PRIORITIES FOR HEALTH SERVICES INFORMATION

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Several years ago the health statisticians of the country were urged to revitalize their profession by developing a broad range of medical care statistics. These new measures would be designed to assist policymakers and administrators in organizing our health resources more effectively and efficiently to meet the health needs of society. It was suggested that State and local vital statistics units be expanded to State centers for health statistics, analogous in their concern with those of the National Center for Health Statistics. Further, it was suggested that we should strive to create systems for reporting data regularly from all levels of our health care organization, including hospitals and sources of ambulatory care, as well as from household interview and health examination surveys (*1*).

What progress has been made in the interim? It seems to amount to a great deal and yet not very much. There has been an enormous amount of activity, a little action, but not too much accomplishment. The whole enterprise is reminiscent of love among the elephants. It is initiated and accompanied by much trumpeting and bellowing, takes place on a high plane, and requires a long time before any results are discernible! Perhaps that is the way it has to be when one is trying to cope with huge problems.

First, the trumpeting and bellowing. Loose talk abounds and jargon substitutes for thought. Terms such as "health data systems," "hospital information systems," "comprehensive health planning statistics," "mental health statistics," "peer review," "utilization review," and "quality assurance" are widely employed without specification of their intrinsic informational value or their prospects for achieving policy objectives or influencing decisions.

Information System Activities

The ready availability of computers has often hindered more than helped matters. Because data can be captured and stored, on the one hand, or can be retrieved and manipulated automatically, on the other, does not mean that they should be automated. To place great emphasis, for example, on automating the clinical record seems to me to distort priorities with respect to the realistic contributions of computers to improving health care in the foreseeable future. This is a trivial problem compared with the major issues associated with redirecting and reorganizing the nation's health services. Indeed, there is little point in automating mousetraps when we are trying to deal with elephants!

Now for the lofty plane on which all this takes place. The planning of information systems is often removed from realistic awareness of what data physicians, nurses, receptionists, admission officers, record librarians, fiscal intermediaries, hospital administrators, the general public, or ill people can or are prepared to provide. Requirements or requests for even more data are unlikely to be heeded unless it is believed that they have a bearing on improving patient care and providing health services. The need to know and the reason for knowing have to be made crystal clear by those designing the specifications for data collection. At another level of abstraction, engineers and systems analysts design elaborate flow charts that purport to reflect, on the one hand, the way a "health care delivery system" works and, on the other, the manner in which it is believed the data will improve matters. Unfortunately the central feature that characterizes the vast bulk of medical transactions is ignored.

In space, defense, and to an increasing extent in the air, ship, and rail transportation industries, human beings are subservient to technological transactions. These major service systems of contemporary industrialized societies are technologically based, and human beings manipulate the controls, which are increasingly protected from human failure—they are designed to be "idiot proof."

In medicine, the reverse is true. Psychiatrists have taught and most other clinicians now recognize that the patient-physician relationship is at once both the largest and the most sensitive element in the entire array of health services. This intimate one-to-one relationship between the physician—and perhaps a physician surrogate such as a nurse practitioner—and the patient establishes and moderates the confidence and trust required for the exchange of honest information.

To the mental health statisticians this emphasis is unnecessary, but it should be recognized by all of us concerned with designing information systems. In medicine, technology can be used to support, not supplant, intensely personal transactions between patients and physicians, and certainly not as the primary mode by which the patient interacts with the health care establishment. At least this is my view of the situation, and I believe it is the view of the overwhelming bulk of the people we serve. Whatever we do to improve health statistics, we need to recognize these medical facts of life and to design our information systems with the concrete operational realities of providing health care foremost in our minds. Thus, statisticians, communications scientists, systems analysts, engineers, and computer technologists have to know a great deal about the way medical care is provided before they can make useful suggestions for improving matters (*2*).

Finally, the long gestation period before results are obtainable is partly due to the enormous size of the U.S. health care industry. Health care may soon be the second largest industry in the country, whose expenditure level approaches $80 billion annually (or 8 percent of the gross national product), and, its cost is one of the largest items in the Federal budget. Size, however, seems to be less of a problem if, as in the case of the elephants, you know what you are trying to do!

The overriding problem in health care in the United States is that until recently we have had no national health policy. Even now we have only a strategy. And, we have no clear loci for policy analysis and decision making at Federal, State, or local levels nor, so it appears, even within the institutional or professional organizations that provide health services and purport to give leadership. Once organizational responsibilities for policy analysis and decision making have been fixed, the specifications for information systems to support their needs can be developed. Similarly, where authority has been assigned for population surveillance of health needs and for monitoring the efficacy and efficiency of health services, the necessary information systems can be designed. Again, when the agencies and institutions for providing personal health services to defined populations have been identified, it is possible to develop patient care management systems required to relate resources, services, and needs. Airlines, banks, and large contemporary production industries have good information systems because they know what they are trying to do. In health, we have not yet specified our objectives except in general terms, such as improving access to care, containing costs, and elevating quality.

