

Stanford Heart Failure Summit

May 5 – 6, 2003

Synthesis and Report

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An Open Letter from the Summit Participants

On May 5 and 6, 2003, a group of experts in the medical and public policy aspects of heart failure met at Stanford University to discuss the current and future of heart failure policy and treatment.

The focus of the group was on understanding the complex linkages that affect the delivery of high quality treatment to patients suffering from chronic diseases, particularly heart failure. The Summit participants found that they had a high degree of consensus around the key issues, and we are writing this open letter to share our perspectives with those in the medical community and government in

the hopes that this will contribute ideas and momentum toward the implementation of badly needed reforms.

In particular, it's clear that there are three aspects that desperately need improvement. First, the very **structure** of the medical system needs to be changed so that those suffering from chronic diseases such as heart failure may receive the same quality of care as those suffering from acute problems. Since the medical system as a whole is geared towards treating acute problems, new ways of working are needed. Better chronic treatment methods will lead to better outcomes for patients, and lower costs for everyone. Both are necessary and important.

In addition, new **methods and tools** are needed to enable the system as a system to operate more effectively. These include a new national registry of patient information, which would be used to improve care to individual patients, to aggregate data for population management purposes, and to provide meaningful feedback on the performance of individual health care providers and institutions.

Finally, it's clear that the current structure of Medicare **reimbursement** is a direct impediment to experimentation and innovation. While there are pockets of innovation, notably at the Veterans Administration and in providers such as Kaiser, these affect only a tiny portion of all patients. In order to make the right changes to the system in the right way, the best approach is clearly to conduct a wide range of experiments that result in a portfolio of reasonable options for improving the system.

/signed

Stanford Heart Failure Summit Participants

Report Abstract

(Pending)

Introduction

Nearly 40 million Americans suffer from one or more chronic conditions such as heart failure. Moreover, this number will continue to increase as members of the Baby Boom generation approach their years of prime susceptibility. Providing treatment for these diseases claims 70% of the healthcare budget. Clearly, costs will continue to increase.

Recent experience has shown that there are promising treatment approaches to chronic conditions that can reduce costs and simultaneously improve patient outcomes.

However, these novel approaches to care delivery do not fit within the existing medical care system, which is primarily organized to treat acute diseases rather than chronic ones. Thus, more effective treatment of chronic conditions will require changes in the structure and operations of the medical system as a whole.

The Stanford Heart Failure Summit was convened to explore the most effective treatment approaches for heart failure, and the systems, structures, and policies surrounding the delivery of these treatments.

In an open, collaborative forum, twenty leading members of the medical community with extensive experience in heart failure treatment and policy discussed the problems and prospects of heart failure treatment.

We are pleased to offer this report.

Background and Statistics

Vascular diseases, including heart attack, heart failure, and stroke, are the leading cause of death for Americans today, as they were in each year of the 20th century except for 1918, when a massive flu epidemic swept the world. Today vascular diseases kill nearly a million Americans each year, approximately twice the deaths from all cancers combined.

Nearly 18 million Americans have been diagnosed with vascular diseases, of whom an estimated 4 to 5 million suffer from heart failure. Half a million new cases of heart failure are reported annually. As the incidence of heart failure has been steadily increasing in recent decades due largely to the increasing numbers of aged people in the overall population. As the Baby Boomer generation approaches the age of prime susceptibility, the prevalence of heart failure is destined to increase substantially.

“Heart failure is a chronic, progressive disease that is characterized by frequent hospital admissions and ultimately high mortality rates. Because of its high medical resources consumption, heart failure is the most costly cardiovascular disease in the United States.”¹

Call to Action

In the face of the rising prevalence and costs of heart failure and the need to provide more effective treatment for this condition, it is evident that a major change in society’s response is needed.

Not only must new treatment methods be found and adopted, but also new approaches to financing health care services are required.

¹ Grady et. Al., “Team Management of Patients with Heart Failure.” American Heart Association Scientific Statement, 2000.

