

Institute for Alternative Futures
Foresight Seminars on Health and Innovation

SUMMARY

FORESIGHT SEMINAR ON THE
INFORMATION REVOLUTION IN HEALTH CARE
JULY 30, 1984

ABSTRACT

Both the information revolution and cost containment measures are sweeping the health care system toward a focus on health outcome measures. These measures are designed to answer the question "what difference did an intervention make?" These answers are not yet developed for most medical therapies, in large part because traditional techniques have been unable to cope with the complexity of tying therapies to outcomes. As the pressure to cut health care expenditures mounts, however, the benefits of therapies will be scrutinized more closely, and techniques for measuring outcomes will be increasingly important.

Many problems have inhibited the use of health outcome measures. They are expensive, and scientific and ethical issues have challenged the design of instruments to quantitative outcomes. There are, however, promising developments.

Researchers are adopting the data gathering and statistical analysis techniques of the social sciences to measure the psychosociomedical outcomes of treatment. Such techniques move beyond traditional outcome measures, such as death and morbidity, to more comprehensive measures which include disability, discomfort, cost and iatrogenic effects. Using survey techniques, large data bases can be computerized to make what was traditionally considered "soft" information available. While this information is expensive to gather, it does provide a new capability to assess the medical benefits of care more accurately.

Despite the difficulty and expense of creating valid health outcome measures, cost containment efforts are driving demand for this information, and the computer revolution makes the information gathering and analysis more feasible. Given the forecasts from futurists for a communications revolution and an information society, health outcomes are likely to consume increasing attention.

Health care reimbursements are now tied to services, not outcomes. The development of computer-based outcome measurements, such as ARAMIS in the arthritis field, create a model for comparing treatments for other chronic diseases. This may challenge therapies in the future to prove their benefits in order to gain reimbursement. A model for outcome-based reimbursement is now developing for long-term care. While the development of outcome measures is at an early stage, they are potentially a major force for change in the health care system.

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BACKGROUND

The July 30 Foresight Seminar in the health care information revolution concentrated on the use of measures of outcome to solve the crisis in health care costs. James F. Fries, M.D., Associate Professor of Medicine at Stanford University, a developer of health outcome measures for the American Rheumatism Association Medical Information System (ARAMIS) has designed arthritic patient questionnaires that accurately measure the outcomes of therapies for arthritis. Robert L. Kane, M.D., Senior Researcher with the And Corporation and Professor at UCLA School of Medicine, has studied methods of "rationalizing" health care for patients in long term care facilities by reimbursing to reward success rather than services, which may or may not produce desirable outcomes. Marilyn Bergner, Ph.D. Professor of Health Services at the University of Washington in Seattle, has developed methods to incorporate behavioral factors into the measurements of outcomes.

JAMES F. FRIES

In the new medical world, health care must include methods for measuring the impact of treatment. Development of these measures will be driven by changes such as: improved health and increased costs; a change in the .distribution of diseases from acute to chronic diseases; decreased death; and a concentration on lifestyle and risk factors. Without these measures of "outcome", scientists could devise a remarkable treatment for disease and not know how good it is.

These methods are the cutting edge of medicine; they quantify such medical care outcomes as death, disability, discomfort, iatrogenic effects and the economic impact of the treatment. Surprisingly, the best measures of outcome are not those traditionally considered "hard," such as laboratory tests. The more reliable measures of outcome are "instruments" from the social sciences-questionnaires answered by patients about their health status. These instruments measuring outcome are being developed in many disease categories, including arthritis, stroke and coma, oncology, cardiovascular disease and gastrointestinal diseases. National computer-based systems are being developed with data bases from large numbers of patients followed over long time intervals. These computer systems are producing outcome profiles that demonstrate the balance between the various dimensions of outcome. These provide the information for making policy decisions that may involve tradeoffs, for example, between low expenses or prolonging life.

