:40 a.m. Audience Discussion

10:00 a.m. BREAK

10:20-11:35 a.m. Education of Public, Patients, and Health Care Providers

James M. Atkins, M.D., F.A.C.C.
Chair
Education of Public, Patients, and Health Care
Providers Task Force
Mary Jo Deering, Ph.D.
Vice Chair
Education of Public, Patients, and Health Care
Providers Task Force

10:20 a.m. Heart Attack Rapid Early Action for Coronary Treatment (REACT): A Community-Based Intervention To Reduce Patient Delay in Seeking Emergency Care for Heart Attack Symptoms

Deborah J. K. Alexander, M.A.
Program Coordinator
Heart Attack REACT/Midwest
Division of Epidemiology
School of Public Health
University of Minnesota
Minneapolis, MN

10:35 a.m. Using a Comprehensive Web Site To Attract, Identify, and Educate People at Risk for Heart Attacks

Fran Carl, M.P.H.
Health Education Manager
National Member, Technology Group
Kaiser Permanente
Oakland, CA

10:50 a.m. Using New Technology To Deliver Consumer Health Information: Focus on Information Kiosks

Victor Strecher, Ph.D., M.P.H.
Professor and Associate Director
Health Media Research Laboratory
Comprehensive Cancer Center
University of Michigan
Ann Arbor, MI

11:05 a.m. Stimulating the Use of Information Technology in Support of Information Seeking

J. David Johnson, Ph.D., M.A.
Dean
College of Communications and Information
Studies
University of Kentucky
Lexington, KY

11:15 a.m. Audience Discussion

11:35 a.m.-

12:45 p.m. Medical Records Access

Reed M. Gardner, Ph.D.
Chair
Medical Records Access Task Force
Joseph P. Ornato, M.D.
Vice Chair
Medical Records Access Task Force

11:35 a.m. Executive Summary G-7 CARDIO Project Subproject III: Improving Prevention, Diagnosis, and Treatment of Major Cardiovascular Diseases

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Rome, Italy

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12:05 p.m. Accessing Medical Records Using the Internet

John D. Halamka, M.D., M.S.
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Beth Israel Deaconess Medical Center
Executive Director
Center for Quality and Value
Harvard Medical School
Boston, MA

12:15 p.m. Portable Information Storage Devices for Immediate Access to Cardiac Data at the Point of Care

Aziz Boxwala, M.B.B.S., Ph.D.
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Decision Systems Group
Harvard Medical School
Brigham and Women's Hospital
Boston, MA

12:25 p.m. Audience Discussion

12:45 p.m. LUNCH

1:30-

2:50 p.m. Diagnosis and Treatment Decision Support

James J. Cimino, M.D.
Chair
Diagnosis and Treatment Decision Support Task Force
Robert J. Zalenski, M.D., M.A.
Vice Chair
Diagnosis and Treatment Decision Support Task Force

1:30 p.m. Use of Interactive Decision Trees for Patients To Decide About the Need To Call an Ambulance

J. Robert Beck, M.D.
Vice President
Information Technology Program
Baylor College of Medicine
Texas Medical Center
Houston, TX

1:40 p.m. The Promise and Problems of Community-Based Measurement of Biochemical Markers of Acute Coronary Syndromes

Robert H. Christenson, Ph.D.
Professor of Pathology
University of Maryland School of Medicine
Baltimore, MD

1:50 p.m. Home 12-Lead ECG Acquisition in Patients at High Risk of Acute Myocardial Infarction

Robert J. Zalenski, M.D., M.A.
Associate Professor
Emergency Medicine and Internal Medicine
Wayne State University
Detroit, MI

2:00 p.m. Access to Electronic Medical Records

Zak Kohane, M.D.
Director of Medical Informatics Program
Division of Endocrinology
Children's Hospital
Assistant Professor
Harvard Medical School
Department of Pediatrics
Boston, MA

2:10 p.m. Understanding Cognitive Processes in Medical Decision Making

Vimla L. Patel, Ph.D.
Professor and Director
Centre for Medical Science Education
McGill University
Montreal, Quebec, Canada

2:20 p.m. The Use of Computerized Electrocardiograph To Provide Decision Support for the Use of Thrombolytic Therapy as Well as to Record Retrospective Analysis of Performance for Feedback

Harry P. Selker, M.D., M.S.P.H.
Chief, Division of Clinical Care Research
Director, Center for Cardiovascular Health Services Research
Associate Professor of Medicine
New England Medical Center
Tufts University School of Medicine
Boston, MA

2:30 p.m. Audience Discussion

2:50 p.m. STRETCH BREAK

3:00-

4:10 p.m. Large-Scale Databases

Dr. William Tierney
Chair
Large-Scale Databases—Entry, Mining, Research Task Force

Dr. Costas Lambrew
Vice Chair
Large-Scale Databases—Entry, Mining, Research Task Force

3:00 p.m. Use of the Internet for Database Access

James J. Cimino, M.D.
Associate Professor
Department of Medical Informatics
Department of Medicine
Columbia University
Columbia-Presbyterian Medical Center
New York, NY

3:10 p.m. Continuous Quality Improvement in the Care of Patients With Acute Myocardial Infarction: The National Registry of Myocardial Infarction (NRMI)

Costas T. Lambrew, M.D.
Director, Division of Cardiology
Maine Medical Center
Portland, ME
Professor of Medicine
University of Vermont
Burlington, VT

3:20 p.m. Validity and Efficiency in Collecting Quality Data in Acute Myocardial Infarction Patients: A Comparison of the Cooperative Cardiovascular Project (CCP) and NRMI-2

Nathan R. Every, M.D., M.P.H.
Assistant Professor of Medicine
Division of Cardiology
University of Washington
Seattle, WA

3:30 p.m. The Cochrane Collaboration and the Agency for Health Care Policy and Research's Evidence-Based Practice Centers: The Benefit of Systematic Evidence Reviews in Achieving the Mission of the National Heart Attack Alert Program

Jane D. Scott, Sc.D., M.S.N, R.N.
Health Sciences Researcher
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University of Maryland School of Medicine
Baltimore, MD

3:40 p.m. Use of Clinical Trial Data To Support Advances in Emergency Cardiac Research

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Chief, Division of Clinical Care Research
Director, Center for Cardiovascular Health Services Research
Associate Professor of Medicine
New England Medical Center
Tufts University School of Medicine
Boston, MA

3:50 p.m. Audience Discussion

4:10 p.m. Symposium Assessment/Next Steps

Mark S. Smith, M.D.
Audience

4:45 p.m. Adjournment

Donald Lindberg, M.D.
Mark S. Smith, M.D.

INTRODUCTION

Mark S. Smith, M.D.

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Clinical Professor of Emergency Medicine
The George Washington University School
of Medicine and Health Sciences
Washington, DC

This opening welcome highlights the unique focus of the symposium—information technology and its application to early recognition and treatment of patients with potential heart attacks—and the sponsoring agencies that made the symposium possible.

Welcome to the symposium, “New Information Technology and the National Heart Attack Alert Program: Setting a 5-Year Agenda.” This is a unique symposium for several reasons. First and foremost, the symposium is unique because of its subject: the intersection of the National Heart Attack Alert Program (NHAAP) with the discipline of medical informatics.

The NHAAP is part of the National Heart, Lung, and Blood Institute (NHLBI). The mission of the NHAAP is to reduce morbidity and mortality from acute myocardial infarction (i.e., heart attack) through early recognition and treatment of these patients. The scientific basis underpinning the NHAAP is that if time is reduced from the onset of symptoms of a heart attack to delivery of the *right* therapy, lives can be saved and substantial long-term cardiac damage can be avoided. The NHAAP has been in existence for 6 years and has been very successful at improving emergency department (ED) management of the patient with symptoms and signs of a heart attack.

The NHAAP faces three distinct challenges in the future: how to shorten the access time to definitive care for the patient with symptoms and signs of a heart attack, how to help ensure that the correct care is rendered once the patient enters the health care system, and how to better measure the outcome of these new programs and interventions. Stated succinctly, the NHAAP must promote improved access, improved decisionmaking, and improved outcomes measurement. The agenda of this symposium is how medical informatics and new information technology can help further and fulfill the mission of the NHAAP.

The idea behind the symposium is to shine the laser beam of medical informatics onto the challenges faced by the NHAAP and see what can result. This is not a generic emergency cardiology conference nor a generic medical informatics conference. This is a marriage of two disciplines, the intersection of two worlds that are orthogonal to each other. The purpose of the symposium is to explore what happens at the crossing point.

The goal of the symposium is to develop an agenda of innovative ways in which the domains of information

technology and medical informatics can be used to help fulfill the NHAAP’s mission, and proposals for new programs and projects that could and should be undertaken and completed in the next 5 years. The proposals must meet only two criteria: they have to involve an application of new information technology and they have to be in the service of the mission and goals of the NHAAP.

This is also a unique symposium because it brings together an unprecedented collaborative effort of three respected Federal agencies as cosponsors of the event: NHLBI; the National Library of Medicine; and the Agency for Health Care Policy and Research. It is relatively unusual to have dual Federal agency cosponsorship of a program such as this, much less tri-agency cosponsorship.

Finally, the symposium is unique because it utilized a novel method for generating ideas for presentation. The symposium issued an “RFI,” a “Request for Ideas,” over the Internet. The call for contributions was posted on the World Wide Web and on various mailing lists and professional societies. The RFI garnered 96 responses, several of which were chosen for presentation at the symposium.

The symposium is structured in two parts. The first part is a series of six tutorial presentations—three covering issues of the NHAAP and three covering topics in informatics. The second part consists of presentations of specific ideas and proposals for how information technology can further the mission of the NHAAP. The purpose of these tutorials is to give everyone, regardless of his or her background and discipline, a similar core level of knowledge. Those familiar with the NHAAP need to be conversant with key issues in medical informatics, and those who are informaticians need a comprehensive overview of the issues facing the NHAAP.

James Atkins, M.D., will present an overview of the NHAAP—its goals, missions, and accomplishments. Craig Feied, M.D., will host a tour of the world of the next generation Internet. Paul Clayton, Ph.D., will speak about the thorny issues of privacy, confidentiality, and security. Robert Zalenski, M.D., will cover the emergency physician’s diagnostic decisionmaking process. Clement McDonald, M.D., will speak about the very important topic of databases and data standardization. Joe Ornato, M.D., will close the tutorial section of the program with an exposition about the real, social, psychological, and behavioral obstacles to the NHAAP’s achievement of success.

The second part of the symposium comprises idea presentations. There will be 24 presentations of ideas about how new information technology can further the mission of the NHAAP. The presentations are organized around five informatics domains: telehealth; education; medical records access; diagnostic and therapeutic decision support; and large-scale database entry, access, and mining.

The specific proposals that were selected for presentation were chosen by five task forces comprised of experts in informatics and emergency cardiac care. Each task force was responsible for the presentations in one of the five informatics domains. Each of the task force chairs and vice-chairs solicited topics and speakers to present their visions and ideas for the future.

There are certain premises underlying this symposium. The first is that the single most important and influential scientific advance and major force that will change clinical medical care in the United States in the next 10 years is the application of new information technologies and the discipline of medical informatics. The application of new information technology to the practice of medicine will transform the landscape of the practice of medicine, more so than any particular diagnostic or therapeutic advance. In general, the field of medicine has lagged behind other disciplines and industries in the application of that technology. The next 10 years will be dramatic and dizzying—part catch-up and part envelope-pushing.

This symposium is also borne out of the belief that sometimes the best way to change things is not to tackle a problem head on, but rather to approach it obliquely, to think laterally. This is especially true when talking about changing human behavior, which is really at the core of the challenge facing the NHAAP. People must be able to decide to become patients and seek care within minutes and not within hours of their experiencing the symptoms of a heart attack.

What information technology can do is change the landscape and effect changes in behavior that otherwise would take countless frustrating hours of trying to reshape old patterns with little success. New information technology provides the tools to approach human behavior problems obliquely. Human beings are complex systems. It is neither desirable nor possible to control 100 percent of the behavior

of such a complex system. The key is to find the 15-percent leverage point and let the remaining 85 percent self-organize into a desirable configuration.

Permit me a personal story that illustrates why knowledge and education alone are probably not sufficient to change a patient's behavior of not seeking care immediately after symptoms of a heart attack occur, and why a technological solution may well be one answer. Several months ago, I awoke at around 1:00 a.m. with terrible substernal burning. By all measures, I constitute an educated consumer. I know the symptoms of a heart attack. I teach the symptoms of a heart attack and what to do if one experiences them. If anyone had the symptoms that I was having and asked me what to do, I would tell them to either be driven to the hospital by their spouse or to call 9-1-1. What did I do? I stumbled into the bathroom, took some antacid, and went back to bed, hoping that what I was having was the heartburn of esophagitis and not the pain of a heart attack. I had a fair amount of anxiety at that time and was planning what would happen if I was wrong. But I shied away from the inconvenience, embarrassment, and disruption of calling an ambulance and going to a hospital ED.

What would I have liked at that moment? I would have liked to have had a home ECG machine that I could have strapped onto myself, taken a tracing that would have been compared automatically to my previous ECG that was stored, and then be informed by the machine whether or not ST-segment elevation or some other change from my previous tracing was present. This is an information technology solution to what is perceived as a human behavior problem.

The goal of this symposium is to venture into uncharted territory by using new information technology to develop innovative and different approaches in the service of the mission of the NHAAP.

THE NATIONAL HEART ATTACK ALERT PROGRAM: ITS MISSION AND ITS ACCOMPLISHMENTS

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This tutorial session provides an overview of the history and goals of the National Heart Attack Alert Program (NHAAP).

During the past 50 years, the National Heart, Lung, and Blood Institute (NHLBI) has made significant contributions to improving the quality of care of people with heart disease, lung disease, and other blood vessel disease. There have been significant reductions in mortality rates from cardiovascular disease. The number of deaths per 100,000 population peaked in 1964 and 1965.¹ Since that time the population has significantly increased and the number of individuals over 65 years of age has dramatically increased; both factors would be anticipated to increase the number of deaths from cardiovascular disease. In spite of the increased population and older age, the absolute number of deaths decreased from a high of 1.06 million to 918,000 in 1992. Since 1992, the absolute number of deaths from cardiovascular disease has increased to the 940,000 to 955,000 range. This represents an absolute decline of more than 100,000 deaths since 1972.¹ Such a decline in mortality is particularly impressive considering that during this period the percentage of the population over age 65 has quadrupled. In addition, the average life expectancy has increased by 6 years, with 4 of those years most likely due to improvements in cardiovascular care.

The results from a study done in Minneapolis/St. Paul, Minnesota,² show that from 1970 to 1990, both in-hospital and out-of-hospital mortality rates for men due to cardiovascular disease declined significantly. Mortality data for women also indicated a decline but at a lower rate than that for men. In 1984, the total mortality for women equaled that for men for the first time. Currently, more women than men die from all cardiovascular disease.³ Therefore, addressing cardiovascular disease in women will be one of the challenges for the NHAAP in the future.

Time is an essential element in treating cardiovascular disease, and a similar course of action should be applied to heart attack patients as is currently applied to trauma patients. The phrase, "the golden hour," has been adopted by surgeons to highlight the importance of providing treatment quickly to trauma victims. Prompt treatment is equally critical for cardiac arrest victims. There is a 0 to 2 percent chance that cardiac arrest victims will survive if an ambulance arrives and paramedics defibrillate at

approximately 10 minutes. If a bystander administers cardiopulmonary resuscitation (CPR) within 10 minutes, approximately 2 to 8 percent will survive. In addition, if CPR is administered and the victim is defibrillated within 7 minutes, 20 percent will survive. The survival rate increases to 30 percent if CPR is administered within 2 minutes and defibrillation occurs within 4 minutes.⁴

The same trends occur in patients with acute myocardial infarction (AMI) and acute coronary syndromes. With medical advances such as thrombolytic therapy and acute interventional angioplasty, lives can be saved. The earlier the intervention, the greater the number of lives that can be saved. Data from the Myocardial Infarction, Triage, and Intervention trial demonstrate a reduction in mortality from 12 percent to less than 1 percent if interventions are begun within an hour of the onset of symptoms. The average amount of muscle loss can be reduced from approximately 15 to 18 percent, to less than 5 percent in 80 percent of the patients.⁵

Many studies have addressed the issue of delayed treatment and have calculated mean and median times. Mean times are not as valuable an indicator because they are skewed by extremes (e.g., one person who waits 38 hours before deciding to seek treatment may offset many who decide within an hour of onset of symptoms). Although median times appear to have improved, studies have indicated that the median time is at least 2 hours. Transport times and time spent in the emergency department before treatment are considerations. All of these times must be decreased in order to reduce mortality rates.

Initiation of the NHAAP

In 1990, the NHLBI sponsored a symposium that addressed the need for a national education program focusing on reducing morbidity and mortality from AMI. The structure for this program was developed at this symposium and the NHAAP was launched in 1991. The initial goal of the program was to reduce morbidity and mortality from AMI, including sudden cardiac death, through rapid identification and treatment of individuals with symptoms and signs of AMI, thereby heightening the potential for an improved quality of life for AMI patients and those around them. This goal has since been broadened to include patients with acute coronary syndromes.

At the 1990 symposium, three phases of the treatment process were identified: patient/bystander recognition and action, prehospital action, and hospital action. The NHAAP first addressed the prehospital and hospital phases because implementing an effective medical response system appeared to be a logical first step. For example, an effective 9-1-1 system should be in place nationwide before a public campaign encouraging patients to use that resource is implemented. Methods have not yet been identified for intervening in the patient/bystander phase.

Hospital Phase

One of the first undertakings of the NHAAP was the 60 Minutes to Treatment Working Group report headed by Drs. Mark Smith and Costas Lambrew. The report, "Emergency Department: Rapid Identification and Treatment of Patients with Acute Myocardial Infarction," was published in 1994 in the *Annals of Emergency Medicine* and as a Government Printing Office (GPO) document by the same name in 1993. The recommendations from this report have been widely quoted and accepted. In this report, critical timepoints were identified at varying stages where delays from door-to-drug time are likely to occur in the emergency department. The report provides recommendations on how to reduce delay at these stages utilizing a continuous quality improvement process. Each step of this complex process requires intervention.

Several studies have demonstrated a substantial reduction in the time that elapses from the patient's arrival at the emergency department until thrombolytic therapy is administered. In 1988, the average door-to-drug time was 144 minutes; in 1991, 72 minutes; in 1993, 46 minutes; and in 1994, 21 minutes. Some hospitals have reported times as low as 15 or 16 minutes (verbal presentations).

Patient/Bystander Recognition and Action Phase

A report from the NHAAP targeting the patient/bystander recognition and action phase was published in 1993 as a GPO document titled "Patient/Bystander Recognition and Action: Rapid Identification and Treatment of Patients with Acute Myocardial Infarction." This report identified a number of key factors that influence the time that elapses before a patient decides to seek treatment. Factors such as lay consultation with a spouse or friend, medical consultation, and self-treatment may increase the delay time. Lay consultation occurs 93.2 percent of the time, with the greatest delay being caused by consultation with a spouse, followed by consultation with a friend, a coworker, and a stranger. If a spouse is consulted, denial on the part of both spouses and an unwillingness for them to confront one another may contribute to a lengthy delay. Past medical history, such as a history of diabetes mellitus or stable angina, has been shown to be a factor in increased delay. With the latter, the patient might have difficulty determining whether the symptoms were indicative of angina or a more acute condition. Demographic factors that have been shown to increase the delay time include older age, being female, African-American race, low socioeconomic status, and a low educational level. Also, daytime onset or being at home during onset of symptoms may contribute to delay.

Certain conditions have been shown to decrease delay time; for instance, whether the patient recognizes the symptoms as cardiac in origin, whether the pain is severe, or whether the patient is hemodynamically unstable. Being at work during the onset of symptoms also decreases the delay time. Factors that do not appear to have an effect on the delay time

include personality type, a prior cardiac event, and having heart failure, hypertension, or known coronary artery disease. Education about cardiovascular disease hopefully decreases the delay time, but results to date on this aspect have been mixed. The results of the NHLBI-funded Rapid Early Action for Coronary Treatment trial should provide more guidance.

Prehospital Phase

The emergency medical services (EMS) system is a complex system with many components. These components include discovery, the bystander's reaction, access into the EMS system, dispatching, on-scene activities (e.g., assessing, resuscitating, and extricating the patient), and transportation to the hospital.

In 1995, the NHAAP published three articles addressing prehospital areas including 9-1-1, staffing and equipping EMS systems, and emergency medical dispatching. Currently, 86 percent of the U.S. population is covered by 9-1-1 systems. Although many larger cities and suburbs have these systems, they are less likely to be found in rural areas. In fact, a significant portion of the country does not have complete 9-1-1 coverage. When the NHAAP started in 1991, only 2 States (Rhode Island and Delaware) had border-to-border coverage; today that number has been expanded to 20 States. But 30 States still do not have statewide 9-1-1 services and most 9-1-1 centers do not have enhanced 9-1-1. This technology enables a caller's phone number to appear on a center's computer screen as the call is answered, followed shortly by the caller's address that is supplied from a database. This enhancement overcomes the problem of dispatchers not being able to locate an emergency caller who is unable to give a correct address, or callers who become unconscious.

Another problem is that the majority of EMS systems do not have dispatchers who are trained in medical protocols. Although computer-assisted systems are available, most cities do not use them. Recommendations on this and on ambulance staffing and equipment were made in the NHAAP paper addressing staffing and equipping of EMS systems. One of the recommendations—automated external defibrillation—has been widely adopted. Other NHAAP publications related to EMS include an article on the need for community planning, a 1997 article on diagnostic technologies, and several versions of a paper on identifying and treating high-risk patients.

Challenges

Many challenges remain for the NHAAP, posed by the complexity of the emergency medical care process and the intervention options. The process not only involves many steps but also many components, such as patients and bystanders, the EMS system, and the hospital. These components each involve technology, but the technologies are not always integrated into a systems approach. The

intervention involves both psychological and sociological considerations. One-third of patients with an AMI do not display even moderately classical symptoms, and the symptoms are difficult for patients to differentiate from indigestion. There is not a straightforward, simple message for the patient, family, and bystanders; rather, the goal is to enable the patient to recognize a range of symptoms and then initiate a chain of events that involves multiple players.