Our long-term goal is to see that new initiatives to improve heart failure management are implemented. The goal of this report is to specify the key issues that need attention – the “what” – and begin to identify approaches to the “how”.

Understanding the Limitations of the Existing System

The medical system in the US is presently oriented to acute rather than chronic medical conditions. Most urgently needed today are complementary treatment approaches geared to treatment of chronic conditions such as heart failure.

We have identified seven major problems in the present system of care:

1. Lack of Time
2. The Structure of Medicare Reimbursement
3. Fragmentation of Care
4. Lack of Information Infrastructure
5. Inappropriate Care Model
6. Broken “Feedback Loops”
7. Lack of Agreement on Treatment

1. Lack of Time

The treatment of acute medical conditions is crisis-oriented. It requires effective mobilization of medical personnel, facilities and equipment to address immediate, generally short-term issues. Cure is the goal. The locus of care is the clinic, emergency room and hospital ward. Health care professionals direct the care and patients often play a passive role.

In contrast, the treatment of chronic disease requires the effective mobilization of not only medical personnel, but of patients, families and caregivers to address persistent, often life-long issues for which a cure is often not feasible. The locus of care is the patient’s home. Health care professionals guide the care, but patients must play an active role. Self-management of lifestyle, including

exercise, diet, adherence to medications, and self-monitoring are paramount in mitigating the effects of chronic disease and maximizing function.

In other words, treatment of acute problems generally requires effective action by medical professionals, while effective treatment and mitigation of chronic problems depends primarily on the actions of the patient, often involving significant changes in lifestyle.

But changing a lifestyle is difficult. Patients require education and support, which often begins when the physician and patient discuss the key issues in a way that helps the patient to understand the benefits of change, and perhaps to accept the need for it. Detailed discussion with patients about these long-term issues often competes with the short-term need to deal with more urgent aspects of care: “the tyranny of the urgent” is a major impediment to the provision of more effective management for chronic medical conditions.

Reimbursement in the present medical system is generally organized in a way that prevents health care professionals from spending the necessary time with each patient, and this problem is destined to worsen as the number of people suffering from chronic conditions increases. It seems inevitable that there will be even less time available for patient visits, and the pressure to deal with the urgent will only increase.

Reimbursement for other team members, such as nurses, occupational or physical therapists, and pharmacists is frequently non-existent even when they have important roles in assisting the patient with their self-management efforts.

2. The Structure of Medicare Reimbursement

An important indicator of effective treatment for heart failure is the avoidance of hospitalization. Achieving this goal requires *prevention* of heart failure exacerbations and their attendant costs.

However, the fee-for-service system supported by Medicare reimbursement provides specific incentives for hospitalization for treatment of heart failure exacerbations, but none for **avoiding** hospitalization. And of course it is hard to imagine that a hospital could dedicate itself to reducing hospitalizations when it is hospitalizations that it is being compensated for.

Thus, the overwhelming structural problem that accounts for inadequate treatment of chronic care is the perverse financial incentives that drive the health care system to provide short-term hospital-based treatment in lieu of long-term preventive and rehabilitative care. Furthermore, there is no alignment between reimbursement and outcomes.

Finally, there is meager support in the system for innovation. The reimbursement system ensures perpetuation of the status quo: when the rules of reimbursement are narrow and narrowly construed, innovations are not made.

3. Fragmentation of Care

Most Medicare patients are at the stage in their lives in which they suffer from multiple chronic conditions, commonly including heart failure, hypertension, hyperlipidemia, diabetes, and coronary artery disease. Patients often see different doctors for these conditions, and since little or no coordination exists between these various health care teams, care is often so fragmented that it is an exaggeration to say that there is a 'system' of care at all.

Effective management of heart failure and other chronic medical conditions entails knowledge of co-morbid conditions, concurrent medications, laboratory test findings, symptoms and changes occurring in these parameters over time. In the absence of a system to provide these data, there is ample opportunity for under-treatment and untoward effects from the interaction of multiple medications.