Accomplishments

So much for the activities and the actions of the past few years. What about the accomplishments? First, there has been a gradual recognition in most quarters that large-scale social enterprises require reliable information for decision making and planning, if not for management. In a country which still enjoys the advantages of diversity and pluralism in its health care arrangements, it is essential to have comparable information that makes possible informed choices and decisions. How can we choose, if we cannot compare?

At decentralized operating levels, the need is for management information. In what is essentially an agglomeration of decentralized health care arrangements in the United States, it seems foolish to talk about "managing" the nation's health care system from Washington, D.C. Stimulating, monitoring, guiding, supporting, and probably regulating, yes, but managing, no. The supportive functions are inductive processes characterized by learning, planning, standard setting and evaluating; the managing functions are deductive processes of organizing, implementing, administrating, monitoring, and evaluating. It is increasingly recognized that both types of information systems are needed but for different purposes and at different levels of organization and responsibility (*3*). More importantly, it is being realized that policy analysis, as well as research and development, directed at improving health services in contrast to just operating them as they are, requires the purposeful generation of focused information (*4*).

I am not suggesting that quantitative information is the only basis for decision making. Nonquantifiable factors, especially political and social considerations and above all judgments in the light of contemporary values, are equally or perhaps even more important, but gradually some of these too will become susceptible to the influence of social arithmetic. Information contributes to an iterative process designed to improve the climate of decision making in health just as it does in other industrial and social enterprises. I believe we have made progress in our thinking at all levels in this regard (*5*).

Second, a clear national commitment has been made to create Federal-State-local health statistics systems that will coordinate all health statistics, including, of course, those bearing on mental health problems. This important innovation recognizes as a matter of great urgency the need for multipurpose data collection for use at different administrative levels by different agencies, through the introduction of coordinated instruments and forms for capturing data. It recognizes the powerful contributions to be made by imaginative forms designers in collecting data and by computer technologists in aggregating and manipulating inputs from differing instruments, forms, and code sheets and in providing outputs in an equal diversity of formats. The outputs can be designed for use by a wide variety of agencies and institutions, each concerned with specific needs, services, and accomplishments related to different population groups.

The capacity of the computer to accept data in different formats, to manipulate, aggregate, and analyze the data, and to provide output again in equally diverse formats for different purposes cannot be overestimated. The principles are simple, but the implications for health statistics are enormous. One implication is the need for many more health statisticians trained in contemporary information theory, in computer technology, in management sciences, and in health care organization as well as in fundamental statistical concepts and methods. It requires the development, promulgation, and widespread, if not universal, use of comparable and compatible terms, definitions, and classification schemes, and the integration of data generated through surveys with data generated from records of operating health care organizations and systems. And above all it requires the fullest cooperation of statisticians at different levels of government and in different data collection and processing agencies.

Third, a start has been made on the promulgation of uniform terms, definitions, and classifications that can be used for hospital discharge abstract systems and for ambulatory medical care record systems. As in the case of the terms and definitions on birth and death certificates, a uniform hospital discharge abstract data set has been developed and is now being tested and evaluated in five settings. Its use is a requirement for receipt of Federal funds, for experimental health services delivery systems, for participation in Federal-State-local health statistics systems, and in a variety of demonstration projects.

The uniform hospital discharge data set will be introduced shortly into the National Hospital Discharge Survey conducted by the National Center for Health Statistics. The survey itself is being expanded and the publication of the results accelerated. The uniform hospital discharge data set has been adopted by many State health data committees and also by virtually all the regional hospital discharge abstracting systems throughout the country. We hope that it will shortly be adopted by the mental hospitals and the Veterans Administration. It is about to be adopted by the Social Securiy Administration for use on the revised Medicare claims forms (*6, 7*).

More recently, progress has been made in the development of a uniform basic data set for ambulatory medical care records. Presumably this basic data set will eventually be refined and advocated for use in encounter forms that describe patient-physician contacts in a wide variety of ambulatory medical care settings, including the offices of private practitioners, hospital outpatient departments, clinics, and health maintenance organizations. It will also be used in the forthcoming National Ambulatory Medical Care Survey to be made by the National Center for Health Statistics. The progress in developing the National Ambulatory Medical Care Survey is undoubtedly the most important and exciting innovation in the collection of contemporary health statistics (*8*).