Health maintenance organizations (HMOs) and preferred provider organizations (PPOs) are concerned about the costs to the health care system for patients with no disease, and there also are psychological costs to these patients. There also are concerns about how to frame messages given to women to encompass their increasing risk as they age. And to target high-risk patients, one must be able to identify them; one-third of people who experience an AMI or sudden cardiac arrest do not know that they have cardiovascular disease prior to the event. Other challenges include countermeasures from many HMOs and PPOs (such as calling the nurse/screener first) and areas that need improvement, including the wider use of enhanced 9-1-1 systems, training of EMS dispatchers, and improved triage in emergency departments.

Future Goals

In 1996, upon completion of its first 5 years, the NHAAP held a retreat meeting at which goals were developed for the future. These goals included the following: to use evidence-based evaluation of diagnostic technologies, strategies, and protocols to identify quickly patients with acute coronary syndromes in the emergency department; to develop a health care system and community-planning approach to integrate the messages of the NHAAP; to apply new information technologies to the goals of the NHAAP; and to improve the education of professionals, high-risk patients, other patients, and bystanders. In addition, the NHAAP plans to address the problem of patients discharged from emergency departments who have been ruled out for an AMI but who may have future cardiac events. Presentation to the emergency department provides an opportunity to train patients to recognize symptoms and to encourage them to call for help if these symptoms occur.

Hopefully, achieving these goals will help further reduce the time from onset of symptoms to treatment and, therefore, reduce the loss of lives. Technology can contribute to these goals by facilitating the development of an organized, integrated system that will provide the fastest, most effective assistance to patients.

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TELECOMMUNICATIONS AND THE NEXT GENERATION INTERNET

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This tutorial presentation provides an overview of the past, present, and future of telecommunications—including the next generation Internet.

The Evolution of Connectivity

Before the advent of the telephone, information exchange was, with few exceptions, limited by the need for face-to-face conversations or the delivery of written documents. Lengthy delays (a high latency) attended information exchange over any significant distance, and these delays largely defined the communal life of a country in which news of a presidential election could take several weeks to cross the continent. Technological innovations such as the railroad and the telegraph allowed a more speedy exchange of written information, but it was not until the widespread adoption of the telephone that person-to-person interaction at a distance became possible. The telephone eliminated some of the natural constraints of distance and catapulted the world into the first era of rich information exchange.

This ability to exchange information can be called “connectivity”—the ability to give to other people information that we possess, and to receive from other people information that we want. The more rapidly we can exchange information, the richer the types of information that we can exchange, and the larger the universe of people

with whom we can exchange information, the greater the degree of connectivity we enjoy. Since the introduction of the telephone, the maximum achievable degree of connectivity has grown dramatically, and this growth has had a transforming effect on a society that has become increasingly dependent on information transfers for the economic, political, business, and personal vitality of its citizens.

Initially, the telephone created small islands of connectivity with large gaps between them. In the 1870's, the earliest telephone installations connected up to 48 subscribers on a single exchange. All subscribers had to be within a fairly close geographic proximity, and there was no connection between any two exchanges. In larger cities, many different companies operated telephone exchanges, and calls could not be connected between competing companies. End-to-end voice connectivity came about only when one telephone company succeeded in obtaining a monopoly, eventually unifying the entire country within a single proprietary standard for telephone connectivity. It is now difficult to imagine a life without telephones, but the public was initially slow to accept them. The first branch exchanges were installed in 1877, and it was not until 50 years later that the number of telephone subscribers reached 20 million.

In contrast to hard-wired telephony, mobile cellular telephony was adopted very rapidly. Once considered so unlikely a concept that they appeared only in science-fiction novels, 20 million cellular telephones were installed in the first 9 years after their introduction in 1985. At the beginning of 1998 there were more than 50 million cellular telephones in use in the United States. Rapid growth in the number of cellular telephones continues to be fueled by portable units that are ever smaller and ever cheaper, a trend that is exemplified by the recent introduction of a cellular telephone built into a wristwatch.

Just as telephony created a tremendous network of voice connectivity, other devices have piggybacked onto the telephone network to add richness and complexity to that connectivity. The first of these was the facsimile machine, permitting the rapid transmission of a document between two standard units that can be attached to any telephone instrument anywhere in the world. When facsimile transmission first became available, few people recognized its value and importance, but the speed and convenience of facsimile transmission eventually became widely recognized. Today, facsimile equipment is nearly ubiquitous, adding significantly to the richness of global connectivity as compared to voice-only connections.

During the 1970's and 1980's, computer systems were also being piggybacked onto the voice communications network. With a computer at each end of the line, not only could a facsimile of a document be transmitted over great distances, but the editable content of the document could also be sent as a computer file. Large numbers of computer enthusiasts

subscribed to a tremendous network of public-access file exchange systems known as "bulletin board systems." The system was effective, but cumbersome, because a direct telephone connection between the two machines was needed. Like an isolated telephone branch exchange, a bulletin board system was an island of connectivity because it could serve only a few people in an isolated geographic area and could not route files or messages to people using other systems in other areas.

In the 1990's the widespread adoption of TCP/IP, a standard for exchanging messages between computers from different manufacturers, facilitated the development of local-area networks (LANs) of interconnected computers and then of connections between networks to form "internetworks." For the first time, information could be freely exchanged between any two computers connected to any part of a far-flung network of networks, known collectively as "the Internet."

The number of Internet-connected computers grew from 0 to 20 million in the first 4 years of its existence. As of July 1998, there were nearly 37 million host computers registered as accessible in the Internet domain name system (DNS), with many more host systems connected to the Internet but not registered for public access. This level of connectivity is without precedent: for the first time, it has become possible to obtain information on virtually any topic at exactly the place and time at which the information is needed. If the Internet continues to grow at this same phenomenal rate, by the year 2002 there will be one computer connected to the Internet for every man, woman, and child in the United States.

Underlying Communications Technologies

Whether by voice, by facsimile, or by computer connection, modern communication depends upon the underlying telecommunications technologies that link together buildings, cities, states, and countries. The power of a particular mechanism for information exchange depends partly on the highest speed with which a very small amount of information can be sent (the latency) and partly on the amount of information that can be sent per unit time (the bandwidth). An overnight delivery of a shipping crate full of documents has a high latency (it takes an entire day for a single bit of information to be delivered) but also has a high bandwidth (a huge amount of information can be transferred per day). A flashlight used by a Girl Scout to transmit Morse code has a low latency (the first bit of information is delivered at the speed of light) but also has a low bandwidth (very little information can be transferred per day). With the exception of satellite connections, modern telecommunications modalities typically have a low latency, but the amount of bandwidth varies greatly from modality to modality.

Voice Origins of Digital Communications Circuits

Today many different kinds of information are delivered through telecommunications links, but these links are not optimized for the traffic they carry because they were originally developed solely to carry human voices. The microphone inside a telephone handset converts a sound wave into a continuously varying voltage (an analog signal). The sound waves from a normal human voice oscillate up to 4,000 times per second; thus, an analog voltage signal representing that voice will have up to 4,000 cycles per second, or 4 kilohertz (kHz). This 4 kHz signal can be sent through the wires directly as an analog (continuously varying) voltage, or it can be digitized and sent through the wires as a series of high and low voltages representing digital ones and zeros (a digital signal). End-to-end analog connections are rare today: in most cases an analog voice signal goes from the telephone handset through a “local loop” to the telephone company branch exchange, where it is converted from an analog to a digital signal and passed along to a destination branch exchange. At the destination exchange, the signal is converted back into analog form and sent through the “local loop” wires to the telephone handset at the other end.

When a 4 kHz human voice is converted from an analog to a digital signal, it requires two digital samples per cycle and eight levels of measurement per sample; thus, $4 \times 2 \times 8 = 64,000$ bits of information per second (64K bps). A single 64K bps channel is often referred to as a “basic channel” or “B-channel,” and most high-bandwidth connections are defined as multiples of this channel. For example, an Integrated Services Digital Network (ISDN) line carries two digital B-channels, or a total of 128K bps. A leased T-1 line offers 24 B-channels plus one-eighth of a channel used for timekeeping, for a total of 1.544 million bits per second.

When an “end-to-end” digital circuit is available to connect two computers, all of the potential bandwidth of the circuit is available for sending and receiving information. When some part of the circuit must carry an analog signal, however, some of the potential bandwidth is lost—the computer’s digital signal is converted from digital (at the sending end) to analog (at the telephone connection) to digital (at the sending telephone company branch exchange), to analog (at the receiving telephone company branch exchange) and finally back to digital (at the receiving computer). A conversion from digital data to an analog signal and back to digital again is known as modulation-demodulation, hence the term “modem.” Similarly, when an analog voice signal is converted to a digital signal and back again, the term “coder-decoder” or “codec” is used.

With a pure digital connection, the 64K bps of a B-channel can carry a full 64K bps of data, but the same channel used with a modem at each end carries much less data. Modem technology originally permitted only 120 bps through a B-channel, but evolved over a 30-year period to support higher transmission rates over the same basic channel.

Today a standard B-channel modem can transmit or receive 38,400 bps when connected to another modem, and data rates can go as high as 56,000 bps in special situations where one end of the circuit is digitally terminated.

High-Speed Digital Landlines

Under the right conditions, a four-wire copper wire circuit can be made to carry as many as 1 billion bps (gigabit, or 1G bps), but this type of transmission requires high-quality lines and expensive line conditioners and can run only short distances before signal regeneration is necessary. In contrast, light passing along a single fiber of spun glass can carry 2.4 billion bps and the fiber can run 200 miles between regenerators. For this reason, high-speed network traffic today is carried almost exclusively over fiberoptic cable.

Compared to new copper wires, fiberoptic cable is very cost-effective. When fiber cable is made, many fibers are bound together in a single bundle. Only a single fiber strand is needed to make a high-bandwidth connection, and there is a large amount of still-unused capacity (known as “dark fiber”) remaining in most cable runs. Advances in a technique known as “wave-division multiplexing” have increased per-strand bandwidth by making it possible to send and receive data encoded into many different wavelengths of light through the same fiber strand all at the same time. The amount of data that can be carried by a single fiber strand has been increasing rapidly, and is likely to continue to increase over the next few decades.

With the same amount of data being squeezed into narrower and narrower parts of the visible spectrum, there is no theoretical limit to the potential future data-carrying capacity of fiber connections. Today, commercially installed synchronous optical network (SONET) systems carry voice and data traffic in a digital format at channel speeds up to 2.4G bps. Laboratory prototype SONET channels now handle up to a trillion bps (1T bps).

In the United States, fiberoptic cables now connect every main telephone company exchange as well as many local branch exchanges and commercial buildings. Unfortunately, it has not proven cost-effective to run new glass fiberoptic cables the “last mile” into every home and office. For this reason, there remains a great interest in new technologies that can improve data transmission over existing copper wires. The principal “last mile” solutions being deployed today are “cable modems” that can transmit data over the coaxial cable used for cable television and “digital subscriber lines” (DSL) that use special conditioners to boost the digital speed of existing copper loops belonging to the local telephone system. Under the proper conditions, each of these can be a cost-effective solution carrying anywhere from 750K bps to 64M bps of data.

Computer Connectivity Over Cellular Telephony

When digital data are sent over wireless radiotelephone circuits, there is another added layer of complexity.

The radio frequency spectrum is a scarce resource, and current cellular technologies use a variety of tricks to squeeze every possible bit of voice traffic into the limited bandwidth. The first trick used is just to throw away data: so long as the speaker is recognizable, voice quality can be sacrificed to save bandwidth. A pure analog cellular telephone voice channel can carry only about 48K bps, rather than the 64K bps carried by an analog landline. Other digital and hybrid systems encode and compress a voice signal using algorithms that can deliver a recognizable voice using much less bandwidth. The resulting cellular channels are adequate for voice transmission, but when used with a computer and a modem, they provide much less bandwidth than a voice-quality landline. Many applications that work well when a laptop is connected through a modem and a landline will fail miserably when the same laptop is connected through a modem and a cellular phone connection. This bandwidth problem severely limits the connectivity of mobile systems such as those in ambulances and helicopters. Of all the digital systems, only Code Division Multiple Access (CDMA) systems can deliver usable data rates over a single channel. Unfortunately, CDMA is not a good final solution for mixed voice and data transmission, because adequate data bandwidth is only obtained at the expense of other cellular users who share the channel. Figure 1. shows the maximum amount of digital data that can be delivered over different types of cellular channels compared to the amount that can be delivered over a landline.

Satellite Telecommunications

Communications satellites may be grouped into three broad categories according to the height at which they orbit the Earth. The period of an orbit depends upon its distance from the Earth: the greater the distance from the Earth, the slower the orbit. At a distance of 22,241 miles above the Earth's surface, the orbital period is precisely 24 hours, and the orbit is called "geosynchronous." If a satellite in a geosynchronous orbit travels in exactly the same direction

as the Earth's own rotation, the satellite can remain above the same spot on the Earth at all times. Such an orbit is called "geostationary." Because they are so high above the Earth, a single geostationary Earth orbit (GEO) satellite can transmit to nearly an entire hemisphere. Despite this advantage, GEO satellites are poorly suited to voice communications and other real-time applications because data transmission, signaling, and receipt acknowledgment over this great distance introduces an overall round-trip latency of approximately one-half second. The high power and large satellite dish required to send a signal from the earth up to a receiver at so great a distance also makes GEO satellites a poor choice for two-way communications. GEO systems have found their principal niche in applications that require one-way broadcasts of information, such as digital television and digital data downlinks.

Medium Earth orbit (MEO) satellites orbit at 6,000–12,000 miles above the Earth, and although they move with respect to the ground, each satellite can cover a lot of the earth and can stay within view of a single ground-receiving station for a long time. A moderately large satellite dish and a lot of power are required to transmit from the ground to an MEO satellite, but round-trip signal latency is acceptable for voice communications. Inmarsat and TRW mobile communications systems use MEO satellites both for voice and for private network data transmissions at up to 9,600 bps over a standard channel.

Low Earth orbit (LEO) satellites have a short signal latency and are close enough (100–600 miles above the Earth) that hand-held cellular telephones can connect to them using a low-power transmitter and a standard antenna. Because they are so close to the Earth, LEO satellites must travel about 17,000 miles per hour to remain in orbit, circling the globe about every 90 minutes. As of this writing, there are no global commercial telephony services operating via LEO satellites, but the first such system ("Iridium") has 66 active LEO satellites already in orbit 420 miles high and is scheduled to offer cellular satellite telephone service

Figure 1. Basic Channel Bandwidth

Standard landline:

- 56K bps with standard modem in optimum configuration
- 64K bps if digital

Analog cellular connection:

- 33.4K bps with typical modem
- 48K bps maximum with a custom-designed modem

NA-TDMA

(North American Time Division Multiplexing):

- 8K bps if a standard modem is used with a cell phone containing a codec
- 16K bps if the system permits a digital signal

EU-TDMA

(European Time Division Multiplexing):

- 13K bps if a standard modem is used with a cell phone containing a codec
- 33K bps if the system permits a digital signal

CDMA (Code Division Multiple Access):

- 13K bps if a standard modem is used with a cell phone containing a codec
- 48K bps if the system permits a digital signal

worldwide commencing in the last quarter of 1998. Prototype satellites have also been launched for another system (“Teledesic”) that proposes to place 288 satellites into orbit 339 miles above the ground, linking them together to create an “Internet in the sky.” Teledesic ground stations will use small roof-mounted satellite dishes that will give each home or office a high-speed wireless connection carrying 64M bps, a capacity 2,000 times greater than a current analog modem and 6 times greater than most hardwired LAN connections.

Figure 2. shows the time it would take to download the 16 megabyte Netscape 4.0 Web browser via several different types of connections.

Growth and Congestion of the Internet

The power of the Internet to transform society cannot be overstated. In a few short years, this network of networks that allows an immediate exchange of data between any two computers nearly anywhere in the world has become not only ubiquitous, but essential to the functioning of many industries.

The Internet as it exists was never planned nor developed by any formal group. It grew upon the scaffolding of existing telephone and computer connectivity, and came into existence mostly as the result of the independent efforts of scattered visionaries working in laboratories at universities

and colleges, in the Government and military, and in private industry. Two decades of underlying work was largely funded by military and government grants supporting research in a variety of seemingly unrelated areas, much of it aimed at providing distant connections to supercomputers and other shared resources across the country.

The United States has benefited greatly from a position of leadership in worldwide connectivity. Increased production and an improved competitive position in the worldwide economy are just two of the many ways in which the connectivity of the Internet has made a difference. Unfortunately, some of the benefits of this connectivity are being eroded away by the very success of the Internet. Other countries are increasing their presence on the Internet and are moving forward in ways that may well erode the commanding lead the United States has enjoyed in technology fields. Private enterprise and governmental agencies are afraid that the country will lose its competitive edge now that the rest of the world has become heavily committed to the Internet.

At the same time, the network bandwidth available for research and development has been nibbled away by private and commercial users. University, Government, private lab, and military researchers once enjoyed the exclusive use of a network with bandwidth more than ample to meet the needs

Figure 2. Time to Download 16-megabyte File

Connection	Speed	Download Time
Modem (circa 1975)	120 bps	12 days
Modem (circa 1980)	300 bps	5 days
Modem (circa 1984)	1,200 bps	30 hours
TRW or Inmarsat satellite modem	9,600 bps	4 hours
Digital cell phone with modem	13K bps	2.7 hours
Modem (circa 1992)	28.8K bps	75 minutes
V.34 modem (circa 1994)	38.4K bps	56 minutes
V.90 modem (circa 1998)	56K bps	38 minutes
Dual ISDN	128K bps	17 minutes
Cable TV modem	750K bps	3 minutes
T-1 leased line	1.544M bps	83 seconds
Ethernet LAN	10M bps	13 seconds
T-3 leased line	45M bps	2.8 seconds
VDSL digital subscriber line	54M bps	2.3 seconds
Teledesic satellite connection	64M bps	2 seconds
Fast ethernet LAN	100M bps	1.3 seconds
Gigabit ethernet LAN	1G bps	0.13 second
SONET OC-48 fiber-optic channel	2.4G bps	0.05 second

of any achievable project. Today, new applications demand more and more bandwidth as research capabilities continue to improve, yet researchers find that their high-speed connections to important resources are slowed to a crawl as Internet traffic continues to rise beyond all expectations. At the current rate of growth, by the time the next generation of applications are released there will be so much Internet traffic congestion that the system would hardly be functional at all.

Next Generation Internet and Internet 2

The recognition of certain shortcomings in the current Internet and the desire for continued growth and leadership in technology have sparked several initiatives to underwrite the development of a “new Internet.” Just as the current Internet has led to profound and unforeseen changes in our ways of life, a next generation version might permit the development of as-yet unimagined applications that could continue to redefine modern life as the current Internet does today. Two main initiatives are underway in support of many different groups working to bring this future vision to life. The first is known as the “Next Generation Internet” (NGI) initiative, and the second is known as the Internet 2, or I2, initiative. The two share many of the same goals but have different constituencies and complementary approaches to the goals.

NGI

The NGI initiative (<http://www.ngi.gov/>) is a multi-agency Federal research and development program with three goals: to connect national laboratories and universities with high-speed networks that are 1,000 times faster than today’s Internet, to promote experimentation with the next generation of networking technologies, and to demonstrate new applications that require advanced networking to meet important national goals and missions.

In an effort to replicate the dynamics that led to the creation of the current Internet, a 1998 Federal investment of \$100 million was allocated as a catalyst for additional investment by universities and by the private sector. The initiative is directed by the National Coordination Office for Computing, Information, and Communications (<http://www.ccic.gov/>), and the principal agencies involved have been the National Science Foundation (NSF), the Defense Advanced Research Projects Agency, the Department of Energy, the National Aeronautics and Space Administration, the National Institute of Standards and Technology, the National Institutes of Health, and the National Library of Medicine. Most of the project focus is on building a new, very-high-speed network infrastructure to support national goals. The NGI initiative is a logical outgrowth of the existing High Performance Computing and Communications initiative, and all high-performance mission-specific networks now operated by Federal agencies are elements of the NGI initiative, which builds upon such networks as the NSF’s very-high performance Backbone Network Service (vBNS).

Internet 2

The Internet 2 (<http://www.internet2.edu/>) initiative is a project of the University Corporation for Advanced Internet Development (UCAID) (<http://www.ucaid.edu/>), a collaborative effort by more than 120 universities together with their research partners in industry and government. The goal of the project is to establish a distributed knowledge system for achieving ongoing innovations in research, teaching, and learning—to develop advanced Internet technologies and new applications that will support the future research and education needs of institutions of higher education.

One Internet 2 goal held in common with the NGI initiative is the effort to connect universities, national laboratories, and private partners with high-speed networks that are 1,000 times faster than today’s Internet, networks that can handle at least 1G bps of connectivity for any user or application that needs it. One often-quoted aim is to be able to transmit and receive the contents of the entire *Encyclopaedia Britannica* in under 1 second. Consortium members have established extremely high-capacity network links to a separate national network with an infrastructure parallel to the commodity Internet, operated by many of the same common carriers. Members connect to the high-speed backbone through special “point-of-presence” service providers that are known as “gigapops” because they can deliver 1G bps of data flow to each connection. Today it costs about \$500,000 in commitments and upgrades for a university to join UCAID and become connected to an Internet 2 gigapop.

The project will demonstrate prototypes for a new generation of high-performance applications that support scientific research, national security, distance education, environmental monitoring, and health care, and that need more speed, more bandwidth, more reliability, and more security than can be obtained using today’s Internet. It is recognized that most of today’s applications would perform better if the existing Internet worked smoothly and reliably within its current design parameters, but I2 is not an effort to improve the speed of today’s Internet connections or to resolve shortcomings in the existing Internet. Instead, the Internet 2 project aims to support the development of new classes of applications that *by their very nature* need substantially higher application-dedicated bandwidth, bandwidth reservation, improved security, guaranteed quality of service, and other advanced features of a new generation network.

Problems With the Current Internet

Improving the current Internet is not a goal of the I2 project, but in order to support advanced “next generation” applications, Internet 2 will address many recognized problems with the current Internet, including problems with network management, end-to-end control, security, reliability, and the need for embedded functions to support

distributed systems. The lack of directory services and of provisions for inter-realm authentication will also be addressed. A new addressing scheme (“Ipv6”) will be implemented, since the current Internet protocol (IP) address space is too small to support the number of devices that now need to be connected.