4. Lack of Information Infrastructure

As the present reimbursement system does not support an information infrastructure, communication doesn't occur as frequently or to the depth that it would if the focus were on maintaining patient health.

The lack of a standard medical information infrastructure precludes effective sharing of data among health care providers. The advent of the Internet has enhanced the prospects for a national record keeping system to support the delivery of effective care, and the sooner that happens the better. Until it does, the quality of care, especially for chronic medical conditions, will necessarily suffer.

5. An Asymmetric Model of Care

The acute care medical system is built around a model of a heroic healthcare team that can fix anything. Marcus Welby, M*A*S*H, and ER have shaped a public perception of the health care team as all-powerful — at least for trauma management and acute medical conditions.

However, as noted above, management of chronic conditions requires the active, effective participation by patients themselves, as well as their family members. No healthcare system can fix unhealthy lifestyles.

Thus, the underlying problem with the acute disease care model is that chronic disease patients carry a mental model of the hero-doctor that is often not applicable to their own situation, and so they rarely understand their own vital role. Our society needs to adopt a patient-centered model of care that galvanizes patients' participation in their own care.

6. Broken “Feedback Loops”

Positive reinforcement is needed to guide patients' efforts at lifestyle change. Yet the present system provides little or none of the feedback that patients need to make the most effective choices and change their behaviors.

Chronic conditions generally develop gradually as a result of long-term unhealthy behavior patterns. What this means is that the lack of immediate reward or penalty – or, in other words, the lack of feedback - causes unhealthy behaviors to persist until they become deeply ingrained. In most cases the underlying problems develop too slowly even to be noticed.

Once the latent chronic disease does emerge, the true costs of its treatment are hidden from patients so they are unable to make intelligent economic decisions about their lifestyles and their own care.

Finally, there is no link between compensation received by doctors and hospitals and the quality of care that they provide. Therefore, there is no way for the “system” to pay for quality or efficiency. Clinical excellence is not rewarded; clinical mediocrity is not penalized.

In fact, mediocrity may be rewarded if a key characteristic of mediocrity is spending less time with patients. By spending less time with each patient,

providers are able to see more patients during a given period of time, thus maximizing reimbursement, which is based almost exclusively on volume. Conversely, those willing to spend extra time with patients to address psychological and behavioral aspects of care will receive less compensation because they will see fewer patients in the same period of time.

7. Lack of Agreement on Treatment

Further complicating the evaluation of various care models is that the medical community lacks widespread agreement on treatment methods.

Although there are a lot of ideas, it is not universally understood what actually constitutes cost-effective system change. Experimentation is needed, yet, as noted above, the financial structures in place virtually prohibit experimentation and innovation. Consequently, there is a lack of systematic analysis of what treatment strategies work best.

Proposed Principles for System Redesign

The following principles describe interventions and systemic changes that we believe are needed to create a care delivery system that is effective in treating heart failure and other chronic diseases.

Before we review these changes, however, it's appropriate to offer some thoughts here concerning the nature of complex systems and why the systems changes are needed.

Fifty years of extensive research in systems has shown that the behavior of any system, reflected in the outcomes it produces, is the result of how it is structured and how its component parts interact. But because structures are often hidden, and because the interactions of the component parts often lead to unexpected and undesired results, it is very difficult to make meaningful improvements to complex systems. Society is all too familiar with the great many attempts at improvement that go badly awry.

The outcomes obtained by complex systems are largely mediated by what people know, what attributes of the system are measured, and particularly what behaviors are rewarded. Consequently, most of the systems changes suggested below reflect how information and knowledge are gathered and shared, how performance is measured, and how compensation is provided.

To improve patient outcomes and reduce overall treatment costs, interventions are needed on two levels:

1. Change the overall **structure** of chronic disease management that establishes the macro-level means by which the treatment system attains better outcomes while operating at lesser cost.
2. Change the specific **processes** used to communicate with, and provide treatment for, heart failure patients: that provide the micro-level means to help individual patients to attain optimal outcomes.