ROBERT L. KANE

Outcome measures can be used to "rationalize" the health care system for long term care. Medical skills alone do not always create better outcomes for patients: when you do not know how to treat a condition, it is wise to focus on results, not on process. We must develop systems that emphasize the outcomes of care rather than the care itself.

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Outcome measures can be used to improve the well being of nursing home patients. Nursing home patients respond to therapy; their environment is so deprived that almost any amenity produces impressive improvements. The primary goal is to "create appropriate incentives" for these institutions to improve their care.

We have the opportunity to use the marketplace to encourage providers who demonstrate ability to produce good outcomes. Outcomes can be used to understand the effectiveness of interventions and to form a basis for reshaping regulatory systems to "rationalize" the system toward social responsibility.

Pay more for better results rather than rewarding poor care. Currently, poor care is rewarded in two ways. First, we pay on a cost basis so more care means more rewards, regardless of effect. In fact, deterioration in patient status can result in greater payments because the cost of care increases. Second, we bail out poor performers in an effort to improve their care--backward reward system.

Basing payment on outcome creates incentive for improving outcome. This is easier to do for long term care than for acute care because outcomes are slower. Payment could be based on cost and a multiplication factor that adjusts for a patient's actual outcome relative to what is reasonably expected for similar patients receiving good care. For example, the factor might be 1.5, 1.0, or 0.5 if a patient does better than expected, about as expected, or worse than expected, respectively.

Studies of outcome must correct for patient variation at entry. Patient status must be determined when they enter and exit, at all levels of disease and health.

Nursing homes could be evaluated by independent investigators who make measurements at various times using computer programs to predict and monitor patients' outcomes. Outcomes can be measured in a variety of functional domains (e.g. physical, psychological and social).

The way we aggregate these outcome domains into desirable profiles reflects our values. Values for various groups within the health care system share some uniformity and some disagreement. Families of patients differ most from the patient and the health care professional. These groups sometimes conflict with the patients' interests, and patients also differ among themselves over what outcomes have the greatest value.

MARILYN BERGNER

The pharmaceutical industry is now beginning to investigate whether drugs arrest or reverse the psychosocial and behavioral impacts of disease processes. The use of drugs in medicine has long had to submit to some outcome measures -- a drug's efficacy (whether it is effective at the dosage meant to be taken) determines whether or not it can be used.

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However, in the past, the pharmaceutical industry has had to look only at whether a drug arrests or reverses biomedical disease processes.

Creative therapy could be directed at improvement of outcomes such as a patient's normal functions, well-being and quality of life at a reasonable cost, as well as decrease in improved mortality and morbidity. While measures of palliative outcomes have not been used much in recent years, they are properties of such tried and true drugs as nitroglycerine, which does not cure heart disease but improves everyday function and ameliorates pain. Non-curative outcomes are common to a variety of therapies including surgery. Measurement of efficacy in terms of outcome should include measurement of cost, including indirect costs such as time lost from work. Since long term and short term outcomes can vary widely for medical care, measures of outcome should be conducted over a long period of time. For example, in the short term some drugs can relieve symptoms, but in the long term cause addiction. And some forms of surgery can relieve symptoms but not improve mortality--they may even lead to earlier mortality.

Computers are making the analysis and application of outcome measures easier. For example, pharmacies are beginning to keep computerized records of their clients' drug use. Such computerized systems can be combined with patients' medical records to study the relationship of diagnosis, medical care --including drugs--and biomedical outcomes. With some additions, behavioral outcomes could be examined as well. As we begin to use behavioral outcomes to determine specific medical treatment and general medical policy, we cannot assume patients' values and preferences for outcomes. Some prefer the fast, short life and others prefer the long, slow life. Some prefer the absence of pain to the absence of disability.

Knowing about outcomes allows the future possibility of making choices based on expectations. Real choices rather than guesses will then be possible, but outcome measures need to be expanded beyond death and disease and to consider preferences when advocating treatment.