In building the NGI, the most important function that will be added to IP is a set of “internetworking” protocols for managing the end-to-end connection. Central management was intentionally designed out of IP, because IP is meant to be deliberately nondeterministic in the sense that each information packet traversing the network “finds its own way” to its destination based on the local conditions it encounters along the way. This makes the network self-healing, as individual packets can be independently routed around broken connections or highly congested areas. Unfortunately, because there is no mechanism for sharing information about global conditions along an entire path, each packet can be re-routed only *after* a problem is encountered. Internet 2 will improve the sharing of knowledge about distant conditions along a desired route and will permit more sophisticated route management.

The ability to guarantee delivery is another important function missing from the current Internet, which uses a delivery service called “best-effort” delivery. “Best-effort” means that all packets are accepted from all senders, and are sent on their way whenever possible. If there is too much traffic at a particular router, that router randomly discards packets without any concern for where they are coming from or where they are going. Not only is there no guarantee of timely delivery, there is no guarantee of delivery at all. If an expected message or response fails to arrive, the sender and the receiver will negotiate a resend of the incomplete data, in which case even more packets have to be handled by the network. This is satisfactory for the exchange of e-mail messages, but not for a mission-critical system that needs guaranteed delivery with a guaranteed maximum latency.

Along with guaranteed delivery, Internet 2 aims to improve the end-to-end quality of service of the network by recognizing that while dependability and reliability are critical quality parameters for all applications, different applications have different networking needs. A text file transfer can tolerate a 10-second delay in delivery, but a command going to a robotic control system in a nuclear power plant cannot safely be delayed. Under Internet 2, quality of service (QOS) controls will permit applications to reserve a specific quality of service from the network and to be guaranteed that the reserved latency and bandwidth will be available when needed. Electronic commerce will be able to obtain secure delivery guarantees. Real-time audio and video services will be able to reserve bandwidth and to obtain guarantees of maximum packet loss rate and jitter. Even when an application makes no quality-of-service

demands, new “type-of service” (TOS) headers can help routers to know what type of material is included in each packet. If a Web page request and a fragment of a telephone conversation are competing for the same slot, the router can make intelligent decisions about prioritization. TOS can actually reduce congestion in absolute terms, because preferential delivery of an acknowledgment packet prevents the original material from being resent by the sender.

One implication of the availability of quality-of-service controls and multicast capability expected in the next generation Internet is that Internet 2 will be far more hospitable than today’s Internet to connecting very large numbers of sensors. The capacity to make large amounts of “public” shared sensor telemetry available to the Internet 2 community represents an exciting opportunity to explore new classes of applications. The ability of the network to handle large amounts of data that is irrelevant to most people might be seen as the very definition of today’s Internet, but in reality it is easy to swamp nearly any real-life network segment by attempting to pass real-time telemetry data for any complex event or series of simple events. I2 promises to allow such data to exist on the network without interfering with other applications.

As an example of the potential for this kind of sensor-based data, consider that today there are a few stores whose inventory is managed across the Internet, and there are a few IP-enabled soft drink vending machines whose contents can be queried by their owners via the Internet. With this sort of sensor data widely available, it may soon be possible to query from any public point of presence and learn in a few seconds where the nearest cola brand of your choice is available—including both stores and vending machines. Another example of IP-enabled equipment that is being widely deployed is vehicular traffic sensing units that report local traffic conditions on a constant basis. When enough of these have been deployed, it will be possible to receive a constant stream of sensor-provided data about traffic load at most busy intersections across the country.

Prototype Health Care Applications of the NGI

The NLM has a history of sponsoring health care activities related to high-performance computing and communications, and now is funding the development of a variety of health care applications that will use and require the next generation Internet. Areas of particular interest to the NLM include advanced telemedicine, digital libraries, distance learning, image distribution, and other medical applications that require the high-speed transfer of large amounts of data. Other funding agencies are also underwriting the development of advanced applications in health care that can serve as demonstration projects for the next generation Internet. Medical applications can qualify as NGI applications without involving large data sets or high-speed networking if they require other features of the NGI, such as guaranteed delivery, guaranteed quality of service, or security of private

medical information that is to be transmitted over the public network. There are many examples of NGI and I2—qualified projects that have been funded in the past. Some are from fields other than health care, but they all serve to illustrate the kinds of things that could or should be done in the design of health care projects for NGI.

The virtual temporal bone (VTB) is a shared virtual reality (VR) simulation based on an accurate 3-dimensional (3-D) model of the temporal bone, designed as a teaching aid for residents in otolaryngology who are learning about the anatomy of the middle and inner ear. The VTB project was developed by the Virtual Reality in Medicine Laboratory, the Department of Otolaryngology, and the Electronic Visualization Laboratory at the University of Illinois at Chicago. This is considered an Internet 2 project because the quality of service and end-to-end bandwidth made available by Internet 2 will be necessary to share this application between educational institutions. More information is available at <http://www.sbhhs.uic.edu/vrml/>.

The Collaborative Architectural Layout Via Immersive Navigation (CALVIN) is a testbed for applying VR in architectural design and collaborative visualization that uses multiple perspectives in an effort to take advantage of VR in the earlier, more creative phases of the design process, rather than just as a walkthrough of the final design. CALVIN is being used to investigate issues in collaborative VR, including network needs, avatar representations, audio and video communication, and unusual user interfaces. This is considered an Internet 2 project because for participants to collaborate effectively, virtual environments require high bandwidth and low latency not possible on the current Internet. CALVIN is another project of the Electronic Visualization Laboratory at the University of Illinois at Chicago. More information is available at <http://www.evl.uic.edu/spiff/calvin>.

Some of the most important projects in health care are those requiring shared access to extremely large data sets that cannot be accessed in a reasonable amount of time without the high-bandwidth connections promised by the NGI. The most well-known of the large data sets in health care is the NLM's "Visible Human" data set, a complete, anatomically detailed, 3-D digital representation of the male and female human body. Transverse computed tomograms, magnetic resonance images, and cryosection images of representative male and female cadavers were acquired at 1 millimeter and 0.33 millimeter intervals to make this data set. The female data set is approximately 40 gigabytes in size, and would take 97 days to download through a standard modem in 1998. More than 50 projects and products have been based on the visible human data set, including the 3-D Virtual Colonoscopy project, demonstrating static images and fly-through animations from the Departments of Radiology and Computer Science at SUNY Stony Brook, the Interactive Knee Program from the University of Pennsylvania Medical

Center, and "CathSim," an intravenous training system that includes a tactile feedback device.

Another example of large shared data sets is the Human Genome Project of the National Center for Biotechnology Information (NCBI). These are the most extensive databases on DNA and protein sequence data in existence, and they are very heavily used by researchers around the world. The NCBI Web site attracts more than 2 million hits a day. While the basic search engines serving these data do not require NGI attributes, such attributes may be needed by other applications using large portions of the data set, or by those using it for visualization or rendering.

The "Terabyte Challenge" is a distributed testbed for research into the management and mining of truly massive data sets. Data mining is the automatic discovery of patterns, associations, changes, and anomalies in large data sets. Developing scaleable data mining algorithms, software tools, and applications is a fundamental scientific challenge with important implications for health care as well as for many other scientific and business disciplines. The terabyte challenge project facilitates prototyping of new ideas and software tools and allows them to be tested against large data sets, and against distributed data sets. This is considered an Internet 2 project because the mining of geographically distributed massive data sets cannot be done without high-performance links. The terabyte challenge is a collaborative project of the University of Illinois at Chicago, the University of Pennsylvania, and the University of Maryland. More information is available at <http://www.nscp.uic.edu>.

The term "collaboratory" is a neologism describing a distributed collaborative laboratory. Collaboratories often support teleconferencing as a basic collaboration tool, but more importantly they also permit remote access and collaborative (simultaneous) access to physical resources at a distant site. Collaboratories need not deal with scientific data: an existing music collaboratory ("jam session site") actually allows two or more musicians to practice together over the Internet. At least one CD has been released featuring music that was created and recorded through collaborative telepresence. Another existing collaboratory is a meteorological site that allows multiple users to communicate in real-time while simultaneously displaying weather maps and other streams of meteorological data that are germane to a discussion.

Other interesting wide-area projects provide access to and control of special imaging techniques. Examples have ranged from single-photon imaging in cultured cerebellar granule cells to radio astronomy synthesis imaging, a process in which 27 radio astronomy antennas track the galactic center while the data are recorded, merged, and processed in real-time to show a visible simulation of the Fourier transforms. CMDA, the "Collaboratory for

Microscopic Digital Anatomy,” makes a unique research tool available over Internet 2 connections: An intermediate-high-voltage transmission electron microscope at the National Center for Microscopy and Imaging Research at the University of California, San Diego, has been modified to be like a computed tomography scanner. The specimen is tilted to a series of different angles for a series of scans, and the resulting data are tomographically reconstructed to give 3-D information about its internal structure. Researchers can control the electron microscope lenses and the 4-axis specimen stage by remote control. The tomographic reconstruction is very computationally intensive, so as the scans are performed the data are transparently sent out (across Internet 2) to high-performance supercomputers for calculation. The resulting 3-D images are returned to the remote researchers, who possess neither microscope nor supercomputer, but who have enjoyed the use of both to capture 3-D structural images that would otherwise have been impossible to obtain.

One of the most exciting tools for investigating the possibilities of NGI is a visualization tool called the CAVE. Created by scientists at the University of Illinois’ Electronic Visualization Laboratory in 1992, the CAVE is a multi-person, high resolution, 3-D graphics video and audio environment. It is a 10x10x10-foot structure that sits in a 35x25x13-foot darkened room and has rear-projected screen walls and a front-projected floor. Inside the CAVE, a user wearing 3-D shutter glasses is fully immersed in a virtual environment. Objects appear to float in space, and the computer tracks a user’s position to keep the perspectives correct while the user “walks” around objects. A “desktop” version of such a display also exists, called an “Immersadesk.” These visualization capabilities are already available to those who can afford the supercomputing power needed for real-time rendering—in fact, General Motors designed its 1997 and 1998 automobiles using an automobile simulator that uses the CAVE principles. NGI and I2 offer the promise that CAVE environments could offload their real-time rendering to supercomputing centers connected via the next generation of network connections.

Summary

From the earliest days of small telephone exchanges until the present time, connectivity has been a driving force for change. The Internet and the World Wide Web arose out of the existing base of telephone connections and computer networks and inherited their bandwidth restrictions, but nonetheless have brought a previously unimagined richness to connectivity, changing the world dramatically as a result. The NGI is being specifically designed to provide high-bandwidth connectivity on a scale so vast that is difficult to comprehend. It is our task to imagine into existence the richness and complexity of the applications that will exploit this new connectivity.

CONFIDENTIALITY AND MEDICAL INFORMATION

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This tutorial presentation discusses the thorny issues of privacy, confidentiality, and security in the digital age.

Social problems related to medical informatics potentially could be greater than technological ones. Much of this talk draws from a report on protecting electronic health information that was funded by the National Library of Medicine and Massachusetts Healthdata Consortium in 1995 and conducted by the Computer Science and Telecommunications Board of the National Research Council.¹ An eclectic committee—including sociologists, computer scientists, a dean of nursing, an attorney, a pharmacist, and a clinical researcher—examined practical aspects of technology such as the status of current technology, related problems, and strategies to address these problems.

Several key terms relate to confidentiality issues: (1) privacy is the desire of individuals to limit the disclosure of personal information; (2) confidentiality is a condition in which information is shared or released in a controlled manner (e.g., the release of information to a physician to benefit the patient); and (3) security involves measures to protect the integrity, confidentiality, and availability of information (e.g., if security is breached and an information system is disrupted or data are changed, the data are unavailable to users).

Advantages of Electronic Records

There are numerous advantages to using electronic records. First, with worldwide connectivity, electronic records are readily available from virtually any location. Electronic records also facilitate organizing the information in medical records. Based on the data that are available and organized in the records, reminders, suggestions, alerts, and critical pathways can be generated electronically. Electronic records also make it possible to link to appropriate medical literature and to analyze the health care delivery process, a task that would have been too cumbersome with paper records.

Threats to Confidentiality

For these reasons, paper records are being replaced with electronic ones. However, serious issues of privacy and confidentiality are associated with the improved access afforded by electronic records. One of the most difficult challenges is how to balance accessibility and confidentiality. One of the main reasons to use electronic records is to improve access to data; unlike paper records

that can be viewed in only one location; electronic records provide access to multiple users in multiple locations. However, increased access also means increased opportunities for breaches of confidentiality. To determine appropriate protection measures it first is necessary to identify the threats to confidentiality. The study group felt that insider abuse accounts for 80 percent of the confidentiality infractions in the United States. Often these abuses are perpetrated by individuals with access to the information system and are motivated by curiosity. Other reasons include vindictive retaliation, humiliation, and blackmail. Malevolent hackers, on the other hand, generally are not motivated by personal reasons; their purposes more likely involve the denial of service, blackmail, or the destruction of data integrity. Investigators also pose a threat; for a modest fee, a determined investigator usually can find anybody's electronic or paper medical history. No absolute security exists with either paper or electronic records. The committee strongly felt that the biggest threat to ordinary individuals concerned the way in which our health records could be used to cause economic harm.

Increased access is a factor as data are shared among various users and organizations. Because data no longer are controlled by a single organization, even if some organizations maintain security, information loses confidentiality once it leaves the originating organization's control. Many of the systemic threats are related to economic gain. If companies have access to potential employees' medical records, they can greatly reduce their health care costs and improve their profitability by not hiring individuals with certain medical conditions. In addition, under the Employment, Retirement, and Income Security (ERISA) legislation, self-paying insurers (health insurance companies merely manage the claims) have a right to learn what drugs their employees are taking because they are paying for those prescriptions. This information could affect personnel decisions. Unprotected information on genetic susceptibility to disease also could have broad economic implications. In order to prevent fraud, the Medical Information Bureau tracks and shares information among life insurance companies on everyone who applies for life insurance. In addition, records of test and control patients from a major medical center were subpoenaed in recent litigation related to breast implants.

The lack of consistent policy on confidentiality issues confounds the problem. Currently, no Federal policies exist to govern the flow of medical information, and there is no widely accepted definition of what constitutes fair information practice. Although some Federal and State legislation exists, it is not sufficient to ensure confidentiality of medical records. The Kennedy-Kassebaum bill mandated that Congress would enact legislation on the privacy of medical information by August 1999. Otherwise, by February 2000, the U.S. Secretary of Health and Human Services is obligated by law to institute regulations on privacy and confidentiality.

Technical Remedies

The following are practical, cost-effective technical remedies to confidentiality problems:

- *Authentication:* It is important to accurately identify system users. Strong authentication involves techniques such as iris recognition, retinal scans, and thumbprint recognition; weak authentication includes using passwords and individual logon identification.
- *Authorization:* Within an institution and across the system, someone must establish who has access to what data. This is probably the most difficult task and has little to do with technology.
- *Audit trails:* Audit trails track users and the data they have accessed. Although unauthorized users can be detected through audit trails, legislation is needed to ensure that sanctions are imposed when security violators are identified.
- *Physical security:* Do not allow unauthorized users access to the system or the data centers.
- *Control of external communication links:* In addition to building firewalls, control the circumstances under which modems and PC emulators may be used.
- *Software discipline:* If you have a library of structured query language (SQL) calls that allow anyone to query a database, those routines must conform to a security architecture.
- *System backup/disaster recovery:* Routinely back up data on tapes.
- *Self-assessment:* Hire experts to determine if the system security can be violated.

Disincentives and Challenges

Encryption security software for transmitting data over the Internet is available currently but is used rarely. The Data encryption standard uses a single key, which is shared between the sender and the recipient. However, this key tends to get widely distributed. With an asymmetric key method, a public key is used to encrypt the message, but a private key is used to decrypt the message. This method, however, is considerably slower and requires a certificate authority to ensure the identity of the user. The secure socket layer protocol allows a practical approach to encryption and provides security on a nonsecure network. This process entails the use of a one-time session key and a public key. Newer applications can use this technology seamlessly and painlessly. However, in an information system with many applications, it is likely that only pieces of a security solution are implemented rather than an entire system.

Development of policies can pose an even greater challenge than the technical measures, because people often do not

think about policy until there is a crisis. However, it is important for an organization to establish a policymaking body, to designate an information security officer, and to establish sanctions. Because there often are extenuating circumstances related to security violations, specifying sanctions after the fact may be difficult. It also may be difficult for Congress to pass legislation that satisfies both privacy advocates and organizations that—for increased profit and/or improved quality of care—are funding systems which increase access to medical information.

There are several disincentives for organizational solutions, including cost, a lack of external incentives, and a lack of focus on information technology. If cumbersome and lengthy sign-on procedures discourage users from logging off when finished, then users will circumvent the intended process. Therefore, there is substantial difficulty in balancing the need for access with the need to limit legitimate access, which again is related to policy issues.

Conclusion

Overall, widespread flow of information poses the greatest threat to confidentiality of medical information. This flow may cause economic harm to an individual. The development of medical informatics to support the National Heart Attack Alert Program could involve policy issues that are more daunting than the technological issues. Until social policy on confidentiality is established and confidentiality issues are resolved, the advancement of technology will be difficult.

Reference

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DIAGNOSIS OF PATIENTS WITH ACUTE MYOCARDIAL INFARCTION AND OTHER ACUTE CORONARY SYNDROMES

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This presentation describes the pathophysiology of acute myocardial infarction (AMI) and other acute coronary syndromes and examines diagnostic challenges for the emergency physician, including options for diagnostic testing and techniques used in making appropriate treatment decisions.

Acute Myocardial Infarction

As the body ages, plaques develop in the coronary arteries with a lipid-rich core covered by a fibrous cap. When the plaque ruptures, coronary thrombus, or clot, forms. People often are not aware of this process in their bodies. However, when the process reaches the dynamic phase, the artery is blocked by coronary thrombus and no blood passes. If this condition persists, the patient will experience pain, electrocardiogram (ECG) changes, heart attack, and, finally, death.¹

In the asymptomatic phase, the plaque ruptures, thrombus forms, and blood flow to the heart is reduced (myocardial ischemia). When myocardial ischemia occurs, the phase of the syndrome is called unstable angina, characterized by attacks of pain that are unpredictable or suddenly increase in severity or frequency. If the thrombus remains and this state persists, it leads to myocardial necrosis.

Importance of Reducing Cardiovascular Disease

AMI is an extremely prevalent phenomenon; it is expensive, and it is lethal. There are nearly 6 million hospitalizations per year for cardiovascular disease and over 1 million first or second discharge diagnoses of AMI per year in the United States. Each year there are 500,000 mortalities due to coronary artery disease including 300,000 cardiac arrests. Out of 100 patients with AMI, there are 25 deaths per month.² In addition to being associated with \$33 billion per year in medical costs, coronary artery disease is a leading cause of malpractice payouts.

Strategies

Early treatment is essential to reducing mortality from AMI. If patients with elevated ST-segment myocardial infarction (MI) (the actual stage of heart attack) are identified and treated early, mortality can be greatly reduced. However, if this condition is not identified, it can be lethal. The GISSI study found that when heart attack patients were treated within the first hour of the occurrence of symptoms, the 21-day mortality rate was reduced by nearly 50 percent.³ In the MITI project, patients who received early treatment with thrombolytic therapy in the ambulance or hospital had a 1 percent mortality rate, compared to 8 percent for those who received later treatment.⁴ McCarthy found that 10 percent of patients discharged with unrecognized AMI died and that the mortality rate was 25 percent.⁵

In 1996, there were approximately 10 million ambulatory visits to the hospital for chest pain,⁶ and the number most likely has increased. Most of these patients need to be considered for diagnoses of AMI or ischemia, as well as other diagnoses, but unfortunately the diagnostic tools currently available are limited. An ideal diagnostic tool would be applied easily in the emergency department (ED), and it would have high sensitivity and specificity, enabling accurate diagnosis. In addition, it would have low interpretation error, carry minimal risk, and be cost-effective.

Existing Diagnostic Tools

Existing diagnostic tools include the physical examination, the ECG, biochemical markers, and imaging tests. Because most patients do not present with obvious symptoms, the physical examination is useful for diagnosing AMI and other acute coronary syndromes only in certain patients. Therefore, diagnostic technologies are essential.

The electrocardiogram

The ECG is the most important diagnostic tool. If patients have chest pain and shortness of breath, an ECG is indicated. A finding of ST-segment elevation on the ECG is 95 percent specific for an AMI with a thrombus in a large artery, a condition that should be treated quickly. A finding of ST depression, indicating ischemia, has moderate sensitivity and specificity; ST depression is not as accurate a test. Other ECG findings are of lower sensitivity and specificity. Therefore, a patient with a normal ECG or one with flattened T waves still might be experiencing an acute coronary syndrome and not be identified through the ECG.

The American College of Cardiology/American Heart Association guidelines state that ST-segment elevation is strong evidence for thrombotic occlusion and makes the patient a candidate for immediate reperfusion therapy. According to the National Registry of Myocardial Infarction, about 45 percent of patients have this finding, and a variety of studies have found that approximately 50 percent of patients with AMI have ST-segment elevation.

With a finding of ST depression, indicating a clot in the coronary artery, it is not clear whether the clot will resolve (with no heart damage) or will persist and result in a non-Q-wave MI. With a non-Q-wave MI, damage occurs to only part of the wall of the myocardium, as opposed to a Q-wave MI that suggests myocardial necrosis transmurally (i.e., through the wall).

Cardiac markers

If sufficient information is not obtained from the ECG, other diagnostic modalities are used. Cardiac markers detect myocardial necrosis in the blood and can indicate whether the patient has experienced a heart attack; if any part of the heart is dying, the patient needs additional treatment and study. One of the markers, myoglobin, is found in both skeletal and cardiac muscle, which makes it difficult to identify the source without additional indicators. Creatine kinase (CK) and CK-MB, which is relatively specific for heart muscle, is another cardiac enzyme. However, because CK-MB is primarily present in the heart rather than skeletal muscle, it requires analysis to determine if the heart is the most likely source. The third cardiac marker, troponin, is nearly perfectly specific for cardiac muscle. The major advantage of troponin is that it can indicate small quantities of heart damage, so that small infarcts—not just large ones—can be detected.

A study by DeWinter of 307 ED patients who complained of chest pain examined the cumulative proportion of patients who rose above the positive cutoff zone for 4 cardiac markers: myoglobin, CK mass, CK activity, and troponin.⁷ Myoglobin rose faster and reached 100 percent sensitivity (at 6 hours) more quickly than did the other three markers. The study indicated that all the markers could be effective. However, troponin may prove to be particularly useful because of its ability to detect small amounts of heart damage.