The two kinds of changes must be designed, implemented, and operated in conjunction with one another.

1. Changes to the Structure of Chronic Disease Management

Applications of the Registry for Treatment

Coordination among health care providers is critical to effective treatment of chronic diseases. The necessary tool to support a high degree of coordination among providers is information technology in the form of a **database registry** that records and tracks the medical history of each individual patient.

The registry is would be accessible on the Internet, enabling authorized health care providers and patients to access current, accurate data about individual patients. The registry should be a dynamic, real time database with information that reflects patients' current health care status.

To complement the net, Smart Cards bearing individualized medical data would be used as portable recordkeeping devices.

Applications to Populations

In addition, the database would be used to obtain population-based data on treatment and provider effectiveness- information critical to long-term improvements in results.

There are 2 important issues here. First, most PCPs take care of a relatively small number of heart failure patients, and therefore there is an insufficient number of patients to reliably assess quality. Second, it is extremely difficult to adjust for disease severity and comorbidity, and no reliable method for doing so. A systemic effort at gathering data could address both shortcomings.

But “systematic” is key. Data gathering is inherently very difficult due to the multitude of confounding factors, and the difficulty in adjusting for disease severity. For example, heart failure specialists who take care of predominantly class III-IV patients may appear to have worse outcomes than generalists who only take care of class I-II patients and refer their sicker patients to specialists.

Applications to Feedback

Successful operation and improvement of the treatment system requires provision of effective, timely, and comprehensive feedback to all participants in the treatment system, including patients, health care providers, insurers, employers, and Medicare.

Therefore, another key function of the registry is to measure the performance of health care institutions and providers by enabling measurement of quality improvement and accountability, and providing feedback to patients on how well they are managing their illnesses.

The system must:

- Measure quality and outcomes
- Measure cost
- Evaluate cost effectiveness on a population-wide basis
- Provide public reporting of results

Since the Database Registry permits tracking of the performance of individual practitioners and caregivers as well as institutions, it could link performance to compensation. The structure of Medicare reimbursement could be adjusted to reflect characteristics such as patient outcomes, cost effectiveness of care, and compliance with treatment guidelines. Excellence could be rewarded, and mediocrity revealed. It might also be effective to implement a gain-sharing approach with providers, so a portion of net savings attained by insurers from better chronic care management is returned to practitioners.

Improvement Process. A built-in Continuous Quality Improvement (CQI) process enables step-wise improvements in clinical care to be incorporated into treatment practice.

2. Changes to the Process of Care Delivery

A. Patient-Centered

According to the Institute of Medicine report *Crossing the Quality Chasm*, patient-centered care is respectful of and responsive to individual patient preferences, needs and values. A partnership between health care professionals and patients helps to foster care that is consistent with patients' values and experience.

B. Continuous Access

Patients have access to health care professionals by telephone at any time, day or night, 365 days a year.

C. Support for Self-management

Patients with heart failure need to access to information learn about their disease state including, prognosis, and end of life issues.

Tools for self-management need to be provided to all people with chronic conditions.

The purpose of supporting patient self-management is to help patients achieve self-determined changes in lifestyles – better diets, more exercise, adherence to medications and elimination of smoking.

D. Education

Patients' understanding of how their own behavior influences their health is crucial. Patients' decision- making is facilitated by an understanding of evidence-based guidelines for heart failure, in the usefulness of daily self-monitoring of signs and symptoms, and the benefits of adhering to regiments of diet, drugs and exercise.

While patients may understand how their lifestyles affect their health, they may lack the skills to change unhealthy lifestyle behaviors. Training and coaching models have proven effective in training patients to adopt new lifestyles. These need to be implemented on a widespread basis in patients with heart failure.

E. Anticipatory

The data systems and self-management training should allow early

recognition of decompensation in patients' clinical status so that timely intervention can prevent crises.

F. Care Management

Patients who experience difficulty maintaining control of their symptoms and disease should be offered participation in specialized care management programs. These programs, tailored to the needs of older, sicker patients with a fragile social "safety net", can be conducted in many ways, including specialized heart failure clinics, home visits, telephone, rehabilitation programs or automated phone systems.