QUESTION AND ANSWER

When asked about the impact of outcome measures on the future medical care system, Dr. Fries said, outcome measures will force us to look at medical technology. Technology will sort out different ways. Most medical technologies, such as CT scanners or coronary artery bypass surgery will fail parts of the outcome measures test. Others, such as total hip replacement will pass.

The questions of the next decade will be about joint replacement, such as prophylactic teflon replacement for arthritic joints, not just hip replacement, Dr. Kane said. These have tremendous functional payoff. Similarly, studies of surgical mortality show tremendous differences in outcome for the same operation at different hospitals, Dr. Fries said. Surgical mortality is related to the number of procedures performed. If we pay for

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outcome, the poor performers will stop doing surgery; and regulatory problems will improve. Focusing on outcomes puts responsibility where it should be, he continued. Health status measures, as well as blood pressure and laboratory values, determine what happens to the patient and whether treatment is doing good or ill to the patient.

As we move more toward outcome-based care, Dr. Kane said, less responsibility can be assigned to a single component of the health care system, such as the physician. Responsibility becomes more global -- a corporate responsibility. Patients are also responsible, but somebody has to be put in charge and subcontract responsibility.

At the moment, Dr. Bergner said, the problem with patient incentives is that the providers have the information. Without giving the information to patients, the system is suspect. We may select low-cost options without knowing if they are optimal.

Information by itself does not change behavior, Dr. Kane said. We need rewards and incentives.

Dr. Bergner disagreed, saying information about outcomes changes the way physicians act. When they pay attention to function and other psychosocial activities, such as whether patients participate in society, they prescribe more social services and become more aware of impacts other than blood pressure.

When asked about the impact of consumers on health outcomes, Dr. Fries predicted that patients will monitor and change their risk factors using computerized health appraisal forms. There is a great potential for this self care, which is now just beginning.

On the other hand, Dr. Kane said, the tenor of this discussion has been that we will have better medical care as we become better shoppers. That approach has costs. We give up something in the pursuit of the better consumer role. We lose something from being just a buyer. We lose the other benefits of a relationship. There is a danger that when we reduce medicine to measureables, that providers become less spontaneous and less human.

We are breeding a generation of consumers who want more and more. We must alter perceptions of what is possible, force people to make choices.

Asked what kind of expectations we should have, Dr. Kane said, we should develop a more systematic view of what is feasible. Outcome measures provide the grist for these calculations of marginal gain for the next dollar invested. We should base our expectations on probability. Too often we use a simple factor such as age as a cutoff for medical services, when the decision should be based on the probability of benefit. We do not behave rationally; we are emotional. Take liver transplant, for example. We invest enormous amounts in child leukemia and child liver transplants with low probability of their survival for five years, yet we dump older patients because we think they have only

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five years to live, when the average 65-year old can be expected to live another 15-20 years.

The tricky part is what you use as quantifiers. These determine whether subpopulations come out ahead or behind. These are not value free decisions. A patient brought up in poverty may see life as a negative and may be less likely to receive the benefit of medical care than a person who gets a kick out of life.

It will be a shame if we let people make decisions for us based only on statistical markers. The measure used must be appropriate and real. We just came through an era where we gave vent to quantifiable measures of success that turned out to be erroneous because they were off target. "I do not think we want to see body counts in health care any more than we did in the Viet Nam War."

We have to change our expectations. The only way to ration health care feasibly is to limit our expectations, not by denying services but by limiting demand.

When asked if patients' assessment of their status is better than a provider's, both Dr. Fries and Dr. Kane agreed that instruments depending on patients' responses to questions have proven more reliable than physicians' assessments based on "hard measures". The outcome model can incorporate physician-oriented information along with such data as a patient's response on the stress test or tests for depression, for example, Dr. Kane said. But the real issue is how to organize it into a format to determine what outcomes are looked at. We tend to look at simple or taxonomic diagnostic factors. Now we are trying to find more reliable measures of outcome using "soft" sciences.