Imaging tests

Some patients may have a complete occlusion of the artery that is not indicated by ECGs or biochemical markers. Imaging tests examine the state of perfusion in the myocardium and help identify areas that are not perfused, even though the nonperfusion may not last long enough to kill the heart muscle.

Technetium (Tc) 99m sestamibi is a radiopharmaceutical ideally suited for the ED. When injected with this agent, the ischemic area appears as a “cold spot” within about 15 minutes, and imaging can take place up to 4 hours later. Even after the patient’s pain has subsided, a positive scan may be obtained. Imaging tests add the additional dimension of capturing patients who have unstable angina or acute cardiac ischemia without infarction. In addition, patients who need further treatment and study, even those with AMI, can be identified earlier than with markers, which take between 6 and 12 hours to reach 100-percent sensitivity.

An ECG stress test is an additional option for diagnosis of cardiovascular disease. Rather than waiting for a reoccurrence of chest pain, the physician can perform ECG stress testing after an initial period of survey and observation once acute symptoms have ceased. Ischemia may be detected through the patient’s inability to meet the additional oxygen demands of a stress test.

Selecting Appropriate Treatment

The number one priority in the ED is to identify reperfusion candidates. All patients with chest discomfort receive an ECG, and this screening applied widely and early (including in the field) translates into earlier treatment. If ST-segment elevation or depression is not present, the next step is to exclude MI, which can be accomplished with the biochemical markers or with Tc 99m sestamibi. The latter also is useful for detecting acute ischemia without infarction.

Risk stratification

Once patients with coronary artery disease have been identified, they undergo risk stratification according to their place on the spectrum of acute coronary syndromes. A patient with chest pain or dyspnea with ST-segment elevation, indicating coronary thrombosis, would undergo immediate reperfusion. If a patient’s ECG does not indicate ST-segment elevation, only a positive biochemical marker

would confirm a non-Q wave MI, in which case thrombolytic therapy would not be indicated and medical therapy would be indicated. A patient with positive rest imaging, which would indicate ischemia without necrosis, also would receive medical therapy.

Decision aids

A variety of decision aids and algorithms are available to organize diagnostic information and facilitate treatment decisions. The Acute Cardiac Ischemia Time-Insensitive Predictive Instrument may be particularly useful with patients whose diagnoses contain areas of uncertainty. This instrument collects some simple demographic data, such as age and gender; determines whether the patient has chest pain and if so, whether that is the chief complaint; and collects information on five ECG variables. It produces a valid and reliable score of the risk of ischemia with a range between 0 and 100. It initially was tested and validated in 5,800 patients and subsequently has been in trials with over 10,000 patients.⁸

In summary, various diagnostic tools and approaches are used to identify patients with AMI and other acute coronary syndromes. Their usefulness will be substantially augmented by additional biochemical markers that are being developed for detecting cardiovascular disease in even earlier stages of symptomatology. With current and emerging diagnostic tools, ED physicians are fortunate to have an opportunity to identify coronary artery disease before it leads to myocardial damage, arrhythmias, or death.

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DATABASES AND DATA STANDARDIZATION

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This tutorial presentation discusses access to databases and data standardization in general. It serves as background for subsequent symposium presentations on databases relevant to clinical care and research of heart attack patients.

A rich lode of clinical data exists in laboratories, pharmacies, hospitals, and other clinical care settings. Health insurance companies, researchers, pharmaceutical manufacturers, and physicians require data in a variety of forms, leading to increased demand for data automation. In addition, cardiology procedure reporting systems, cardiology outcome data, and medical records are all becoming available in electronic format.

However, there are several barriers to the pooling of these data. The data are stored in many isolated locations; each system has a different internal system, conceptualizations, and internal codes; and there is a radical mismatch in the conceptualization of the systems that generate data and those that use them. Analysts tend to conceptualize data as a flat file, where the case is one record, the fields contain the individual values of interest, and these values are often derived (or rolled up)—they are often conclusions rather than the raw information available from a production system. In the flat file, the definitions of the questions are buried in the definitions of the fields. So what one sees in the data does not really fully define the questions, making it difficult to merge these different kinds of data from many different sources.

In the application conceptualization, each question has its own record, and this record contains many attributes, e.g., the name of the variable (question), its value (answer), its units, and normal range when applicable. Indeed, the answers are often in raw data form, and the questions are fully defined in a separate master file. In comparison with the analyst model, the application model has more records and greater detail. Individuals who want to extract data from systems for administrative and research purposes should use the application conceptualization standard and then convert these data as needed into the analytic form in their own systems.¹

Entropy leads to different data structures and different idiosyncratic codes within different computer systems. We need to apply standards² to the outputs of these systems in order to reduce this entropy.

Several different types of data standards are needed: security standards, message standards, code standards, and person and place identifier standards. The technology exists to address privacy issues, but the challenges lie in developing procedures for implementing them. Likewise, the Internet Engineering Task Force and Health Level Seven (HL7's) security, special interest group provide standard tools for implementing security measures.

Message Standards

The principal clinical message standard is HL7³, although ASC X12⁴ provides claims transmission and other administrative information, and the National Council for Prescription Drug Program⁵ provides message standards for community pharmacies. HL7 is the American National Standards Institute-approved clinical message standard and is widely used in the United States and in a number of countries throughout the world. The Centers for Disease Control and Prevention (CDC) has implemented the Data Elements for Emergency Department Systems (DEEDS)⁶ database using HL7.

HL7 was established to develop standards for the electronic interchange of clinical, associated financial, and administrative information both within and among care institutions. It defines data types and structures for the records within the messages. Sixty-five percent of those surveyed at a Health Information Management Systems Society conference said that HL7 was the most important standard in their environment.⁷ In the HL7 standard, field types are standardized; for example, dates are represented as CCYYMMDD (e.g., Christmas of 1998 is 19981225). This makes HL7 automatically year-2000 compliant, and allows birth dates for patients over 100 years of age.

Code Standards

HL7 has a coded data type. It requires that users always send a code source with the code so that there is never confusion about the source book for the code. This will be very helpful during the overlap period from updating the International

Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) to ICD-10-CM.

An electrocardiograph is another source of patient information. Comité Européen de Normalisation, the European standardization organization, has developed a standard for communication protocol for computerized electrocardiography.⁸ It provides standards for representing the ECG tracing itself, diagnostic codes, and the measurements extracted from the ECG.

Many domains of code standards exist and not everything is covered under one umbrella code system. The Logical Observation Identifiers, Names and Codes (LOINC) system provides standard names and codes for identifying clinical questions, variables, and report headers.⁹ It provides codes for representing the clinical questions, not the answers. LOINC names consist of up to six parts: component, property, timing, system, scale, and method. LOINC has been widely adopted in part due to its availability on the Internet (<http://www.mcis.duke.edu/standards/termcode/loinc.htm>). It is endorsed by the American Clinical Laboratory Association and used by the larger reference laboratories.

Systematized Nomenclature of Human and Veterinary Medicine (SNOMED)¹⁰ is the code source for answers and provides over 250,000 categories of answers. SNOMED is a comprehensive, multiaxial nomenclature classification system created for indexing the entire medical record, including signs and symptoms, diagnoses, and procedures. SNOMED International is rapidly being accepted worldwide as the standard for indexing medical record information.

Person and Place Code Standards

Though many countries have universal patient identifiers, the United States does not. Consequently, each institution creates its own registry and patient chart number. The Health Care Insurance Portability and Accountability Act requires that provider and patient identifiers be put in place, but there may be a reluctance to develop patient identifier codes because of the privacy implications. Provider identifiers also are important to outcomes analysis and health services research. The Health Care Financing Administration is developing a national identifier system for health care providers. This means that we will soon have a national provider code.

Public health organizations have taken the lead in developing standards for patient data, especially the CDC. They have developed a series of standards-based projects, including communicable disease reporting, in which they use HL7 for the message, LOINC for identifying the tests, and SNOMED for identifying the answers. The CDC, in cooperation with the Council of State and Territorial Epidemiologists (CSTE), has developed a series of standards-based projects, including communicable disease reporting, in which they use HL7 for the message, LOINC for identifying the tests, and SNOMED for identifying the answers. The CSTE developed tables for

each of the 50 States, thereby defining all the disease requirements, what lab tests should be performed, and the threshold for reporting a test result as positive. In addition, the CDC has the emergency medical care DEEDS database, which is very relevant to the work of the National Heart Attack Alert Program.

The major goal of medical informatics should be to reduce the entropy of the many sources of health information by developing standards for messages, codes, and for user and component interfaces.

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ECONOMIC, SOCIAL, AND PSYCHOLOGICAL OBSTACLES TO ACHIEVING THE NATIONAL HEART ATTACK ALERT PROGRAM'S GOALS

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This presentation addresses some of the major challenges of the National Heart Attack Alert Program (NHAAP) and examines specific economic, social, and psychological barriers to achieving the goals of the program. Terms that might be confusing to a lay audience are defined. Lessons learned from everyday experiences and observations related to the care of patients with acute cardiac problems are presented. Opportunities for creating a technological partnership within the emergency medical services (EMS) system are described, and methods for bridging emergency medicine (including cardiology) and medical informatics are explored.

The Challenges of Phase I of the NHAAP

Medically, a heart attack is an occlusion or blockage in an artery nourishing the heart, with the potentially resultant death of heart muscle tissue. This occlusion is what causes the chest pain and other symptoms. The lay press often incorrectly defines “heart attack” as a sudden cardiac arrest. In cardiac arrest, the heart stops beating suddenly and unexpectedly; within seconds, the brain and other vital organs are deprived of necessary blood and oxygen, and the patient loses consciousness. Unless cardiopulmonary resuscitation, defibrillation, or other interventions are applied quickly, the patient will die. Sudden cardiac arrest occurs as a complication of a heart attack, or an acute myocardial infarction (AMI).

Most deaths from AMI are caused by cardiac arrest, usually within 1 or 2 hours of the onset of the coronary artery occlusion. This narrow timeframe for prevention of cardiac arrest provides the major challenge for the NHAAP: to not only increase awareness and education of patients, potential patients, and those around them, but more importantly, to influence their behavior. Patients must not only recognize AMI symptoms, but also take the essential next step—seek emergency care.

Facilitating this initial link between awareness and action is a major concern of the NHAAP and the foundation of the Rapid Early Action for Coronary Treatment (REACT) project. The findings of the REACT project may indicate that public education has some measurable benefit but, by itself, is not enough to substantially reduce patient delays in seeking care. The existing system for emergency cardiac care is not user-friendly and it is not focused on the patient's

psychological, emotional, economic, and sociologic needs. As a result, the patient undergoes a complicated reasoning process that delays his/her decision about whether to seek emergency medical care. For these reasons, reducing the time for patient/bystander recognition and action, the focus of Phase I of the NHAAP, remains the greatest challenge. In the other phases of the program substantial progress has been made, particularly through the work of the 60-minutes-to-treatment working group in Phase III (the hospital phase).

Varying Perspectives on Emergency Cardiac Care

Patients

The process of emergency cardiac care can be explored from the perspectives of patients, EMS providers, and emergency department (ED) personnel. When a patient experiences potential AMI symptoms, he/she must decide whether to consult a doctor or spouse, take antacids, or, as advised by numerous health organizations, call 9-1-1. That decision is probably one of the most difficult and serious in a person's lifetime. However, there are significant barriers to calling for emergency care. In fact, patients who have experienced previous coronary events often delay calling longer than those with no prior events. Interviews conducted through the NHAAP and the American Heart Association revealed that patients' experiences had caused them to fear loss of control, embarrassment, inconvenience, and costs. Psychological aspects of patient delay need further study.

Emergency medical services providers

One of the most difficult problems for paramedics or firefighters is identification of the patient. Often, important medical information is unavailable because the patient is unresponsive, there is no identification on the person, or no one is accompanying the patient. Lack of medical information about the patient makes it difficult to make appropriate decisions concerning medications and treatment.

Although 12-lead electrocardiograms (ECGs) are essential for quickly assessing the patient's condition, only a handful of EMS systems are using them in the field. In addition, most EMS ECG systems are unable to communicate with hospital ECG systems to compare information. Therefore, when paramedic units in most cities are dispatched to a patient with chest pain, transportation of the patient to the hospital is virtually required to gain access to the hospital's ECG system.

Although useful information may exist, it cannot always be accessed in the most helpful way. For example, most paramedics document data manually. Although there are some rudimentary documentation systems, they cannot integrate information from monitors into a time-accurate, comprehensive database from the field. The Data Elements for Emergency Department Systems project, sponsored by the Centers for Disease Control and Prevention, is a possible model of a database structure that might allow development of systems that could provide patient information to be shared across EDs.

Emergency department personnel

The ED staff experience many of the same problems as the EMS providers. In many cases, no prior medical information is available. In the optimum situation, a 12-lead ECG is used upon the patient's arrival at the hospital, results from a prior ECG at the hospital are readily available electronically, and a comparison can be made. More often, the ED staff must try to get information from doctors' offices or other hospitals by fax. They also have problems with multiple data sources, particularly because they have individual timepieces set at varying times. In time-dependent events like a cardiac resuscitation, a dissimilarity of plus or minus 2 or 3 minutes can make a tremendous difference. A study in the April 1998 issue of the *Annals of Emergency Medicine* examined various time-keeping devices used in EMS situations, including: wall clocks; watches on nurses, doctors, and firefighters; and timepieces on defibrillators and fire trucks.¹ When this information was combined with a simulation of 5,000 cardiac arrests, 93 percent of cardiac arrest cases would contain a documentation error of ≥ 2 minutes and 41 percent of cases would contain a documentation error of ≥ 5 minutes. A month after synchronizing all timepieces, the 2-minute documentation error rate was cut in half and the 5-minute documentation error rate was cut by three-fourths. However, after 2 more months with no additional synchronization, the original levels of inaccuracy returned.

The problem of manual documentation in the ED also is similar to the situation in the field. Although the ED has more electronic devices, most of them cannot communicate with one another—or if they can, they do not share the same time-base language, which adds to the confusion.

Future Solutions

There are several potential technological strategies for overcoming current barriers to improving emergency medical care. These include: (1) identifying all patients through devices similar to those currently used for fingerprint or retinal technology; (2) making online universal medical records available to EMS and ED medical personnel; (3) linking devices with a common language and data-synchronizing them to the atomic clock; and (4) linking EMS vehicles to the hospitals through prehospital telemedicine to facilitate evaluation of selected patients in the field. Assuming that these technological advances could be accomplished, EMS practices could undergo related changes. Several station wagons or sports utility vehicles could be added to the fire trucks and ambulances used as emergency units. In addition to being staffed with paramedics, they could be equipped with a 12-lead ECG and a portable telemedicine system. Trained paramedics at the 9-1-1 dispatch centers could use specially constructed protocols to stratify patients according to risk. A paramedic would be dispatched quickly—without lights and sirens—to those patients assessed as relatively low risk. The paramedic would evaluate the patient, do a 12-lead ECG, and send it to

the physician at the hospital via a telemedicine link. Further followup could occur the next day. This system would offer the public another possible outcome of a 9-1-1 call: prompt medical assistance at relatively low cost and with no embarrassment, as well as expert assistance in deciding whether hospitalization is necessary.

In this new system, medical record prehospital data would be available, and prehospital ECGs would become standard throughout the country. Telemedicine consultations would be available in many areas, with the ability to link data with the patient's primary care physician. All medical devices would contribute time-synchronized data on a wireless network (e.g. via satellite). The data captured by various devices would be combined in one unified, time-sensitive electronic record, and the system would be integrated into a

quality improvement followup mechanism. Within a system such as this, the NHAAP could achieve its goals.

To overcome current obstacles, it will take a vision of the future; a partnership among the EMS system, emergency medicine, and medical informatics; as well as a favorable climate of research support for implementing these ideas. With all these components in place, it will be possible to develop an integrated, readily available information system for emergency medical care.

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SYMPOSIUM PRESENTATIONS AND ABSTRACTS—WEDNESDAY, APRIL 15, 1998

Presentations are organized around five informatics domains: telehealth; education; medical records access; diagnostic and therapeutic decision support; and large-scale databases. For each domain, there is an overview of the presentations in that area, followed by the abstracts of those presentations.

Telehealth

Carole Gassert, Ph.D., R.N. (Chair),
CAPT David W. Ferguson, M.C., U.S.N.
(Vice Chair)

During the telehealth portion of the symposium, Dr. Forrest Faison III reviewed efforts to expand the infrastructure for telemedicine programs in the U.S. Department of Defense using as many standardized technologies as possible. Future efforts will expand the Department of Defense telehealth infrastructure. Dr. Napoleon Knight discussed how the Carle Rural Telemedicine Project enables physician assistants at three rural hospitals in Illinois to administer thrombolytic therapy to patients. These clinicians are linked through telehealth technologies to physicians who provide diagnoses and recommend interventions from the hub site. The project hopes to expand these same services to additional rural sites and to involve nurses in providing thrombolytic therapy. Dr. Marian LaMonte presented a project that allows thrombolytic therapy to be administered during ambulance transport to patients who suffer an acute ischemic stroke. A similar project could be used to administer

thrombolytic therapy to patients who experience a myocardial infarction.

Dr. Jay Sanders, Dr. Angelo Alonzo, Mr. Jack Horner, Ms. Linda Roman, and Dr. Charles Safran formed a five-member panel to present information about an application of telemedicine termed "electronic house calls." The panel discussed existing telehealth projects and how those or similar efforts could be used to meet National Heart Attack Alert Program objectives. Behavioral and organizational issues of using technology were presented. Telehealth technologies are increasingly available to health care clinicians and patients, but speakers reminded the audience that many of these individuals still have technophobia and will need assistance in adopting telehealth technologies. It was suggested that both clinicians and patients receive training to use the technology before a crisis event occurs, not on a just-in-time basis.

Speakers noted that telehealth technologies may change clinician-patient relationships. Placing telehealth technologies in the home puts the clinician in the role of guest while the patient maintains control of the encounter. Presenters also felt that technology increases the frequency of

clinician-patient contacts. Patients with home technologies expect to contact clinicians more easily for follow-up advice than they would through routine office visits.

Discussions emphasized that in order to be successfully implemented, telehealth technologies need to be flexible concerning patient confidentiality issues, and secondly, they need to be easily integrated into the workflow of clinicians. A further need was recognized for improving the infrastructure to link telehealth technologies with other information technologies used in health care. It also was suggested that telehealth solutions be considered from the perspective of whether to pursue a low-cost and broad approach or a higher-cost and more targeted approach to change behavioral reactions surrounding the onset of heart attack symptoms. It was further suggested that targeting high-risk patients or those who have already made a 9-1-1 call, for example, might result in a more effective intervention for patients responding to acute ischemic symptoms. When developing telehealth solutions, limited resources—particularly in the rural areas—may require that lower-end technologies be considered whenever possible.

TELEMEDICINE IN THE DEPARTMENT OF DEFENSE (DoD)

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How this idea can help the National Heart Attack Alert Program

The use of telemedicine technologies in the prehospital setting can enhance survival and treatment en route to definitive care. The use of asynchronous communications, whether for electrocardiogram interpretation or synchronous communications to allow specialty treatment through an extended care provider, enhances specialty access to cardiologic care, improves early diagnosis, and, through well-defined metrics analysis, yields valuable data to both refine care and plan system expansion.

What currently is being done in this area

Telemedicine is a \$325 million investment for the DoD, which has contributed approximately 58 percent of the total Government (Federal and State) investment in this technology. There are currently 197 ongoing telemedicine projects in the DoD. Most notable for early cardiac care is a cooperative venture in the greater San Antonio area where ambulances are being equipped with synchronous communications that are transmitted through an embedded fiberoptic network used for traffic control. This synchronous communications system allows cardiologists to direct care in the field while minimizing communications costs through use of intrinsic communications systems.

Obstacles to successful implementation of the idea

For the DoD, the cost of use in areas outside the continental United States is a primary obstacle. Standardized methodologies for providing uniform care and creating nonstandard technical solutions are not yet realized, and thus remain primary obstacles.

Steps necessary to implement the idea

Telemedicine is a mature technology, and use of commercial off-the-shelf products is the most cost-effective alternative. Cooperative partnerships for cost-sharing and controlled projects to develop standard technical and clinical solutions are the most logical methodologies for implementing standardized, cost-effective telemedicine in the United States.

USE OF TELEMEDICINE TECHNOLOGY TO ASSIST SMALL RURAL HOSPITALS

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How this idea can help the National Heart Attack Alert Program

This type of program can assist small rural hospitals in their ability to rapidly diagnose and treat patients that present for care of acute myocardial infarction at a small rural hospital. As more and more rural hospitals are faced with financial difficulties, using the type of arrangement that we have with John and Mary Kirby Hospital may enable them to continue to provide high quality care in their communities.

What currently is being done in this area

Since 1994 we have been using Telemedicine Technology Vtel units with full T-1 lines to link the emergency department (ED) at Carle Foundation Hospital with the ED at Kirby Hospital. Kirby is the smallest hospital in Illinois, and at the time that we started our program, they were faced with the possibility of having to close their ED due to the financial difficulty that they were having trying to keep it open. We worked with them to develop treatment protocols that the physician assistants (PAs) used to treat and evaluate patients. This is a low-volume ED, seeing 8-12 patients per day. The majority of patients that are seen are low acuity, and so utilizing the PAs with experience in emergency care, and with advanced trauma life support, advanced cardiac life support, and pediatric advanced life support training has worked quite well. For patients who do not fit the "see, evaluate, treat, and discharge protocols," the PA links with us in our ED, and we help with the evaluation process and the appropriate disposition.

We have been utilizing this method since 1994, and have had acceptance from the physicians in the ED at Carle, the PAs at Kirby, the hospital administration at both facilities, and from the patients as well. The patients who are seen and discharged from Kirby have their charts reviewed by a member of the family practice department to ensure appropriate care, and to date, no adverse outcomes have been reported. This type of program utilized in other small rural hospitals would assure access to rapid care, as the patients would be able to be cared for in their own communities. This would aid in more timely administration of thrombolytics, aspirin, and beta blockers, all proven to decrease the morbidity and mortality in acute myocardial infarction.