G. Follow-Up

Even patients in good condition need reminders and regular follow-up. Based on patients' needs and preferences, this could occur by visits, telephone, or via the web.

H. Guidelines

Patients should receive evidence-based treatment. Use of the database registry system is one way to track and encourage the use of guidelines. Re-hospitalization is an opportunity to reinforce AHA/ACC guidelines for patients, provide additional patient education and self-management skills, and to analyze how best to avoid future rehospitalizations, what went right and what went wrong.

It is not sufficient to merely educate physicians about the guidelines, as there needs to be a systemic approach to embedding the guidelines into daily office practice. The average PCP takes care of patients with a wide range of acute and chronic conditions, for which there are a bewildering array of guidelines. Not only is it

impossible to keep up with all the latest revisions to the guidelines, it is even more difficult to implement the guidelines when the physician is seeing 4-6 patients per hour, interspersed with phone calls and other distractions. Therefore, there is a need to have reminders automatically built into the system to alleviate the physician from having to remember guidelines details for each patient. Ideally, such a system would be incorporated into some form of electronic medical record, and the technology to do this is already available.

Examples

The critical step between proposing system changes and implementing new care models is experimentation, and it's clear that there are some experiments already under way that deserve attention as we undertake a careful redesign of the heart failure treatment system.

1. Kaiser [by Warren Taylor MD, Kaiser Permanente]
2. VA [by Barry Massie MD, Cardiologist, VA Hospital]
3. "How's Your Health", developed by Dartmouth Medical School and the Institute for Healthcare Improvement

Heart Failure: How Patient Input Is Used to Change Practice Methods and Outcomes

Involving patients in their own care is important to the successful treatment of CHF, and this inevitably requires good communication between patient and their doctors and nurses. However, research has

shown that these communications are not nearly as effective as they could or should be. To help improve communication, investigators at Dartmouth Medical School and the Boston-based Institute for Healthcare Improvement have created and implemented a web-based survey tool (www.howsyourhealth.org) that enables patients to articulate their own needs and concerns.

This information then stimulates better communication and care by health professionals, which leads to better self-care by patients. This approach has been applied at the community and practice levels, and building on successful implementation in Chicago and support from the Commonwealth Foundation, it is now being disseminated in New Jersey and Montana, and in the cities of Manchester, New Hampshire, Rochester, New York, and Milwaukee, Wisconsin.

Use of the tool in Chicago is explained to the community this way: (<http://www.howsyourhealth.org/html/chicago.html>)

"How's Your Health, Chicago?" is a first-of-its-kind initiative sponsored by the Chicagoland Chamber of Commerce's Workplace Excellence committee. This six-week campaign will connect area residents with a Web-based survey designed to help them become better health care consumers. The feedback gathered will allow individuals to become more aware of their own health issues, facilitate clearer communication with their medical providers and be more proactive in keeping health care costs down. Mayor Daley has signed a proclamation resolving that Chicago's public and private institutions, government agencies, and businesses are encouraged to help citizens get on the same page with their health care providers by responding to www.howsyourhealth.org.

This patient/population approach can be supplemented with a complementary approach to improving the effectiveness of medical practices, (www.improveyourmedicalcare.org), and it also provides valuable feedback to the medical community as a whole.

Some of the general findings from the use of this system show that fewer than half of the patients with CHF recall receiving good explanations about the importance of monitoring their weight and salt or adjusting their medications. Overall, only about 60% of persons with CHF feel that their doctor or nurse has helped them live with their condition. These generic indicators of low care quality are associated with patient self-reports of low confidence in their ability to manage CHF. Conversely, where patients are confident of their ability to self-manage their care they have a 60% lower rate of hospitalization.

The following figures are based on data from a population sample of about 200 patients using the www.howsyourhealth.org site. It provides a useful snapshot of the needs and challenges confronting patients with CHF and the health professionals who serve them.