Value preferences and multidimensional assessment also must be included, Dr. Bergner said. We have to assess whether a patient prefers to live a painless short life or live longer with less function. We are not going to avoid value judgments. Down the road someone will say the outcomes we find today are not appropriate. People will continue to redefine their preferences for outcomes.

Studies of preferences show variations of preference over time and between the sick versus the healthy, Dr. Fries said. Patients' preferences differ from those of families' and the providers'. These groups may have conflicts of interests.

Society may make decisions, for example, that we have spent an inordinate expense in the last year of a patient's life. Society looks at policy areas to remedy social problems. Values also are a difficult social contract to enforce, Dr. Kane pointed out. Patients can change their values in the middle of the contract.

The outcomes that are eventually used will differ from what academics think is attractive, because they will involve social and political decisions, Dr. Kane said. This choice will affect the decisions we have to make about diseases of aging or how we respond to a

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dependent segment of the population, for example. We will openly discuss euthanasia. The same people discussing the right to life will be discussing euthanasia.

When asked whether outcome-based reimbursement will increase or decrease innovation in health care, Dr. Kane said that he expects to see as much risk aversion and risk taking continue as is found today. As we hold physicians accountable for outcomes, we suddenly change the incentive systems. If something works people will grab at it.

Regulations bind the hands of people working in long term care facilities. Their degrees of freedom are restricted by regulations dictating numbers of staff, hours of care, patient to staff ratios, etc. If we could hold them accountable for outcome, we could give providers more flexibility.

When asked about the impact of outcomes measures on cost Dr. Fries said, "the major thrust of outcome measures is to make cost control easier. It is easier to alter process than outcome."

When asked about medical inflation, Dr. Fries said that we have seen the last year of medical inflation being higher than overall inflation. It already has peaked. Some say medical inflation is so fueled that it will continue, but many factors indicate otherwise:

- Physicians oversupply has peaked.
- Drug prescriptions topped out about seven years ago and are going down 1 to 1.5 percent per capita per year.
- Chronic illnesses, such as heart disease and stroke have decreased.
- Hospital beds are being used less, and hospitals are diversifying into other medical approaches, such as preventive medicine.
- Consumers are more interested in natural host to environment relations.
- People are disgusted with cost. The idea that increasing health cannot be bought with increasing health expenditures has become a political reality. Comparisons with other nations indicate that a 50 percent drop in expenditures for health is possible without measurable differences in health if the changes are engineered correctly.
- Diagnostic related groups (DRGs) and prospective reimbursement plans look like they help contain cost.

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All of these factors are working. Last year medical inflation was 13 percent while overall inflation was five percent. This year the inflation rates are six and four percent respectively.

Whether we pursue diversification or competition strategies will determine what happens to cost inflation in the long run, Dr. Kane said. We are now faced with excess capacity of medical services.

Asked how outcome measures will change health care in the next ten years, Dr. Kane said, that if we succeed, we will do for medicine what Freud did for psychiatry. We will change the terminology and tenor of the debate so that we become more sensitive to outcomes and value preferences.

The system works, Dr. Fries said, but we tend to stay 10 years behind the changing reality. As the illness burden shifts we need to look to the quality of life of people in long term care facilities where we deal with chronic mental and physical debility. We face the biological reality of the genetically determined lifespan but still have to improve Quality of life. We must begin to integrate such outcomes as disability years with total life medical costs to get a 'cumulative outcome' and maximize vigor and well being over time. People will move in the direction of positive or super health based on better outcome measures for practices that improve quality of life over a life time, Dr. Bergner said.

As we focus more effort in these directions, Dr. Fries said, we cannot be sure it will be done right. Special interest and political groups oppose one another. Those who seek more research oppose those who seek more profit. If we accept the coming changes -- more older people and more chronic disease --we have got to revise the health care system. This is an optimistic time. Without any new discoveries or inventions, the next steps are in hand, but we must make them happen.