Obstacles to successful implementation of the idea

There are many barriers to the implementation of this type of program. There are considerable expenses that must be born by the institutions that are considering this type of program. Considerable expenses are inevitable with the ongoing line charges as well. There is a learning curve that the participants in such a program face as well. Physicians are somewhat reluctant to use this type of technology until they become comfortable with it, which makes the creation of this type of program somewhat difficult as well.

Steps necessary to implement the idea

Most of the steps necessary to implement this program have already been developed and are working well in the system that we have implemented. We have been lucky in that the funding for our program has come from grants from the Federal Government, and this has certainly made the implementation of our program much easier than it may have been otherwise.

We have been awarded another 3-year grant through the Office of Rural Health Policy and are connecting two other small rural hospitals and two rural health clinics to the Internet, and we plan to establish video links with them in the future. These links may enable us to establish similar arrangements in the future. We also are going to be establishing video links with a nursing home, and in the third year of the grant we will be monitoring patients in their homes with home-assisted nursing care units. We expect that these links will enable us to obtain diagnostic information more rapidly, aiding in the more timely administration of lifesaving medications as well. Certainly, our links with the small rural health clinics may allow us the ability to consult with cardiologists in a more timely fashion, helping in the identification of patients at risk and the earlier institution of medical therapy or diagnostic testing.

AMBULANCE-ON-THE-WEB: A CELLULAR PHONE-BASED, REAL-TIME VIDEO-MOBILE TELEMEDICINE SYSTEM FOR AMBULANCE TRANSPORT

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How this idea can help the National Heart Attack Alert Program

The transport phase is part of the valuable time between the emergency medical services activation and arrival at the hospital. Transforming this phase into a diagnosis and treatment phase will reduce time to therapy, including

thrombolytics. Furthermore, it is also a time-window for improving triage decisionmaking.

What currently is being done in this area

The Ambulance-on-the-Web initiative was funded by the National Library of Medicine as a part of the Health Applications for the National Information Infrastructure and by the University of Maryland and BDM International. This mobile telemedicine system was designed, implemented, and tested for real-time diagnosis during ambulance transport. The system uses multiple public wireless cellular phones to transmit video and patient biosignals from a moving ambulance to a hospital and delivers these data to the desktop computer of the receiving physician via a Web interface. The mobile unit on the ambulance is turn-key operated and has an image selection controller for paramedics to send images at specific times and to capture video at high frame rates. The mobile telemedicine system was installed on two interfacility critical care transport ambulances. For evaluation purposes, transport of acute ischemic stroke patients was used as the testing task model.

Obstacles to successful implementation of the idea

The system was successfully used in diagnosing acute ischemic stroke during the transport of six patients. Using the system, stroke specialists were able to remotely conduct neurological examinations that required evaluation of facial expressions and movement of arms and legs.

Steps necessary to implement the idea

By linking the ambulance and receiving hospital with easily and widely accessible public wireless phone networks, a physician linked to the Internet can potentially expand diagnostic and therapeutic possibilities before the patient reaches a hospital.

BEHAVIORAL ISSUES IN INITIATING USE OF TELEMEDICINE TECHNOLOGY

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How this idea can help the National Heart Attack Alert Program

Telemedicine offers the potential to enhance the rapidity of acute ischemic cardiac event evaluation, diagnosis, and treatment in new and established coronary artery disease (CAD) patients by offering remote symptom assessment and the potential global positioning systems (GPS) to continuously monitor high-risk CAD patients. Telemedical technology can decrease time from ischemic event onset to definitive therapy in the field by emergency medical services (EMS) transmission of electrocardiogram (ECG) and other vital information to emergency department (ED)-based physicians. In rural and suburban EDs, access to

remote tertiary diagnostic centers can decrease time to definitive therapy. Potential developments in telemedicine could range from automated, independently initiated warnings to patients of impending ECG or other abnormal changes to EMS/GPS “scoop and run” retrieval of high-risk patients in the evolving phase of an ischemic event. Also, it is possible to imagine automatic or physician-initiated treatment from an implantable “pharmacy” of cardiac drugs. The effects on patient utilization of emergency evaluation resources made available through telemedicine technology could be highly positive, due to the peace of mind engendered from constantly available symptom assessment and, among high-risk patients, security through constant online monitoring.

What currently is being done in this area

Telemedical linkages have been made among physicians, clinics, hospitals, and EMS systems for the evaluation, diagnosis, and treatment of CAD patients. The range of medical disciplines using telemedicine is constantly expanding, from dermatology to neurosurgery. The terms “electronic house call,” “video visits,” and “telenursing cockpits” have come into being. Patients can call help lines with questions and obtain automated voice messages or “real” providers. Telemedicine has been used to collect vital signs remotely, improve compliance, educate patients, identify health and self-care problems, and provide support to caregivers. While emphasis is usually on remote and isolated site access to resource-rich facilities, its use has also become intra-urban as well as inter-urban and international. Currently, faxed ECGs assist decisions regarding administration of thrombolytic agents, ECGs are digitally transmitted from EMS or physician offices to intensive coronary care units for interpretation and consultation, ECGs are transmitted for pacemaker monitoring, and Dobutamine stress echocardiographies are being interpreted off-site. British Airways is utilizing GPS technology to maintain 24-hour physician contact in the case of onboard medical emergencies. Commitments have been toward online knowledge-based systems for remote diagnosis of cardiac arrhythmias. Enhanced compliance among noncompliant patients has been reported when telemedicine technology is introduced. Patients using telemedicine report receiving reassurance from providers and show a preference for “sensory-rich modes of communication.” In general, high levels of satisfaction have been reported among patients and physicians utilizing telemedicine technologies. If we can have “virtual” colleagues in e-mail and chat-room systems, can a patient have a virtual physician to assess ischemic signs and symptoms?

Obstacles to successful implementation of the idea

Patient, and provider, acceptance of new technologies is always a potential obstacle. Who will have control over new technologies in everyday settings—the patient, lay people, or providers? Again, the range of options runs from patient self-evaluation systems to automated EMS/GPS retrieval

systems. Patient tutorial systems with diagnostic algorithms have the same problems as the present 9-1-1 systems; patients must make the decision to initiate the call. A study of routine telephone monitoring of pediatric pacemaker performance showed only a 40 percent compliance rate. Automated diagnostic and response systems take away patient control and may be too intrusive. Telemedical technology increases the opportunity to warn patients of silent ischemia or ECG abnormalities. Patients can choose to ignore the automated warnings as some ignore acute ischemic symptoms and the exhortations of lay people to seek care. Telemedicine, in an era of managed care, can further remove the patient from their physician and increase depersonalization. “Automated voice messaging” would also seem to have a depersonalizing potential in an era of the ubiquitous and frustrating automated answering system. As with any new technology, the “technophobic” patient will be the least likely to activate telemedical consultation. Further, in some applications such as radiology and echocardiography, telemedical evaluation and diagnosis may actually require more time than immediate, conventional evaluation.

Steps necessary to implement the idea

Behavioral studies of patient-initiated and -controlled telemedical systems should focus on patient acceptance of current telemedicine technologies and future possibilities; for example, automated EMS/GPS response technologies and implantable diagnostic and treatment devices. Social/psychological studies of decisionmaking during health crises are needed to develop acceptable entry methods into telemedical systems. This would necessitate the development and study of automated messages and diagnostics algorithms. These studies would result in user-friendly and responsive answering systems. In addition, telemedicine training and desensitization need to be studied in the “technophobic” patient. The study of matters pertaining to innovation and diffusion of telemedical technologies among patients and providers would facilitate utilization and decrease CAD morbidity and mortality.

ELECTRONIC HOUSECALLS AT FORT GORDON

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How this idea can help the National Heart Attack Alert Program

‘Early,’ ‘prompt,’ and ‘timely’ are all concepts that come to mind when we ponder the potential improvements that could be made in the detection, diagnosis, and intervention processes for emergency medical situations. This is one facet to the more general issue of access to care. The extension of the provider to the patient in a virtual sense is one potential solution to this problem. The concept of

placing remote monitoring equipment in patient homes for medical purposes is not new. Numerous reports have been presented detailing the success of such efforts for a number of years. There are, in fact, several commercial offerings to support this approach to patient care. The Defense Department's Center for Total Access (CTA) at Fort Gordon, Georgia, has been designated as DoD's executive agent for further study in this field.

What currently is being done in this area

In 1995, the CTA entered into a cooperative agreement with the Medical College of Georgia and Georgia Institute of Technology in support of a congressionally funded proof-of-concept study entitled "Electronic Housecall." The study design was strictly limited to an evaluation of selected technology, evaluation of cable-based connectivity, and the degree of patient acceptance. Subsequent studies are now being conducted to assess the medical efficacy and cost effectiveness of this approach.

The earlier study, concluded in 1997, involved a total of 25 patients and one nursing home. The selected patients suffered from chronic conditions such as asthma or diabetes, were seen in the emergency room more than two times monthly, and were hospitalized more than twice annually for the same condition. The intent was to provide daily visual contact between the patient and a dedicated nurse and to monitor specified vital signs and trends and medication compliance in order to avoid emergency situations. The psychosocial aspects of the daily interaction were also noted as positive results of the study.

The equipment in the home consisted of a PC-based desktop video teleconferencing system operating at a bandwidth of 384 Kb. Also included was an integrated package that provided the following monitoring tools: body weight, temperature, blood pressure, pulse oximetry, 3-lead electrocardiograph, and electronic stethoscopy.

The proprietary software permitted that monitored data could be collected during a real-time interaction with the nurse and logged into a database or collected by the patient at any off-line time. Such off-line data would automatically be transferred to the same database during the next interaction. The real-time interaction could be initiated by either the nurse or the patient at any time. In order to avoid the patient becoming intimidated by the apparent complexities of the computer, the central processing unit and the keyboard were inaccessible to the user. A touch-screen monitor served as the only computer interface with the patient. Suitable icons were used to minimize the training requirements (e.g., a telephone icon need only be touched by the patient in order to initiate the video call).

During online interactions, the patient saw the nurse (or other provider) and the nurse controlled a remote camera at the patient site, with control of focus, pan, tilt, and zoom. In the event that the patient needed assistance in order to recall

how to operate a given feature of the system, suitable video clips were accessible at the mere touch of the appropriate graphic on the screen. In order to further benefit from the placement of a computer in a patient environment, access to educational materials related to patient diagnosis was included.

Obstacles to successful implementation of the idea

The connectivity into the homes was provided at no cost to the project by the local television cable company. This necessitated installation of radio frequency modems at each home and reverse amplifiers in the appropriate neighborhoods. This approach permitted the use of an Ethernet protocol as the standard of communications. The greatest technical difficulty encountered during the conduct of the study resulted from the relatively "noisy" nature of the somewhat old cable infrastructure encountered in most neighborhoods. Subsequent studies using telephone-based communications are planned.

Steps necessary to implement the idea

The findings of this study clearly validated the concept of in-the-home medical monitoring. Despite the limited statistical nature of this study, there were several documented cases of avoided emergency visits and two instances of avoided hospitalizations. The data integrity and reliability were uncompromised by the technology employed. A further study currently in progress is addressing the cost-benefit and medical efficacy aspects of this approach to patient care. It should also be realized that such technology as described here has obvious application in the area of postdischarge at-home care. The recuperative phase of a patient's experience with any serious medical condition is not only one with high risk, but also one of great anxiety. The virtual presence of a provider in the home is not only a real potential benefit medically speaking, but improves the quality of life as well.

USING TELEVIDEO TO IMPROVE PATIENT OUTCOMES

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How this idea can help the National Heart Attack Alert Program

While the explosion of interest in telemedicine over the past 4 or 5 years makes it appear that it is a relatively new form of health care, the truth is that telemedicine has been in use in some form or other for over 30 years. The use of telemedicine in the home, however, is a relatively new phenomenon. The recent advancements in telecommunications technology have made home telehealth care a reality. With this technology, health care providers are able

to offer a variety of services, including monitoring of medication compliance, evaluation of vital signs, patient education, psychiatric evaluation, and most any service that does not require direct hands-on interaction. These services result in fewer hospitalizations and fewer emergency room (ER) visits.

What currently is being done in this area

Although home telemedicine is a relatively new area of health care, the industry has funded and continues to fund case studies and pilot programs, demonstrating the optimism about potential opportunities. In a recent study conducted by Ace Allen, M.D., University of Kansas Medical Center, it was determined that nearly 50 percent of all traditional in-home visits could be conducted using televideo. In a study done by H.E.L.P. Innovations, televideo was used on 46 patients resulting in over 1,400 televideo encounters. One such case involved a 96-year-old female with a primary diagnosis of congestive heart failure. Her problems included medication mismanagement and overuse of high-cost services (ER visits) due to fear, and she was at risk for nursing home placement. During the case study she was monitored for medication compliance using televideo and was instructed on her medication, energy conservation, and self-evaluation of symptoms before calling for emergency response. After being on the televideo case management

plan, she reduced her ER visits from monthly to zero and was able to stay at home with increased social interaction.

Obstacles to successful implementation of the idea

Reimbursement for televideo services has been secured through some insurance providers and state Medicaid programs; however, the national Medicare program does not currently reimburse for these services under its fee-for-service programs. Medicare has scheduled its own pilot studies to determine the feasibility and effectiveness for January 1999, but until a nationwide reimbursement system is established, it will remain as the main obstacle in traditional fee-for-service programs. However, reimbursement is currently available through Medicare's risk-based programs and is appropriated in other risk-based fee arrangements.

Steps necessary to implement the idea

In order to implement televideo services, additional case studies need to be conducted to evaluate the suitability of a variety of diagnoses. These studies can be funded through grants or through cost savings generated by implementation of televideo services. As more data are gathered and telehome services implemented, a broader spectrum of outcomes will be available to support the inclusion of televideo services in the Medicare program.

Education of Public, Patients, and Health Care Providers

James M. Atkins, M.D., F.A.C.C. (Chair),
Mary Jo Deering, Ph.D. (Vice-Chair)

Deborah Alexander, program coordinator for the Rapid Early Action for Coronary Treatment (REACT) trial, shared experiences from the NHLBI-sponsored multi-strategy community education campaign to reduce delay in accessing treatment for heart attack. REACT materials were designed to debunk certain myths associated with heart attacks and emphasize getting to the hospital quickly. The campaign distributed messages utilizing newspapers and the evening news, not just paid advertisements, with fresh messages and new stories every 3 months. The REACT Web site (<http://www.epi.umn.edu/react/>) targets intermediaries.

Fran Carl described a comprehensive, integrated Web site in use at Kaiser Permanente for its members, recommending it as a way to target people for educational intervention, attract them to the intervention, and deliver the intervention. Important profile

information can be collected and messages tailored using the computer. The site includes online appointment requests and prescription refills; they are exploring the possibility of enabling patients to send e-mail to providers. The public's expectation of what can be done using the computer is growing, and there is an increased demand for online services as well as well for information.

Dr. Victor Strecher discussed the use of new media approaches such as kiosks to deliver educational messages. The use of public kiosks, similar to ATM machines, offers an exciting way of reaching the 200 million people who do not yet have access to the Internet or other computer-based educational programs. Many people are not using technology creatively but are using it as "shovelware," or shoveling their printed materials onto the Web. More innovative approaches to content development and delivery are needed. The new technology is best in delivering tailored content through interactive programs.

Dr. David Johnson spoke about patient empowerment to encourage patients to seek information on their own. He described the Comprehensive Model of Information Seeking, which suggests

variables that determine information-seeking action that would need to be factored into any educational campaign. Dr. Johnson proposed front-loading the information to teach people how to negotiate through the maze of available resources so that they can make the correct decisions in a timely manner. He suggested using a campaign or game scenario that could help build a habit of successful choices before an episode occurs. These could be offered through the Web, CD-ROMs, or kiosks.

Some key points were emphasized during the discussion: there is a distinction between the acquisition of well-in-advance, "just-in-case" information versus "just-in-time" information, necessitating flexibility in approach; multiple approaches will be necessary to target different people; technology still has a way to go to support multimedia Internet programs; an intersection of health sciences and communication technology is necessary to provide for the content, creativity, and the technology that will get optimal results; and research is needed to show the impact that technologies can make on preventive behavior changes and clinical outcomes.

HEART ATTACK RAPID EARLY ACTION FOR CORONARY TREATMENT (REACT): A COMMUNITY-BASED INTERVENTION TO REDUCE PATIENT DELAY IN SEEKING EMERGENCY MEDICAL CARE FOR HEART ATTACK SYMPTOMS

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How this idea can help the National Heart Attack Alert Program

Funded by NHLBI to reduce patient delay in seeking emergency medical care for heart attack symptoms, the REACT study is a randomized community trial testing the effectiveness of an 18-month, multi-strategy intervention in reducing delay among patients with symptoms of an acute

cardiac event and a coronary heart disease (CHD)-related discharge diagnosis. Secondary outcomes examined included 9-1-1/emergency medical services (EMS) utilization in the REACT communities.

What currently is being done in this area

Twenty pair-matched communities in five regions of the United States (Northeast, Southeast, South, Midwest, and Northwest) were randomized to receive the REACT intervention (N=10) or to act as reference communities (N=10). Before intervention, REACT convened 34 focus groups in the five regions, targeted to represent the racial/cultural mix of the research audience. Participants included myocardial infarction (MI) survivors, high-risk CHD/cardiovascular disease patients, and family members of MI patients. Analysis of focus group results revealed false core beliefs about risk and unrealistic expectations of symptom presentation. These data were helpful in developing REACT messages about MI symptoms and 9-1-1/EMS utilization, making direct use of focus group participant input. Following a 4-month baseline period, the REACT research intervention extended from April 1996 to

September 1997 and consisted of the following four strategies: (1) community organization, i.e., involvement of community leaders and health organizations in planning a local intervention; (2) community education, i.e., mass media, small media, group presentations, and magnet events; (3) patient education, i.e., educational contacts with persons at higher risk of MI; and (4) health care provider education, i.e., educational contacts with physicians, nurses, emergency medical technicians, and others. The presentation briefly reviewed REACT, the creation of intervention messages targeting issues pertinent to heart attack delay, and a novel dissemination strategy using the World Wide Web to provide support and assistance to reference communities in planning their own community-wide interventions.

Obstacles to successful implementation of the idea

Outcome data for the REACT study is expected to be reported in the final quarter of 1998.

USING A COMPREHENSIVE WEB SITE TO ATTRACT, IDENTIFY, AND EDUCATE PEOPLE AT RISK FOR HEART ATTACKS

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How this idea can help the National Heart Attack Alert Program

Improving access to care depends largely on the patient, or on lay people who are with the patient, recognizing symptoms and being prepared to act on them. Education after the fact may help in future incidents, but it is important to educate at-risk patients and those likely to be around these patients before the initial incident. In order to educate them, it will be necessary to complete three steps: (A) identify the appropriate audience for the educational intervention, (B) attract them to the intervention, and (C) deliver the intervention.

What currently is being done in this area

A comprehensive Web site, integrated with other information systems and aspects of care delivery, can address all three steps.

(A) Such a comprehensive Web site can help identify appropriate audiences for educational interventions in two ways:

First, a Web site can contribute to the public health definition of "at-risk." As patients interact with the Web site, even when not interacting directly around acute myocardial infarction issues, information about the patient can be collected. Through health-risk assessments, profile forms, self-care decision-support applications, and other online applications, a great deal of longitudinal data about

individuals can be collected. In many cases, these data may be of a nature difficult to collect in other clinical systems that often track episodes and behaviors not directly related to a health care episode. When aggregated with millions of other patients' data and combined with data from other clinical information systems, these data may help lead to a better understanding of who is at risk for heart attacks.

Second, a Web site can help identify the appropriate audience by profiling each user and applying community standards to determine the extent to which each user is at risk. Information contributing to this assessment will come from many sources: data collected from the user on the Web site, data from specific health care systems (e.g., the patient's health plan will provide demographic information, while the patient's physician(s) will provide clinical data), and data from community health networks. This method of identification can identify not just at-risk patients themselves, but also family members and caregivers. Together, these functions help identify who should receive a targeted education intervention on heart attack symptom recognition and response, prior to the incident.

(B) A comprehensive Web site can attract users to an educational intervention. It is often difficult to get an educational intervention to the appropriate audience. Public health campaigns often need to blanket an entire population with a generic message because they cannot get the appropriate target audience to proactively request the intervention. A comprehensive Web site can attract users in a number of ways:

First, users will want to use the Web site because of features not directly related to heart attacks. They may use the site because of any combination of the following:

- the convenience of an online prescription refill service,
- relationships with other patients and with medical professionals that are established or enhanced through online discussion groups or messaging systems,
- decision support systems on a variety of health-related topics,
- entertainment, *or*
- cost breaks; e.g., a health plan or employer may offer financial incentives for using a Web site.

Second, based on profiles compiled on the Web, a health plan, physician, community health network, other interested party, or the automated Web site itself may send a message to a patient encouraging that patient to use the Web site for the heart attack educational intervention.

Third, the Web site can be constructed with logical rules that combine the user profiles with data from other online activities to proactively push heart attack education to the patient. For example, if a particular medication is often

used by patients at risk for heart attacks, when the user requests information on that medication or requests a prescription refill, the heart attack educational intervention can be offered to the patient. The same type of link could be created for health risk assessments, appointment requests, and other online services.

(C) Once the patient (or family/caregiver of the patient) has been identified and has been “pushed” toward an educational intervention, the Web can facilitate that education:

First, the Web site can access databases of educational interventions and refer the user to appropriate interventions. These might be on the same Web site, elsewhere on the Web, or outside of cyberspace altogether (e.g., traditional classes, hot lines). The Web site can also automatically notify a health care professional that this user is an appropriate candidate for in-person counseling.

Second, the Web site can provide targeted, tailored, multimedia, documented education directly to the patient (or family/caregiver).

Some Web-based educational interventions and profiling mechanisms have been created, and some preliminary work has started to connect Web-based systems with other information systems and with care delivery staff.

Obstacles to successful implementation of the idea

First, an information infrastructure must be developed to link Web-based data with data collected elsewhere. This will entail both provider-specific clinical and demographic information systems and community health networks.

Second, difficult implementation challenges must be overcome in order to integrate Web-based services with health care delivery.

Steps necessary to implement the idea

In order to overcome the obstacles described above, this idea can only be tested in the context of a Web site integrated with clinical systems and care delivery. A few very early examples of this are just being developed and tested. One or more of these early tests should be chosen as a pilot. The pilot would use the existing system as a base and add heart attack-specific operational procedures, data, logic, and educational interventions.