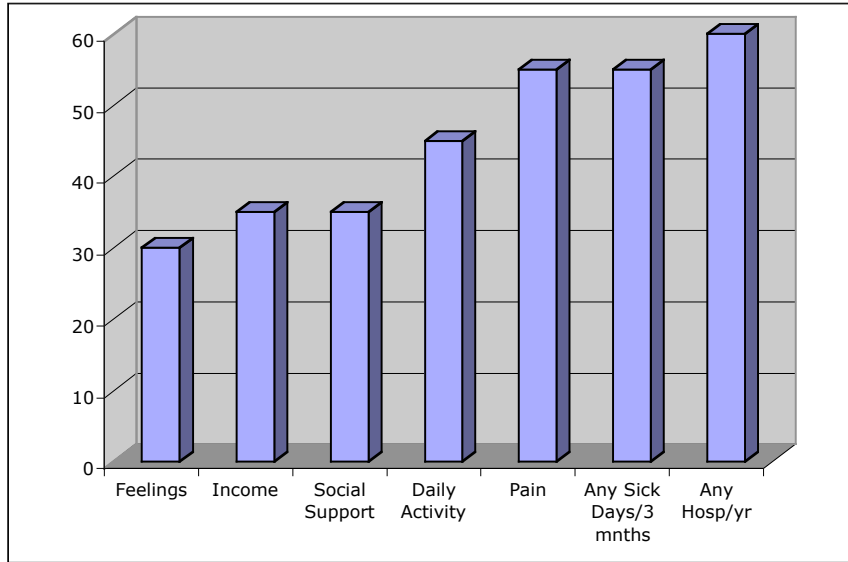


Figure 1. Impacts of CHF

Figure 1 shows the percentage of respondents who experienced these impacts of CHF among persons aged 50+. More than half of the patients have experienced a hospitalization in the previous year, or have been confined to bed in the past three months. The figure shows that many have significant limitations in their abilities to perform daily activities, and are bothered by pain, emotional problems, social support, and financial difficulties, issues that are often overlooked by health professionals.

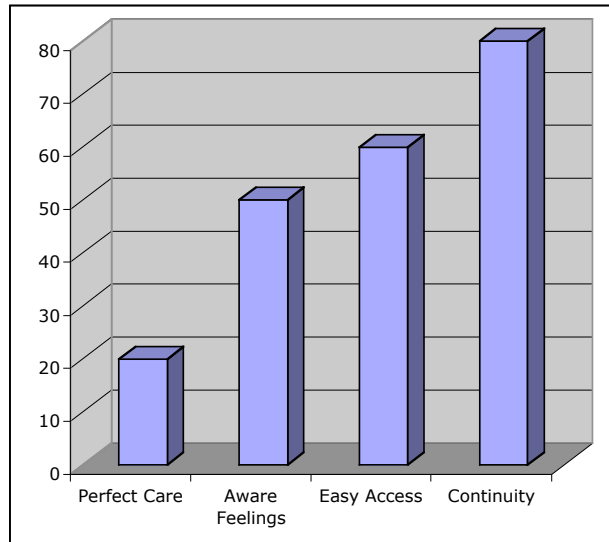


Figure 2: Perceived awareness

Figure 2 shows that only about 50% of patients who have bothersome emotional problems feel that their doctor or nurse is aware of the problem. Although about 80% of these patients have report continuity of care with a doctor or nurse, access to care and quality of care is lower than that reported for patients with most other chronic diseases.

Conclusions

One of the greatest challenges in changing any complex system is understanding the relationship between its structure and its financing; and from such understanding knowing which changes will provide the best results. This is especially germane to the health care system. We believe that the changes proposed here will effectively address both the structure and the financing of the health care system, yet the consequences of various changes are difficult to anticipate. What is needed therefore is to take ideas from the examples cited above and apply them through rigorous experimentation and testing in real-world environments throughout the US. From this a proven portfolio of options can be created, which can then be applied as needed.

References

(Pending)

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