STIMULATING THE USE OF INFORMATION TECHNOLOGY IN SUPPORT OF INFORMATION SEEKING

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Dean

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How this idea can help the National Heart Attack Alert Program

Information seeking, the purposive acquisition of information from selected information carriers, can play a critical role in the accurate recognition, diagnosis, and initial treatment of acute myocardial infarction. While it has become commonplace for health campaigns to suggest that individuals seek more information concerning a variety of ailments, the time frame in which answers must be found suggests critical differences in this context that lead to the need for innovative, new strategies.

An individual’s information field consists of a variety of sources, channels, and messages composing an information carrier matrix. Individuals in today’s rich information environment can spend months, if not years, searching for answers to their questions within this matrix. They can surf the Web, view television news, read a variety of magazines, consult friends, and so on. However, the limited time available to respond effectively to symptoms of acute myocardial infarction suggests that defined paths must be learned by the individual, before he or she is confronted with symptoms, so that no time is wasted in meta-searching or searching for the best sources to consult.

What currently is being done in this area

Similarly, variables contained in the Comprehensive Model of Information Seeking must be addressed before an episode. This model, which has been empirically tested in a range of contexts, suggests that there are two major classes of variables that determine information-seeking actions. Antecedents (demographics, experience, salience, beliefs) provide the motive force, which is shaped by carrier factors (channel characteristics and utility). In this situation, individuals must be convinced of the salience of symptoms and the efficacy of seeking treatment as well as knowing which sources are the most useful. Most individuals seek easily accessible information from a familiar source (e.g., friend, neighbor, coworker) and are relatively unsophisticated in recognizing that a search is necessary and how it should be accomplished. As a result, unique campaigns must be developed to ensure that elements of a normal search process are “front-loaded” for a timely reaction to acute myocardial infarction.

Obstacles to successful implementation of the idea

A PATHS (Preventive/Anticipatory Techniques for Health Seeking) campaign could address these critical theoretical issues through traditional methods (e.g., brochures, public service announcements). Unfortunately, traditional approaches have not been completely successful in addressing this problem. One new medium that could provide a useful training supplement is game-based computer programs that confront individuals with the symptoms and responses (and likely outcomes) to build a habit of successful choices before an episode occurs. Thus, program exposure would build good habits, heighten

saliency, and increase belief in the efficacy of responses. Given the time-dependent nature of acute myocardial infarction and the devastating consequences of bad choices, this approach holds much promise. Individuals could access the PATHS game through Web pages, with information kiosks in community settings, or by CD-ROMs.

Steps necessary to implement the idea

Implementation of PATHS-based approaches using simulation represents creative challenges and considerable

expense in alpha- and beta-testing and development, but such simulation programs have been used successfully in training individuals to deal with time-dependent, critical processes such as military command and control and commercial pilot training. The unique nature of the NHAAP and the lack of success of conventional strategies demand that creative new approaches to this problem be developed in the overall context of a theory-based PATHS campaign.

Medical Records Access

Reed M. Gardner, Ph.D. (Chair),
Joseph P. Ornato, M.D. (Vice Chair)

Dr. Attilio Maseri and Enrico Carlin described the G-7 CARDIO Project, Subproject III, in Europe. This project is funded by the European Commission and has the goal of developing common standard clinical databases and integrating patient care data in a shared, stratified system of care to improve the prevention, diagnosis, and treatment of major cardiovascular diseases in the European community. They propose that the use of health telematics will improve the cost-effectiveness of cardiac care by optimizing resource usage—the system is a Web-based application. As an example of the use of their system, if a physician knows which patients respond to simple treatments, then aggressive treatments can be reserved for those who truly need them.

Some of the ways that telematics is being applied in this project include: the development of a technology infrastructure for information flow, such as the World Wide Web, multimedia clinical records, CD-ROMs, patient “smart cards,” and stratified systems of care (i.e., classification of patients). Many technological problems exist; the infrastructure for this project is very dependent on the Internet, and not all potential users in Europe have IT capabilities. Smart cards have only limited data storage capability and would be difficult to keep current. A promising tool of the future of technology will be increased Internet bandwidth to facilitate greater amounts of data transfer and dynamic hypertext markup language; this

would allow information (such as images) to be shareable on the Internet regardless of the type of connection.

Dr. John Halamka stressed the importance of linking emergency medical records of cardiac patients. He suggested two available architectures to accommodate this: a massive central data warehouse, and a virtual connection using Internet technology. A national infrastructure should be designed that has a standardized vocabulary and a common data representation. Dr. Halamka described the CareWeb project in use between two teaching hospitals in Boston as a model of an architecture. This model uses HL7 as a message standard and Digital Imaging and Communications in Medicine as the standard used for graphical images. He noted that security issues are still a major concern when exchanging patient information through the Internet, but that a robust security architecture such as that proposed by the National Research Council could be utilized to protect health care information.

Dr. Aziz Boxwala discussed the use of portable information storage devices (PISDs) which can be used for providing immediate access to the medical record at the point of care. PISDs such as integrated circuit-based smart cards, optical cards, and information buttons (I-buttons) present potential low-cost solutions to providing ready access to medical information. Some of the challenges in using PISDs include: their current small data storage capacity, standards for interoperability and data representation, universal deployment of PISDs, keeping the data in the PISDs current, and ensuring security and

confidentiality of the data while allowing immediate access.

Among the key points discussed were that privacy and confidentiality must be addressed up front. Likewise, unless legislation mandates use of standard data dictionaries and/or one powerful group assumes financial responsibility for developing standards, it is unlikely that standards will become common in the United States. However, there are professional and public interest organizations that are attempting to bring together industrial partners for the purpose of developing electronic medical record standards. A consumer-driven approach to standardize medical records also may be needed.

There are many different ideas regarding which standards should be employed, but if physicians can come to agreement about which ones to use, it is likely that they will be supported by other groups. Medical informatics groups must get together to establish and implement workable data exchange standards.

From the brief discussion, it was apparent that some sort of distributed yet shareable databases would be the ideal way to archive patient data. Smart cards and other devices may have limited application, but suffer from two major problems: limited memory capability, and difficulty in keeping them “current” with up-to-date medical information. A major effort should be expended in getting medical and informatics experts together to establish standard data definitions and standard data storage and exchange mechanisms.

EXECUTIVE SUMMARY G-7 CARDIO PROJECT SUBPROJECT III: IMPROVING PREVENTION, DIAGNOSIS, AND TREATMENT OF MAJOR CARDIOVASCULAR DISEASES

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State of the project in October 1997

The goal of the project is the development of common standard clinical databases for improving the cost/benefit ratio by integrating patient care data (alphanumeric biosignals and images) and health economics analysis in a shared, stratified system of care. Professional user groups are strongly supporting and requesting this kind of development.

Integration of Intranet-type databases with health cards is considered in the project. Data card validation tests have been started in Italy, involving 600 national contact points. Commitments for implementation in other G-7 countries are welcome (reference for G-7 cards: Dr. H. Doaré [F]).

The feasibility study and a demonstrator were funded by the European Commission. At present, a test application has been implemented in Italy, with a starting network including 10 sites that will soon become 50 centers. The validation test is making use of an integrated research ISDN/ATM network, accessing an SQL patient database with a Web-JAVA application.

Image standardization, integration, and transmission are developed according to the internationally accepted DICOM standard; the huge amount of information in each patient investigation (0.25 MB per image, 500 MB per investigation) requires the availability of high-speed connections (ATM) among centers in the upper layers of the shared stratified system of care, while the other layers can communicate through medium- and narrow-band connection (TCP/IP) (reference: Prof. R. Simon [D]).

Interaction with the G-7 theme 2: Global Interoperability for Broadband Network has already been granted as of April 1997, while cooperation with the Trans-European Network in Telecommunications should be established.

Development of the project since November 1997

At the international level, the contact between the CATCH project (Citizens Advisory System based on Telematics for Communications and Health) and the G-7 Cardio project has led to the participation of the CATCH II project for the diffusion of quality-controlled health care multimedia information for citizens, patients, and health professionals (reference: Dr. Y. Pinto-Schrijver (NL); Dr. T. Reckart [D]).

The Health Promotion Component of the G-7 Cardio project, led by Health Canada, decided (in Montreal, February 1998) to support a validation project for qualitative analysis of the health promotion initiatives to be conducted by telematically interconnected Web-accessible databases (Canada, Italy, WHO), also involving partners from Finland, the United Kingdom, Germany, and Russia (reference: Dr. J. Larivière [CND]; Dr. A. Petrasovits [CND]).

The G-7 Cardio Project also benefited from the efforts of the Swiss coordinator for the G-7 Health Care Sub-Project III in providing experience in remote video medical support and high speed in image transmission (references: Prof. A. Gallino [CH]; Mr. L. Caoduro [CH]).

The state of G-7 Cardio-Project has also been presented at the planning session of the U.S. National Heart Attack Alert Program (NHAAP): Information Technology Symposium, including exchange of ideas and the search of common grounds of cooperation (reference: Dr. D. Lindberg [USA]; Dr. E. Siegel [USA]; Dr. M. Smith [USA]).

At the national level, the cooperation with the Italian National Association of Cardiologists (ANMCO) has proceeded, and 80 further coronary care units are expected to be linked to the already existing 15 centers of the G-7 Cardio Italian Intranet.

These coronary care units will field-test the Cardiology Specific Data Card (50,000 smart cards in 1998). These cards are interoperable, following the already existing guidelines, but a new standard for cardiology data elements may be in the offing.

By June 1998, 50 more cardiology institutes will be linked to test the first phase of implementation of the national cardiological database. The G-7 Cardio Intranet is now used for routine remote consultations among connected centers and for online clinical and scientific seminars, while continuing to accrue data into the database that was developed during the feasibility phase. These latter two phases are completely supported by the private sector.

The ARC Foundation (Associazione Ricerche Coronariche) has granted its support to the continuation of the G-7 Cardio Project with the creation of a G-7 Cardio Data Center and, subsequently, the creation of regional data centers.

Possible interaction with the NHAAP

In the general scheme of interventions that includes low-risk and high-risk individuals and patients, the largest component of the G-7 Cardio Project is targeted to patients who at discharge from a coronary care unit are provided with a cardiac data card.

The project is assessing the symptom-to-needle delay in this select group at the next acute ischemic presentation (acute myocardial infarction or unstable angina) according to their chosen modality of hospital access (call of physician or

ambulance at home or self-reference by car or taxi to emergency room) and in relation to environmental setting (big cities, towns, or rural areas). Their symptom-to-needle delays, in different environmental settings, will be compared to patients with acute *de novo* onset of ischemic heart disease in order to estimate the maximum potential benefit of appropriate educational campaigns of the general population.

ACCESSING MEDICAL RECORDS USING THE INTERNET

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How this idea can help the National Heart Attack Alert Program

With the advent of an increasingly mobile society, job-specific insurance plans, and managed health care, patients are frequently forced to change health care providers, resulting in medical records being spread across heterogeneous institutions. A lack of time-sensitive records such as electrocardiograms (ECGs) and catheterization reports (a focus of the NHAPP) forces emergency personnel to deliver medical care without the benefit of complete information. The fragmentation of time-critical records necessitates a means to access health care information from multiple data sources: regional health care networks, distant hospitals, and other emergency departments. The CareWeb™ project serves as a model for such an architecture. In October of 1996, the Beth Israel and the New England Deaconess hospitals merged to form the Beth Israel Deaconess Medical Center. CareWeb was created to provide common access to the clinical data of both institutions.

What currently is being done in this area

CareWeb uses Health Level 7 (HL7) messaging to retrieve information from each hospital and uses World Wide Web servers and browsers to send and display information. Security is accomplished with institutional firewalls and encryption. All technologies used are based on widely available standard components, and a toolkit has been developed to easily extend the CareWeb methods to other institutions.

The CareWeb technology is currently deployed in the emergency departments of both the Beth Israel and Deaconess hospitals to facilitate common information access and to improve care delivery to patients shared across the institutions. ECG reports and catheterization reports are instantly available for both institutions. Those involved hope

that the experience gained with this deployment will motivate a wider-scale deployment across other institutions, providing a comprehensive network of time-critical medical information to aid health care providers, especially in emergency departments delivering cardiac care, to improve the quality of care.

Obstacles to successful implementation of the idea

Barriers to successful implementation of CareWeb-like technologies include a lack of standards in many clinical computing systems and a wealth of security/confidentiality issues.

Clinical computing systems typically lack standardized vocabularies; one institution may record high blood pressure while another records hypertension. Computing systems typically lack standard data representations; ECGs may be stored as graphics, waveforms, or simple text descriptions. Many computing systems lack the ability to easily exchange information with other systems. All of these issues can be addressed through the use of standards-based middleware tiers. Using HL7 for data representation, LOINC (Logical Observation Identifiers, Names and Codes) for representation of standard vocabularies, and Internet technologies for data exchange, architectures can be designed that provide accessibility and unification to otherwise heterogeneous systems.

Security and confidentiality issues are a major hurdle to implementation of Internet-based medical records. Many would argue that public networks can never be secured adequately and that private networks that utilize Internet technologies to exchange data are the only solution. From a technical perspective, robust architectures for authentication, authorization, role-based access control, encryption, and auditing must be in place before patient-specific medical records can be exchanged. From an organizational perspective, strong policies and sanctions must complement technical solutions to reinforce proper use of the exchanged information. Currently, the Health Insurance Portability and Accountability Act is beginning to define national technical and organizational security standards for the exchange of medical records. Before a technical architecture can be deployed, a clearly defined national policy must be implemented.

Steps necessary to implement the idea

To implement CareWeb-like technologies on a national basis, a consensus on standards and technology toolkits for implementing those standards would have to be developed. Funding would be directed to a national program to develop a platform- and institution-neutral architecture. The resulting components could be pilot-tested among several participating institutions to exchange time-critical medical records over secured private networks using Internet technologies.

PORTABLE INFORMATION STORAGE DEVICES FOR IMMEDIATE ACCESS TO CARDIAC DATA AT THE POINT OF CARE

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How this idea can help the National Heart Attack Alert Program

The ability to rapidly access a patient's past medical records is critical in the management of acute cardiac problems. However, it is very difficult to obtain the past medical records, especially if they were maintained at another institution. This problem of history is further compounded during the management of a patient in the field by emergency medical personnel. Using low-cost portable information storage devices (PISDs) such as smart cards, patients can carry their essential cardiac record on their persons. This information could include a history of past cardiac problems, summary reports of electrocardiograph and other diagnostic tests, and current medications that the patient is taking. Currently, PISDs are based on semiconductor or optical technology. The semiconductor devices are mounted on a credit-card size plastic base (e.g., Gemplus) or in a small button-like container (e.g., Infobutton). Such devices often include mechanisms that offer privacy and confidentiality safeguards. The semiconductor cards have a storage capacity ranging up to 16 kilobits, and the optical cards have a storage capacity in the megabyte range. The content of these cards cannot be erased, i.e., they are "write once read many" (WORM) devices. Devices to read and write data (to PISDs) usually interface with personal computers (PCs) and portable computers. The essential cardiac record stored on a PISD can be rapidly accessed by an emergency medical technician (EMT) in the field using a portable hand-held computer or one mounted in an ambulance. The EMT can also add data about the current encounter to the PISD. Furthermore, the software on portable computers can contain current guidelines on treatment of patients with the given cardiac problem. These guidelines could be developed for use in situations where limited medical data are available. Upon arrival at the acute care facility (emergency room), past history and data acquired in the field can be transferred from the PISDs to the computers located in the department, thus facilitating continuity of care. Upon discharge from the facility, the PISD can be updated with a summary of the episode.

What currently is being done in this area

Oklahoma City has developed and is testing a smart card system for accessing vital patient records in emergency

situations.¹ Hospitals and ambulances in the region have been fitted with smart card read-write devices. Smart cards are being used in other medical applications, including management of diabetes,² primary care,³ and patient identification.

Obstacles to successful implementation of the idea

Among the challenges that exist for the successful implementation of PISDs for acute cardiac management are:

- Development of an essential cardiac record
- Development of standards for compact representation of the cardiac record
- Universal deployment of PISDs and read-write devices
- Development of interfaces to existing health care information systems to read and update the PISDs
- Acceptance by users (patients, providers, and health care facilities)
- Ensuring security and confidentiality of the data while allowing immediate access to care providers in emergency situations
- Standards for interoperability among read-write devices and PISDs from various manufacturers.

Steps necessary to implement the idea

The steps necessary to implement the idea are:

- a. Feasibility testing—assessment of cost benefits for universal deployment of this technology and user acceptance
- b. Development of an essential cardiac record and standards for its representation
- c. Development and deployment of the system in a limited capacity (limited to a defined region) through an industry/academia/health care system collaboration
- d. Evaluation of the system for user acceptance, improvement in time to institute therapy, change in patient outcomes, and cost-effectiveness.

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Diagnosis and Treatment Decision Support

James J. Cimino, M.D. (Chair),
Robert J. Zalenski, M.D., M.A.
(Vice-Chair)

Dr. Robert Beck described the use of interactive, Web-based decision trees to assist patients in evaluating their symptoms and deciding whether or not to call for transport to a health care facility. Because of the time sensitivity of heart attack intervention, conventional decision/analytical models are not appropriate. A prototype of a computer-based clinical system might consist of an algorithmic tree linked through the Web site with options including direct symptom entry, risk stratification, and access or direction to an appropriate level of care, i.e., 9-1-1.

Dr. Robert Christenson discussed the promise and problems of biochemical markers for diagnosing patients with acute coronary syndromes. He stressed that acute coronary syndromes represent a continuum of myocardial ischemia ranging from stable angina, unstable angina, non-Q-wave infarction, to Q-wave infarction. The continuum spans from reversible myocardial injury to myocardial necrosis. He called for development of a panel of new proactive markers to identify myocardial ischemia, plaque disruption/inflammation, platelet response to ischemia/injury, thrombus formation, and minor or major myocardial necrosis. Informatics may be helpful in collecting data and combining information in creating these markers.

Dr. Zalenski discussed community acquisition of a 12-lead electrocardiogram (ECG) for patients at high risk of acute myocardial infarction as a leading technology in risk stratification. He stressed that this is needed because delay is unacceptable and patients have limited options. Three venues for this to occur in the community could be health fairs with ECG testing and screening, prehospital ECGs, and home ECGs. Dr. Zalenski demonstrated a home ECG from one vendor that would be easy to use and recommended that a large-scale study of this technology be considered to determine whether patients receive more rapid and more appropriate care.

Dr. Isaac Kohane addressed the need for immediate access to critical data about the right patient at the right time. He discussed several projects in the medical informatics community, including the World Wide Web Electronic Medical Record System (W3-EMRS) project and the Health Information Identification and De-Identification Toolkit (HIIDIT) project, both of which are funded by the National Library of Medicine. Integral to this is a common set of data elements which are universally accepted, i.e., HL7 and patient identifiers. Confidentiality issues are probably the biggest hurdle to overcome.

Dr. Vimla L. Patel stressed the need to understand cognitive processes in decisionmaking. She recommended that a research agenda be developed in tandem with technological advances to ensure that information technology is effective, efficient, and safe. This will not be achieved without a research agenda that

examines underlying cognitive processes. There is a need to identify a conceptual connection behind a given decision: if thought processes change, then the action taken will change. The normal relationship between action and knowledge is decoupled in emergency situations where the reflex is to act first and think later.

Dr. Harry Selker discussed the use of technology to integrate diagnostic technologies and clinical decisionmaking. He described a thrombolytic predictive instrument, which utilizes a computerized ECG machine to determine if a patient is having a cardiac event and to indicate the necessary level of intervention. This instrument will predict the probabilities of a cardiac event occurring, and it is also time-insensitive in that information can later be downloaded and the data studied retrospectively. This combination of instrumentation and information technology would foster predictive, real-time, and retrospective diagnostic capabilities. More research is needed to fully understand how such advanced technologies can be used.

Some of the main points emerging from the discussion included the necessity to target populations at risk and the need to start identifying patients earlier in the cycle of pathology in order to make a difference. Also, access to technology for all segments of the population should be attempted at every level, but will ultimately require Federal action to eliminate disparities; and, women have more comorbidity factors than men, so decisionmaking support needs to be more sophisticated than merely looking at chest pain.

USE OF INTERACTIVE DECISION TREES FOR PATIENTS TO DECIDE ABOUT THE NEED TO CALL AN AMBULANCE

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How this idea can help the National Heart Attack Alert Program

The mission of the NHAAP is to reduce morbidity and mortality from acute myocardial infarction, including sudden death, by reducing the time to definitive diagnosis and treatment. Phase I of the NHAAP action steps is Patient Recognition and Action: the time between the experience of heart attack symptoms and the decision to seek care. We suggest that interactive, Web-based decision trees may assist patients in evaluating their symptoms and choosing to call for transport to a health care facility. Such trees must have several characteristics:

- Contain all relevant disease states
- Reflect the latest information on probability of various cardiac lesions
- Incorporate risk factors and symptomatology directly
- Enable simple cost and quality data to be entered
- Address patient preferences
- Guide rather than prescribe
- Be easily reached using the World Wide Web
- Tie directly to local emergency transport systems.

A fairly sophisticated cardiovascular disease model can underlie the user-friendly decision support system. We demonstrate some of the attributes of such a system and suggest that a prototype be developed in a metropolitan area where the decision sciences are well supported.

* GUSTO = Global Utilization of Streptokinase and t-PA for Occluded Coronary Arteries.

THE PROMISE AND PROBLEMS OF COMMUNITY-BASED MEASUREMENT OF BIOCHEMICAL MARKERS OF ACUTE CORONARY SYNDROMES

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How this idea can help the National Heart Attack Alert Program

The acute coronary syndromes represent a continuum of myocardial ischemia ranging from stable angina, unstable angina, non-Q-wave infarction, to Q-wave infarction. This continuum spans from myocardial injury that is clearly reversible through frank tissue necrosis. Most importantly from a clinical standpoint, the acute coronary syndromes correspond to a continuum of risk of adverse outcome. Numerous studies have indicated that blood concentration of the troponins, cardiac-specific biochemical markers of necrosis, directly correlates with risk. Most studies indicate that approximately 1/3 of unstable angina patients have detectable levels of these necrosis markers at presentation. Further, studies have suggested that biochemical marker concentrations may be a useful guide for therapy. Ongoing studies also are examining the issue of intervening based on cardiac marker results.

What currently is being done in this area

Time from symptom onset to treatment with thrombolytic therapy is an important variable for predicting outcome. Substantial effort in this area was probably responsible, at least in part, for a decrease in the median time to treatment from 2.7 hours in GUSTO* I to 2.4 hours in GUSTO III. Unfortunately, however, this decrease was due solely to improvements in in-hospital processes; the time from symptom onset to hospital arrival was the same in both studies. Thus, strategies for reducing the "front end" time represent an important challenge that could benefit many patients. Time to treatment is not the only variable for predicting outcome. It has been documented that approximately 50 percent of myocardial infarction patients have prodromal symptoms including intermittent angina, stuttering chest pain, or subtle and nonspecific symptomatology in the weeks, days and/or hours prior to infarction. Identification of (often vague) prodromal symptoms by patients, bystanders, significant others or health care workers in the field could help trigger immediate care and reduce the time from symptom onset to hospital presentation. For many complex reasons, patients often do not seek treatment rapidly. An objective indicator that the patient is at high risk for a cardiac event may prove that immediate treatment is prudent. Measurement of biochemical markers in the blood of patients following suspected prodromal symptoms can provide objective data toward this end.

Obstacles to successful implementation of the idea

The prospect of a single biochemical marker that is the “holy grail” for identifying a patient’s position on the acute coronary syndrome continuum is unlikely. Instead, a combination that includes a marker of myocardial ischemia (glycogen phosphorylase-BB), an indicator of plaque disruption/inflammation (C-reactive protein; CRP), and markers of “angry” platelets (P-selectin), thrombotic potential (soluble fibrin), minor myocardial necrosis (troponin T or I), and extensive myocardial necrosis seems more feasible. The results of these markers should be quantitative, so they could be treated as continuous indicators. Models of these biochemical variables would be developed to predict risk and indicate the urgency for seeking medical assistance. To date, there are qualitative bedside or point-of-care devices available for measurement of cardiac troponin T, cardiac troponin I, myoglobin, CRP and CK-MB. Small devices for quantitative measurement of these proteins are in the late stages of development. Platelet function, P-selectin, and thrombotic potential assays for point-of-care use are also in late stages of development. However, at present, the evolution of this technology remains incomplete and appropriate studies have not been conducted.

Steps necessary to implement the idea

Given the high prevalence of acute coronary syndromes, development and potential implementation of this testing are of substantial interest to industry. Testing in the alpha and beta phases should be performed in collaboration with unbiased experts to provide an appropriate evidence base. Modeling to develop the best possible combination of the markers should be performed in a similar fashion.

Field use of biochemical markers of the acute coronary syndromes may help provide objective data that would convince patients, significant others, bystanders, and health care workers that urgent care is needed. Using validated technology in appropriate models, patient risk assessment outside the hospital could reduce treatment delay and improve outcome.

HOME 12-LEAD ECG ACQUISITION IN PATIENTS AT HIGH RISK OF AMI

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How this idea can help the National Heart Attack Alert Program

A principal problem with the assessment and treatment of patients with acute myocardial infarction (AMI) is an unacceptably long delay from symptom onset to evaluation by the first health professional. Time to treatment is delayed

by median times of 2 to 6.4 hours, resulting in lost opportunities for myocardial salvage and increased chances of unmonitored cardiac arrest.

What currently is being done in this area

One promising technology to reduce this delay in those at risk of recurrent ischemia/infarction is the recording of the 12-lead electrocardiogram (ECG) at home. Technology now exists for the home acquisition of the 12-lead ECG and its transmission to a physician or database. Although previous research in the prethrombolytic era of physician home visits with portable ECGs does not appear to have been productive, direct transmission of ECGs from the homes of patients with symptoms in the era of interventional cardiology has not been tested.

Upon discharge from the hospital after AMI or chest pain, consenting and cooperative patients with a partner, such as a spouse or home aide, would be instructed in the recording of a 12-lead ECG at home. A control group would receive usual care. Patients would be encouraged to obtain tracings when they had recurrent pain, dyspnea, or palpitations that would prompt seeking medical care, but were not of sufficient intensity to call 9-1-1. This judgment would be left to the individual patient; the experimental protocol is not intended to discourage patients from accessing emergency medical services (EMS). The acquiring ECG, a small hand-held battery unit, can obtain single or multiple tracings and then transmit them to a personal computer (PC) through an infrared port. From the PC, modem transmission can then send a tracing to an emergency department (ED) or a database. In the ED, a study physician could interpret the ECG in real time; in a database, a TIPI score (a measurement of the probability of AMI or unstable angina) could be computed, compared to a baseline TIPI score, and then provided to the patient.

In the former scenario, once an ECG had been transmitted to an ED participating in the study, it and a previous (baseline) tracing would be interpreted by a physician: new findings of ST-segment elevation, depression, Q waves, or T wave inversion would prompt an immediate call to the patient to discuss the findings and to advise EMS transport. If there were no changes or nonspecific findings, the physician would discuss these results with the patient and review the options of calling 9-1-1, self-transport to the local ED, or outpatient appointment on the same or following day. Patients would be encouraged to record a repeat 12-lead ECG if they chose not to seek immediate treatment and symptoms persisted, returned, or worsened.

Steps necessary to implement the idea

The primary outcome of the study would be a comparison of times from symptom onset to treatment for patients with unstable ischemia and the rates of detection of recurrent AMI or unstable angina in intervention and control groups. Cost impact would be a secondary endpoint and would include the costs due to a new diagnostic modality and

induced costs/or savings from subsequent ED/hospital or outpatient encounters. A large managed care organization, such as the Veterans Administration Medical Centers, may be interested in testing this intervention.

ACCESS TO ELECTRONIC MEDICAL RECORDS: CRITICAL DATA ABOUT THE RIGHT PATIENT AT THE RIGHT TIME

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How this idea can help the National Heart Attack Alert Program

On initiation of an emergency call or upon arrival of medical care, accurate, up-to-date information can aid rapid evaluation and avoid adverse events during initiation of therapy. Yet this information is not stored in any single location, electronic or otherwise. Nor is the generation of a national emergency database likely to solve this problem. Reliable identification of the patient is obviously essential, yet naive implementation of an identification system, such as the Social Security number, places the confidentiality of the patient's data at risk.

Proposal

In the context of the recent successes of multi-institutional data-sharing efforts, cryptographic identification systems, and the increasing ubiquity of the World Wide Web, a three-pronged approach is indicated to address the aforementioned problem: (1) a patient-based, Internet-accessible critical data set; (2) a multi-institutional collation of a shared critical data set, also Internet-accessible; and (3) a cryptographic health identification system for patients and for providers.

What is already being done in this area

There are several projects in the medical informatics community that speak to the three objectives above. First, the World Wide Web Electronic Medical Record System (W3-EMRS)¹ project, funded by the National Library of Medicine, has led to several successful data-sharing implementations across multiple, heterogeneous hospitals for a variety of applications ranging from sharing of emergency data to dissemination of standardized clinical practice guidelines. Second, there is an increasing consensus around messaging standards for the sharing of clinical data (e.g., Health Level Seven, or HL7) and for the definition of standard data sets (e.g., the Centers for Disease Control and Prevention's Data Elements for Emergency Department Systems/DEEDS). Third, early proposals² for cryptographic health identification systems have been funded by the National Library of Medicine, resulting in the Health Information Identification and De-Identification Toolkit

(HIIDIT). HIIDIT provides a flexible set of tools to generate health identification systems that allow system designers to specify which of a variety of tradeoffs in privacy and access they wish to select. Fourth, work on personal health records and health agents³ has demonstrated feasibility over the preceding 3 years. These earlier efforts suggest that the technical challenges needed to meet the objectives stated here have largely been met. The broader challenges are organizational and societal.

Proposal outline

1. Patient-based, Internet-accessible critical data set

Most of patient care occurs outside the emergency department (ED) or even outside hospitals altogether. The most up-to-date patient information is shared between the patient and his or her primary care cardiologist/clinician. Therefore, a personal data set containing critical data for the management of myocardial infarction (current medications, allergies, prior electrocardiogram) is most likely to be current if maintained both by the patient and primary provider. A trusted third party can maintain this data set on an encrypted portion of a personal Web page, or in an Internet-accessible database. Both the patient and clinician, duly authenticated, have the ability to edit and update this data set. The means to do so can include direct Web access, a telephoned transaction, or even more traditional nonelectronic methods. During an emergency, emergency medical technicians or ED clinicians—using their secure Web identifiers—will have access to these data as well as collated institutional data, as described below. Each of the trusted third parties hosting these patient-based data sets will provide real-time standardized HL7 interfaces to minimize the engineering challenge of merging/collating all relevant data for the emergency provider.

2. Multi-institutional data

Participating health care institutions that might have relevant data in electronic storage will provide a standardized, real-time HL7 interface to respond to queries, issued by authenticated and authorized providers, for the critical data set. Software, in the control of the emergency clinicians, will collate "on the fly" all the critical data sets obtained from institutions where the patient may have received care, as well as the data from the patient-based critical data set. All communications will occur over the Internet, securely encrypted and available only to authenticated and authorized providers.

3. Cryptographic health identification system

Patients enrolled in this system will be assigned cryptographically generated health identifiers. Similarly, duly authorized providers will be assigned cryptographic identifiers stored either on designated computers or on personal hardware tokens ("smart cards"). Appropriately configured cryptographic identification systems can provide reliable access to patient data without revealing

those data to unauthorized parties, nor revealing particularly sensitive data unnecessarily. Furthermore, such systems can generate an irrefutable audit trail documenting all access of the patient data. In concert with the deployment of such identification systems, there is a need for the development of confidentiality policies for the appropriate use of these systems and concordant educational programs.

Obstacles to successful implementation of the proposal

The principal obstacles include (a) achieving widespread agreement on the details of a common critical data set, (b) creation of trusted third party organizations to maintain some of the necessary infrastructure, (c) further standardization in the use of HL7, (d) agreement on a particular health identification system, and (e) institutional agreements for safe and confidential sharing of data.

Steps to implement the proposal

A small number of prototypes should be implemented involving multiple hospitals—preferably not part of the same corporate entity (to test the policy implications of data sharing across corporate boundaries), but sharing geographical overlap in their patient database. Along with some seed funding from the NIH, each participating institution should provide matching funds in kind (for connectivity and implementation) as a prima facie expression of interest. The grant mechanism should involve an ironclad request for formal evaluations, including “hard” outcomes, process measures, and measures of satisfaction and/or concern.

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UNDERSTANDING COGNITIVE PROCESSES IN MEDICAL DECISIONMAKING

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How this idea can help the National Heart Attack Alert Program

The NHAAP has defined three phases of action steps that are essential for obtaining immediate recognition and treatment

when an individual is having symptoms suggestive of myocardial infarction. The relevance of cognitive studies to all three of these phases is discussed in this presentation.

Phase I is related to patients’ or lay people’s recognition of the problem and the time taken to seek appropriate help (while avoiding inappropriate requests for assistance). The challenge here is to characterize and to understand the nature of biases and heuristics (rules of thumb) that people use in making decisions to seek help (to take action). What is the nature of the knowledge used in making such decisions? Based on this understanding, how can we train and educate people who are at high risk of cardiac events to take appropriate action when symptoms occur? Innovative training and educational programs can be based on studies of lay people’s reasoning, where cognitive, social, and cultural factors interact in the decisionmaking process.

Phase II is related to prehospital action by professionals, where decisions and judgments have to be made by triage experts and paraprofessionals under varying conditions of urgency and problem complexity. The challenge at this level pertains to understanding the cognitive processes underlying such decisions and actions. Research should be conducted on how people deal with information that is ambiguous or uncertain, and upon which clear-cut decisions cannot be made. The findings from such studies would provide recommendations and the basis for training of personnel to deal with decisionmaking under conditions of uncertainty.

Phase III is related to the action taken in the emergency department by clinicians and other trained personnel. In emergency conditions, actions are taken under severe time pressure as well as under conditions of stress in the absence of the luxury of time to validate decisions against specific evidence. Under these conditions, knowledge and action for decisions appear to be decoupled. Studies should be commissioned that investigate specific relationships concerning actions that are taken (based on well-learned rules) and how the underlying knowledge is learned or updated through experience (for example, via dialogs, discussions, negotiation, and conflict resolution).

What currently is being done in this area

Prior studies have shown that lay people base their decisions on their own explanations of health and disease. These in turn are influenced by cultural beliefs and values. The knowledge used for decisionmaking is acquired through direct interaction with everyday health problems and is naturally validated in cultural practices. Unlike scientific explanations (such as a physician making a specific therapy-selection decision), lay models of reasoning do not follow strict logical consistency in coordinating hypotheses (about mechanisms of disease) to evidence (e.g., the individual’s explanation for why he or she is ill). This variation among individuals, and the ways in which they respond to symptoms by interpreting severity and cause, make it

difficult to devise a single educational program that will serve the needs of all social and cultural groups in our society. The challenge is to determine, therefore, those factors that are common across all lay people as they make health-related decisions, as opposed to what is specific to special subgroups (such as previously diagnosed cardiac patients, ethnic minorities, and people with varying levels of education). Studies were performed at McGill University (Quebec) that sought to elucidate such factors in other health care settings.

Research investigating task complexity has shown that there is a lower margin of error in making decisions when one is dealing with simple, familiar problems. In these settings, the rules of action are well learned and easily retrieved. Under conditions of high urgency, decisions are often simpler, with straightforward triggering of rules for emergency management. Low urgency settings are similarly easy to handle because there is time to check evidence carefully and to reach a rational decision. It is well documented, however, that under conditions of moderate urgency and ambiguity, decisions are much more complex and less likely to be judged as accurate in retrospect. Decisionmakers must rapidly filter out irrelevant information while performing an accurate situation assessment—a cognitively taxing set of challenges because multiple decisions and assessments are being made in parallel. One's skill in dealing with such ambiguity is a reflection of their training and experience, but can also be enhanced by suitable decision-support tools. The author has performed other studies regarding cognitive issues in the management of telephone triage for 9-1-1 emergency phone calls.

Obstacles to successful implementation of the idea

There is not a direct relationship between the research findings and the implementation of the idea. This would require a need to set up an iterative design system where there would be an intimate relationship between research findings and testing these findings in practice. For example, technology may play a role in all three phases, and the design of such systems, especially their user-interfaces, must be sensitive to the lessons of cognitive research. In Phase I, software programs for teaching a cardiac patient how to deal with acute symptoms will be improved by a better understanding of the factors that define how an individual is similar to—and different from—others, who may need similar education. In Phase II, there is an obvious potential role for software to assist those individuals who receive the emergency phone calls from the field, especially in situations of high ambiguity and moderate urgency.

Steps necessary to implement the idea

Tools and computer-based guidelines intended to assist medical decisionmakers should reflect knowledge of the cognitive tasks that are involved in various settings, as well as the role of evidence, such as data that might be directly accessible from an individual's computer-based medical

record. Systematic, explicit, and formal methodologies to discern knowledge and procedures should be established to help develop guidelines for emergency actions and for providing decision support. These guidelines should be linked directly to information systems and could be easily and quickly accessible through user-interface for any kind of emergency action. Furthermore, our understanding of how people make decisions on ambiguous cases (incomplete or inconsistent information) could be used to support and update the existing guidelines. This aspect is related to education and learning. In Phase III, there are further training issues that are derived from the need to develop shared understanding and collaborative approaches to acute management of patients with chest pain. Cognitive studies will contribute to defining the ways in which communication, negotiation, and consensus development can play a role in such team building. Recent studies on the cognitive evaluation of computer systems in use by professionals and others are highly relevant to the development of information-management and decision-support tools of the type that will help to meet the needs of the NHAAP.

THE USE OF COMPUTERIZED ELECTROCARDIOGRAPH TO PROVIDE DECISION SUPPORT FOR THE USE OF THROMBOLYTIC THERAPY AS WELL AS TO RECORD RETROSPECTIVE ANALYSIS OF PERFORMANCE FOR FEEDBACK

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How this idea can help the National Heart Attack Alert Program

Thrombolytic therapy can be lifesaving in patients with acute myocardial infarction (AMI). However, if given too late or insufficiently selectively, it may provide little benefit but may still cause serious complications and incur substantial costs. We developed the Thrombolytic Predictive Instrument for real-time use in emergency medical settings to be able to identify patients most likely to benefit from thrombolysis, and to facilitate the earliest possible use of this treatment.

What currently is being done in this area

To create the Thrombolytic Predictive Instrument, we created a set of mathematical models that predict the key clinical outcomes from the use of thrombolytic therapy. To

do this, we collected data from patients with AMIs in 13 major clinical trials and registries, and made multivariable logistic regression models that predict the following: The probability for acute (30-day) mortality if, and if not, treated with thrombolytic therapy; 1-year mortality rates if, and if not, treated with thrombolysis; cardiac arrest if, and if not, treated with thrombolysis; thrombolysis-related intracranial hemorrhage; and a thrombolysis-related major bleeding episode requiring transfusion. Programmed into a conventional computerized electrocardiograph, these probabilities are printed out on the top of the electrocardiogram (ECG) for use in the real-time setting. In the emergency setting, the computerized electrocardiograph automatically detects whether or not the patient has ECG ST-segment elevation sufficient to qualify for thrombolytic therapy, then automatically prompts the user to enter the key input variables, and then calculates and prints the Thrombolytic Predictive Instrument's predictions on the ECG header.

Steps necessary to implement the idea

Besides the real-time clinical use of the Thrombolytic Predictive Instrument, to further support improving performance in the treatment of patients with AMI, the

Thrombolytic Predictive Instrument data can also be used for retrospective feedback. Such reports can be generated by using the data collected by the computerized electrocardiograph, basic entered data and the predictions generated for each patient, along with whether reperfusion therapy was instituted, and if so, how long since ischemic symptom onset. Such a database—with reporting software—allows easy analysis of whether patients who have a likely high possibility of benefiting from thrombolytic therapy are being treated, and/or that those who have a high possibility of complications or have minimal likelihood of benefit are not being treated, as well as whether the times to treatment are reasonable. Such a database can be used in specific hospitals, and also can be put on the World Wide Web to allow hospitals to compare and benchmark their performance with other institutions.

The real-time use of the Thrombolytic Predictive Instrument has been tested in a multicenter prospective randomized controlled trial, and the retrospective analysis capability is being built in. It is hoped that the simultaneous real-time and retrospective use will optimize the use of crucial reperfusion therapies for patients with AMI in this country.

Large-Scale Databases

William Tierney, M.D. (Chair),
Costas T. Lambrew, M.D. (Vice-Chair)

Dr. James J. Cimino discussed the value of the Internet as a resource to aid decisionmaking, but stated that the challenges are in identifying the right resources, performing the right queries, and retrieving the right results. Dr. Cimino described Columbia University's use of "infobuttons," which link patient information (e.g., laboratory tests and results) to a variety of online resources (including MEDLINE, electronic text books, image databases, and expert systems) in order to support clinical decisionmaking.

Dr. Costas T. Lambrew urged that physicians take advantage of an industry-sponsored, large-scale database, the National Registry of Myocardial Infarction (NRMI), which profiles acute myocardial infarction patients' presentation, common patient management practices, and delays in the identification and treatment of heart attack patients. These data can help answer questions and improve care by creating an important feedback loop by which hospitals can benchmark their progress in implementing National Heart Attack Alert Program goals, or American College of Cardiology/American Heart Association practice guidelines, for example.

According to Dr. Nathan Every, the demands for quality of care and outcome

data in hospitalized patients have resulted in a proliferation of databases of varying quality. He compared data collected from two large databases—the NRMI-2 and the Cooperative Cardiovascular Project (CCP), sponsored by the Health Care Financing Administration—which utilize very different data acquisition techniques. Overall, the study revealed very similar data results in patient-to-patient matching. The NRMI-2 compared favorably to the rigorous process of the CCP. Voluntary databases can be valid and perhaps less costly. The optimal data collection tool gathers data as part of patient care. Electronic medical records will help with this. The inclusion of guidelines into the data collection systems is important to encourage appropriate practices.

Dr. Jane Scott discussed the importance of systematic, evidence-based reviews to changing clinical practice. She suggested that the use of evidence-based reviews provides enough information to make decisions about changing clinical practices. Databases such as that developed by the Cochrane Collaboration can help prepare, maintain, and disseminate systematic reviews of the effects of health care. Another review source is the Agency for Health Care Policy and Research's Evidence-Based Practice Centers.

Dr. Harry Selker suggested that the databases derived from clinical trials offer a rich source of information that is not being used enough. There are three

ways data can be used: for "secondary" analysis; combining data from different clinical trials to provide sufficient data to address key clinical problems; and the use of special data for methodological advances. Secondary analysis is less costly and time-intensive and, in terms of scientific impact and lives potentially saved, may well exceed that of the original trial. There is a need for standards and support concerning how secondary analyses should be conducted.

Panelists agreed that organizations should be open to collaborating with other groups in sharing their data, as there are often more data than investigators. The data become outdated before one can exploit their value. Panelists agreed that the investigator should be included in the secondary analysis. There are many databases available, and some are better than others. A real concern is that certain data will produce a "garbage in and gospel out" effect. Also, there is no such thing as a "clean" database and anything that wasn't intended to be an outcome should be assumed to be "dirty." This is especially the case with secondary analysis. The study design is critical in analyzing observational data and requires an interdisciplinary team for optimal results. There are often discrepancies in results between observational and clinical trials, indicating that the results are not being translated into actual practice. There was agreement that one universal, standard registry would be optimal.

USE OF THE INTERNET FOR DATABASE ACCESS

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How this idea can help the National Heart Attack Alert Program

Appropriate decisionmaking by health care professionals requires timely resolution of information needs. Other speakers in this program will address issues related to access to patient-specific information (i.e., medical records). This talk addresses the need for access to general health information to resolve specific patient care problems. The Internet provides access to a wealth of information both about patients in particular and medicine in general, and today's clinical information systems are realizing the decade-long dream of "one-stop information shopping."¹ However, identifying the right resource, performing the right query, and retrieving the right results are difficult, especially when performed in the heat of diagnostic and therapeutic decisionmaking. By combining intelligent systems with information about the patient in question, it is possible to carry out these tasks in an efficient and effective manner. The term "infobutton" is used to refer to methods by which these systems can anticipate and satisfy information needs with a minimum of user interaction, bringing us to "one-touch information shopping." For example, consider a case where a patient presents to the emergency room with an apparent acute myocardial infarction. The physician caring for the patient (planning to administer thrombolytic therapy) reviews the available laboratory data and discovers that the patient's coagulation studies are abnormal. Digging deeper, the physician finds that the patient was previously noted to have a positive test for a lupus anticoagulant. A double-edged question now arises: is the laboratory evidence of a coagulopathy a contraindication to therapy, or does the lupus anticoagulant actually signal a hypercoagulable state which might require more aggressive management? Previous studies of clinicians with information needs predict that the physician will ask a colleague or, failing that, try to find something on the bookshelf. The right infobutton, appearing on the computer screen next to the lupus anticoagulant result, could take information about the patient ("rule-out myocardial infarction" and "lupus anticoagulant") and compose a search to find relevant information.

What currently is being done in this area

The idea of linking clinical systems to online resources, such as databases, is not new. The author reviewed several different working systems that use information from the

clinical record to drive Medline searches.² Development of such systems was challenging enough when the resources were simply "hard-wired" into clinical systems. The Internet and the World Wide Web in particular provide greatly simplified access to a vast number of resources, but hard-wiring to these is actually more difficult. The author and his colleagues have developed a number of techniques to help overcome these obstacles to automating the process of access to online resources. Referred to collectively as "infobuttons," these techniques enable using patient data to anticipate information needs, selecting appropriate resources, translating clinical data to a form usable by the selected resource, and then composing and performing an appropriate query. Infobuttons have been created that link patient information (including laboratory tests and results, culture results, medication orders, and x-ray findings) to a variety of resources (including Medline, electronic text books, image databases, and expert systems). Each of these relies on a combination of terminologic methods that use the Unified Medical Language System and traditional, knowledge-based controlled terminology.³ Detmer and colleagues have used similar methods to link information needs raised by one online resource to be resolved by another.⁴

Obstacles to successful implementation of the idea

In order to move beyond demonstration projects, a number of issues must be addressed that relate to the clinical data, the information resources, and basic understanding of how one can be used to drive the other:

- a. Standards for clinical data representation are needed so that electronic medical records are composed of recognizable, understandable terms, rather than the current Babel of home-grown languages.
- b. Information resources must also use standard terminologies for representing the concepts they contain; Medline has a rich tradition of doing so, but most resources are much less principled.
- c. The granularity of terminologies is sharply different between clinical records and medical resources; a method must be developed for reliably and automatically mapping from one to the other.
- d. The cataloging of the resources themselves must be done in a way that can be accessed by automated processes, rather than relying on busy clinicians to have personal knowledge of each, or the time to evaluate and select the appropriate one.
- e. The query mechanisms must be standardized so that one search facility can access multiple resources.
- f. A deeper understanding of clinicians' decisionmaking information needs is required. In the example given above, asking some general question about

“lupus anticoagulant” would not be relevant to the emergency room physician—the system would need to know more about the setting (emergency room), the likely type of question (likely therapy based on admitting diagnosis plus possible contraindication based on test result), and perhaps even something about the user (physician, student, or patient?).

Steps necessary to implement the idea

- a. The development of knowledge-based terminologies (often referred to as “reference terminologies”) that can provide information about the data being manipulated (either used for searching or obtained in retrieval). Much work is already being done in this regard by groups like the Logical Observation Identifiers, Names, and Codes; Health Level Seven; and Systemized Nomenclature of Human and Veterinary Medicine.
- b. The development of structured cataloging of online resources. The Unified Medical Language System information sources map has broken some ground here, but more aggressive development of that resource is needed.
- c. Studies of information needs in the clinical setting. This will require cognitive as well as sociological studies.
- d. Research into ways to automate resource selection and retrieval for particular queries. This will require as much library science as computer science.
- e. Development of standards for information resource construction. The Z31.50 standard is one type of methodology, but others are needed. Current work with XML (extensible markup language) can be directed at ways of marking up resource documents to facilitate retrieval, organization, and presentation to the user.

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CONTINUOUS QUALITY IMPROVEMENT IN THE CARE OF PATIENTS WITH ACUTE MYOCARDIAL INFARCTION: THE NATIONAL REGISTRY OF MYOCARDIAL INFARCTION (NRMI)

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How this idea can help the National Heart Attack Alert Program

Reperfusion therapy for patients with ST-elevation myocardial infarction who have no contraindications to thrombolytics and who present within 12 hours after onset of symptoms is the current standard of care for these patients. However, reperfusion therapy either is not offered or may be offered variably within institutions and between regions of the country. Such therapy is frequently inappropriately delayed despite its time-dependent relationship to outcome (as reflected in mortality) because of practices related to identification and treatment of these patients in emergency departments and hospitals. Interventions that have been shown to reduce morbidity and mortality, as recommended in widely disseminated guidelines and published by the American College of Cardiology and American Heart Association, are not implemented in practice. The gathering of data in the NRMI, a large-scale database, serves to profile patients in terms of presentation, profile common practices in the care of patients with acute myocardial infarction (AMI), and identify delays in identification and treatment as well as voids in the use of appropriate drugs and interventions in the treatment of such patients. Feedback of these data and profiles to participating hospitals and physicians should allow them to critically examine process and practice as well as outcomes, and change practice where appropriate to improve adherence to evidence-based guidelines, thereby improving outcomes. Trends over time can therefore be tracked, as can performance of one individual institution compared to a benchmark of other institutions. Furthermore, national practice trends can be tracked because of the large scale of the database.

What currently is being done in this area

The NRMI is an observational, collaborative endeavor, sponsored by Genentech, Incorporated, in which participating hospitals throughout the United States record demographic, procedural, and outcome data on patients with AMI. The purpose of this registry is to collect uniform, prospective data on the treatment of patients with AMI that: can be used globally to analyze national practice patterns for infarct treatment; can be used locally to assess individual

hospital practice patterns and outcomes to facilitate the continuous quality improvement process; and can be used by the sponsor to monitor the frequency of specific adverse events with the use of their product, recombinant tissue type plasminogen activator (Activase). Data collection in NRMI depends upon local patient identification and chart abstraction in combination with centralized data entry. A study coordinator at each hospital is instructed to enroll consecutive confirmed infarcts utilizing AMI criteria, which include electrocardiogram, cardiac enzyme, or angiographic abnormalities as well as the discharge diagnosis of 410.X1. Coordinators attend a half day training course and are provided with a reference manual that includes a case report form, field definitions, and examples of correct responses. Patient information is transcribed onto a two-page case report form. Completed forms are forwarded to an independent central data collection center, ClinTrials Research, Inc. (Lexington, Kentucky). There are electronic data checks to detect internal inconsistencies, omissions, and out-of-range values. Case report forms that fail edit checks are mailed back to the study coordinator for data resolution.

Since enrollment of patients began in 1990, 1,015,719 patients have been enrolled through two phases of the study from over 1,700 hospitals. Acquisition of patients averages approximately 21,000 per month. Quarterly reports have been fed back to participating hospitals where they have been shared with physicians, nurses, and technical staff for the purposes of examining process, effecting change in process, and monitoring patient outcomes. On a national level, practice patterns have been tracked by a national scientific advisory committee with very compelling evidence relating to a reduction of delay in door-to-drug time, increased use of appropriate interventions, and decreased use of drugs which are not recommended for treatment.

Obstacles to successful implementation of the idea

Registry data have been remarkably well received by hospitals when they have been constructively used as opposed to being used to criticize staff. The quality improvement process needs to be continuous as well as multidisciplinary. Very substantial regional variations in interventions such as percutaneous transluminal coronary angioplasty and coronary artery bypass grafting as a reflection of physician practice patterns without evidence of differences in mortality can only be addressed by use of these data on the local and regional levels to compel physicians to examine process in relationship to outcome. The use of these data toward that end frequently meets considerable resistance, but can succeed if the process protects confidentiality of individual physicians and practices.

Steps necessary to implement the idea

The NRMI has been implemented and sponsored by Genentech. The integrity of the data and the analyses has been maintained by a national scientific advisory committee and the confidentiality of the data for each participating hospital through the processing and distribution of the data by the clinical coordinating center. The comparability of the data to a well-validated database has been examined and is the subject of a separate report. Correlation is quite good.

VALIDITY AND EFFICIENCY IN COLLECTING QUALITY DATA IN ACUTE MYOCARDIAL INFARCTION PATIENTS: A COMPARISON OF THE COOPERATIVE CARDIOVASCULAR PROJECT (CCP) AND NRMI-2

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How this idea can help the National Heart Attack Alert Program

The increased demand for quality of care and outcome data in hospitalized patients has resulted in a proliferation of databases of varying quality. For patients admitted with myocardial infarction, there are two national databases that attempt to capture critical process and outcome data using different case identification and abstraction processes.

We compared case ascertainment and data elements collected on patients—35,675 Medicare-eligible patients in the industry-sponsored National Registry of Myocardial Infarction (NRMI 2), and 42,703 Medicare patients included in the Health Care Financing Administration-sponsored Cooperative Cardiovascular Project (CCP)—who were admitted to 1,087 matching hospitals during identical enrollment periods. Comparisons were made at both the hospital and patient levels to evaluate whether or not the simpler case identification and data abstraction processes used in NRMI 2 are comparable to the more rigorous processes utilized in the CCP.

Demographic and procedural use data obtained independently in each database were nearly identical. There was a tendency for NRMI 2 to identify past medical histories such as prior infarct (29 percent vs. 31 percent, $p < 0.001$) or heart failure (21 percent vs. 25 percent, $p < 0.001$) less frequently than with the CCP. Hospital mortality was calculated to be higher in NRMI 2 (19.7 percent vs. 18.1 percent, $p < 0.001$), due mostly to the inclusion of noninsured patients 65 years and older in NRMI 2.

It was concluded that the simpler case ascertainment and data collection strategies employed by NRMI 2 result in process and outcome measures that are comparable to the more rigorous methods utilized by the CCP.

These data show that it is possible to collect process of care and outcome data on acute myocardial infarction patients in a voluntary and nonmonitored setting. Although costs of data collection were not evaluated in this analysis, the use of a voluntary system with a brief case report form should be substantially less expensive than a centralized system, such as the CCP. This less expensive system will allow ongoing quality data to be obtained.

What currently is being done in this area

In general, process of care and outcome data in the scientific sphere have been collected either in the setting of clinical trials where there are many patients who are excluded or in the setting of a quality assurance project. The latter often requires detailed and time-consuming chart review. The national registry is an approach that is inclusive of all patients, but is less rigorous than the usual quality assurance project. Because NRMI 2 was not Government-funded, some concerns about possible use of data for punitive action were alleviated. However, scientific concerns over the industry sponsorship of this database have been raised. Other work in this area has been sponsored by the American College of Cardiology, which has attempted to define a minimal cardiovascular data set. This approach capitalizes on a large experience in cardiovascular database research.

Obstacles to successful implementation of the idea

The first consideration would be funding mechanisms. Although, the national registry has probably reduced the costs of this quality assurance effort, sites are paid a modest, per patient reimbursement, and there are costs involved in data extraction, data entry, and analyses. The registry has also benefited from annual investigator meetings and short training sessions—these have all added to the quality of the registry. A stable source of long-term funding would be required. The next obstacle would be to try to include a reasonable sample of American hospitals. In general, registries tend to exist in tertiary centers. Inclusion of smaller centers would be critical. A mechanism for identifying all acute myocardial infarction patients at a given institution is critical. Exclusion of either high- or low-risk patients could substantially alter the quality of data obtained from the project. Finally, sponsorship outside of the Government-quality assurance mechanisms should be considered. If there is the perception that the data will be used to grade centers, then there is no certainty that centers might “gain” in this quality assurance system. Independent verification of consecutive patients and occasional site visits with medical record verification would be required to assure reasonable patient ascertainment and data retrieval.

Steps necessary to implement the idea

The mechanisms for implementation of a voluntary database, such as NRMI 2, for patients with acute myocardial infarction are already in place. The experience of this organization could serve as a model for similar quality assurance projects. Probably the optimal use of this mechanism would be a partnership between the NRMI 2 organization and the Government, so that this data collection and dissemination mechanism could have continued support to provide data for multiple, different parties. The partnership between a for-profit pharmaceutical company and a governmental agency will be a challenge but can be accomplished. There are multiple areas of interest that are consistent between potential sponsors, and these should be explored, so that this efficient data collection mechanism can continue.

THE COCHRANE COLLABORATION AND THE AGENCY FOR HEALTH CARE POLICY AND RESEARCH'S EVIDENCE-BASED PRACTICE CENTERS: THE BENEFIT OF SYSTEMATIC EVIDENCE REVIEWS IN ACHIEVING THE MISSION OF THE NATIONAL HEART ATTACK ALERT PROGRAM

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How this idea can help the National Heart Attack Alert Program

The article by Antman et al., entitled “A comparison of results of meta-analyses of randomized control trials and recommendations of clinical experts. Treatments for acute myocardial infarction,”¹ (AMI), is an elegant illustration of the benefit of systematic evidence reviews to the NHAAP's mission. The investigators performed systematic evidence reviews of therapies employed in the treatment of AMI (i.e., thrombolytic therapy, beta-blockers, aspirin, rehabilitation, lidocaine) to determine the weight of scientific evidence to support or refute use for each treatment. They also determined the year by which sufficient evidence had accumulated to answer questions of effectiveness for each treatment. The year that standard medical textbooks and experts began to make specific or general recommendations for use of each AMI treatment was then identified. Perhaps Antman and colleagues' most startling finding was evidence of the benefit of thrombolysis. By 1973, sufficient evidence existed to support use of thrombolysis as an effective treatment for AMI; however, the routine and specific use of thrombolysis in patients with AMI was not recommended until 15 years later!

Without the benefit of systematic evidence review, medical experts and textbook authors did not appreciate the benefit of thrombolysis until many years after its clinical efficacy had been revealed. This delay caused innumerable losses in terms of mortality and morbidity for hundreds of thousands of patients. From a research perspective, earlier recognition of the benefit of thrombolysis could have focused researchers' efforts and research dollars to different areas of promising scientific inquiry.

What currently is being done in this area

The Cochrane Collaboration, established in 1993, is an international network of individuals (more than 4,000) and institutions dedicated to preparing, maintaining, and disseminating systematic reviews of the effects of health care interventions. The major goal of the collaboration is the transfer of sound scientific evidence regarding treatment effectiveness into health care practice and policy. Three major activities of Cochrane are systematic identification and "registration" of all clinical trials in all languages, development of systematic evidence reviews for discrete clinical topics, and development of the Cochrane Library. The Cochrane Library, an electronic database of all evidence reviews, is available on CD-ROM or the Web in order to be accessible to clinicians, patients, policy makers, and scientists. Cochrane Review Groups are responsible for developing and maintaining systematic evidence reviews for particular areas of inquiry. A "Cochrane Heart Group" is currently being organized by Professor Shah Ebrahim of the Royal Free Hospital School of Medicine. More than 10,000 heart-specific clinical trials and 15,000 vascular trials are registered in the Cochrane database. However, only 171 systematic reviews in heart disease are available. The sheer volume of available trials suggests that the area is ripe for development of additional evidence reviews. At the present time, 140 individuals are affiliated with the Cochrane Heart Group, and new members are welcome (for more information, see <http://www.Cochrane.org>).

Within the United States, the Department of Health and Human Services' Agency for Health Care Policy and Research (AHCPR) has funded 12 Evidence-Based Practice Centers (EPCs) for the purpose of developing evidence reports for "high priority topics." EPCs are based in academic centers with faculty and staff capable of conducting systematic evidence reviews. Professional and academic organizations are encouraged to submit topics to AHCPR for which evidence-based reports could be

developed. Topic selection criteria include magnitude of the clinical problem, costs associated with a condition or treatment, and potential to inform or improve patient or provider decisionmaking. Several cardiac-specific topics are currently being developed into evidence reports (for more information, see <http://www.ahcpr.gov>).

Obstacles to successful implementation of the idea

Systematic evidence reviews may be useful to the NHAAP in answering questions regarding treatment effectiveness in scientific areas in which studies have been conducted, but in which evidence of benefit remains unclear. Several impediments exist. One broad implementation issue is that the tools and skills required for critically reading and understanding systematic evidence reviews are new and still relatively unfamiliar to potential users. These skills must be fostered among clinicians, educators, and students.

Steps necessary to implement the idea

The elements required to develop a systematic evidence review include a clinical team capable of formulating the research question (and parameters) to be investigated, a methodologic team trained in evidence-synthesis methods, and funding to support investigators' time. Depending on the scope of the science reviewed, it is estimated that the direct costs of developing a systematic review range from \$75-200K. In Europe, systematic evidence reviews have been recognized as important scientific activities, and governmental funding of discrete topical areas has been responsible for the development of many reports. Systematic evidence reviews may answer questions of importance to the NHAAP's mission. If these activities are deemed useful to NHAAP, then questions need to be answered concerning topic selection, whether funding of such activities is possible, and whether collaborative linkages can be made with AHCPR's program and/or the Cochrane Collaboration. If funding of evidence reviews is deemed important and possible, then issues of funding mechanism, peer review, funding level, and anticipated outcomes will need to be addressed.

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USE OF CLINICAL TRIAL DATA TO SUPPORT ADVANCES IN EMERGENCY CARDIAC RESEARCH

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How this idea can help the National Heart Attack Alert Program

There is no substitute for careful clinical trials of methods by which we can improve the process and the outcomes of emergency cardiac care. However, such clinical trials are expensive, take a long time to carry out, and typically can address directly only one specific question. However, the databases generated by such trials, particularly those with broad inclusion criteria and that run in diverse settings (“effectiveness trials”), can have potentially as much, and sometimes even more, impact on scientific understanding and clinical care than the original clinical trials. There are a number of ways that data collected by previous clinical trials can be used; this presentation will review examples of three general uses of clinical trial data: the use of clinical trial data for “secondary” analyses for clinical and clinical care research; the combination of data from different clinical trials to provide sufficient data to address key clinical problems; and the use of special data for methodologic advances.

What currently is being done in this area

The first type of work is the conduct of analyses of data from a clinical trial to yield yet further clinical and scientific insights. For example, our multicenter original Acute Cardiac Ischemia Predictive Instrument Trial (published in 1984) was supported by the precursor of the Department of Health and Human Services’ Agency for Health Care Policy and Research (AHCPR). In the years since then, 12 directly related articles have been generated from its data, plus additional indirectly related articles. For example, analyses of the trial’s data revealed that when a hospital’s coronary care unit (CCU) is full, emergency department triage adapts to preserve admission for patients with acute infarction or unstable angina pectoris while reducing unnecessary admission for those without acute ischemia. Another secondary study showed that elderly patients with acute infarction, with greater comorbidity and more severe infarctions than younger patients, nonetheless, were twice as likely not to be admitted to the CCU as younger patients with acute infarction (back in 1981). Another showed that the traditional classical coronary risk factors, such as histories of hypertension, high cholesterol, and diabetes, are,

in fact, of minimal consequence in predicting whether a patient in the emergency department will truly have acute cardiac ischemia. Other clinical analyses characterized those patients inadvertently sent home from emergency departments with acute infarctions and a variety of other clinical insights. Analyses of this trial’s data also led to the development of the acute cardiac ischemia time-insensitive predictive instrument (ACI-TIPI) as well as predictive instruments for acute infarction mortality and for congestive heart failure mortality, all of which have led to new large clinical trials. A pattern has emerged of performing secondary studies from trial data. Although the 10,700-patient multicenter ACI-TIPI clinical trial is just now in press, based on support from the NHLBI and AHCPR, already several secondary clinical articles have been published based on its data, and many more are in various stages of development, writing, or review by journals.

A second way that clinical trial databases can be used directly is by combining them into single large databases to achieve the statistical power needed to address key clinical problems in emergency cardiac care (aside from meta-analysis, which does not directly use the data, but rather their published results). For example, to create the Thrombolytic Predictive Instrument, which was supported by the AHCPR, extensive data were needed on the impact of thrombolytic therapy and the occurrence of infrequent complications, such as stroke. It was no longer ethically or practically justifiable to run a placebo-controlled trial of thrombolytic therapy, so the data had to be extracted from trials already completed (and also combined with data from pre-thrombolytic era trials). Ten rules were developed for the process of combining these databases that were used to build the component predictive instruments for a Thrombolytic Predictive Instrument (and, of course, a new large data set could then generate additional clinical studies). Another example of this was the Fibrinolytic Therapy Trialists’ article, which summarized the results from available thrombolytic trials to generate more powerful analyses of the effects of thrombolytic therapy.

The third approach is to use special data collected from clinical trials to develop new methods for emergency medical care and medical care in general. For example, in the 10,700 patient ACI-TIPI trial, data were collected electronically from computerized electrocardiograms on all patients, including precise measurement matrices for all waveforms. With the support of the National Library of Medicine, this unique database with its linked clinical outcome data is being used to investigate which mathematical models most accurately predict acute cardiac ischemia and other cardiac outcomes—as well as to compare logistic regression, neural networks, recursive partitioning, generalized additive models, and hybrids of these methods. Not only are these results likely to be of use for emergency cardiac care, but also for the general field of the creation and assessment of mathematical models of medical outcomes.

Obstacles to successful implementation of the idea

Obstacles that stand in the way of using databases for clinical trials are significant. Collection of clinical trial data is very expensive, takes a lot of time and effort, and understandably, those who conduct trials have a sense of data ownership. However, most principal investigators from such studies quickly realize that the research opportunities to exploit their data greatly exceed their own abilities and resources, and typically they are pleased to encourage participation and analysis by other investigators who will add to the trial's eventual productivity. Nonetheless, rules of engagement in these circumstances are crucial, as is quality control of the data (especially when variables are used that were not originally intended to be used) and of the analytic process. There needs to be an accurate appreciation of limitations of the trial's databases, which would require involvement of the original trial team. Inclusion criteria might not have been explicit, biases in inclusion and in followup can be hard to detect, and data become out of date over time, to mention a few potential limitations.

Steps necessary to implement the idea

Nonetheless—given that the typical large clinical trial costs millions of dollars, whereas a secondary data analysis can be done for far less, perhaps by a fellow as a seminal part of their training—the importance of encouraging and supporting this kind of work is obvious. In terms of scientific impact and lives potentially saved, such analyses may well eventually exceed the impact of the original trial. Thus, there are needs for both standards of conduct of analysis for such work, as well as greater support. Specifically, it now seems time that a group address these issues; its efforts would be well rewarded by enhancing cost-effective and rapid investigation of key areas in emergency clinical care.

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