Three other developments constitute substantial progress. The first is the development of reporting documents, including registration and encounter forms, and more importantly the creation of model tables for reflecting information required for both patient care and management of health maintenance organizations. This set of recommendations represents a carefully conceived presentation of the kinds of information needed to meet the health needs of populations enrolled in formally organized health care systems (*9*).

The second example is the MADOC (Medicare Analysis of Days of Care) report prepared by the Office of Research and Statistics of the Social Security Administration. In this regular report, data on predicted length of stay are compared with the actual length of stay of persons admitted to individual hospitals within selected areas. By use of a multiple regression technique, a number of factors that influence hospital use can be incorporated and those that are generally regarded as external to the hospital can be separated from those that are traditionally regarded as within the control of the hospitals.

Among the interesting features of this analysis are provisions for controlling variations in the case-mix of hospitals and the use of selected charges for certain ancillary services such as proxy measures of the intensity of care provided and the severity of the patient's condition. But the whole exercise is limited to Medicare patients and tells nothing about the rest of the hospital's activities or accomplishments. It is an important start but only a start (*10*).

The final development is the now widespread recognition by clinicians that it is the patient's problem that matters, not the diagnosis of his disease, his visits, or admissions. The problem-oriented medical record advocated by Weed reflects the realities of the great bulk of clinical practice (*11*). As psychiatrists and primary physicians have known for a long time, patients do not present with diagnoses, they present with symptoms, conditions and, above all, with problems. They want help in understanding and resolving their health problems. The belated recognition by academic clinicians that the health care establishment's only responsibility is to identify, prevent, ameliorate, or resolve the health problems of individual persons and populations must now be accepted by health statisticans and health care adminstrators and reflected in the information systems they develop (*11*).

So much for what seems to me to be the most promising recent accomplishments in improving the nation's knowledge about its health services and health care. I turn now to consideration of the principles that should guide the evolution of this field in the immediate future and that should determine the priorities for data collection.

National Health Policies

First, there needs to be a clear political commitment to the enunciation of national health policies that establish objectives and standards as a basis for encouraging, stimulating, requiring, or providing mechanisms that will relate society's health resources to its biological and psychological health needs.

Associated with this commitment is the need to establish a health policy research and analysis capability within the Office of the Secretary of the Department of Health, Education, and Welfare. It should be the function of this continuing group of permanent civil servants to consider the possible options available to the decision makers and to suggest the possible implications of various courses of action. Information about health problems and health services is essential grist for this important mill. Related to this activity is the need for coordination of all statistical efforts in health in a centralized authority within the Office of the Secretary.

Perhaps a Bureau of Health Statistics headed by a presidentially appointed Commissioner of Health Statistics akin to the Commissioner of Labor Statistics or the Director of the Bureau of Census is needed. Such a bureau could combine the functions of the National Center for Health Statistics and elements of the Office of Research and Statistics of the Social Security Administration, the statistical activities of the National Institute of Mental Health, the information and data activities of the National Center for Health Services Research and Development, and other health related statistical responsibilities in the Department of Health, Education, and Welfare. This function, or something similar, it seems to me, is essential if information from records systems, either those associated with payment systems or with direct services, and those derived from health surveys are to be interrelated, complementary, and comparable.

If agencies at State and local levels in a universal national health insurance system are to be responsible for monitoring and planning health services and for relating those services to resources and budgets, it will be essential that all data be comparable on the basis of uniform terms, definitions, and classifications. The Bureau of Health Statistics, of course, would not operate all the Department of Health, Education, and Welfare's health data systems, but it would be responsible for developing most of the systems and for establishing the design and performance standards for all of them in much the same way that the Office of Management and Budget now approves questionnaires, survey instruments, and forms design.

A commitment to the development of a policy research and analysis capability and to a centralized health statistics function in the Office of the Secretary seems essential if we are to raise the level of empiricism in evolving health policies for the country.

Second, we need to understand the differences between data, information, and intelligence. Data consist of bits of discreet observations or facts that when aggregated provide simple descriptions of events, or the characteristics or attributes of people, things, or places. When tabulated in some purposeful way, particularly so that differences and variations are illuminated and questions are posed or answers provided, the aggregated data constitute information.

For example, age-sex standardized tabulations for all patients admitted annually to all hospitals in a standard metropolitan statistical area with a diagnosis of cardiac failure or, better still, with shortness of breath, arrayed by hospital length of stay, could describe deviations from the means and medians and suggest the need for further examination of these differences. These figures would constitute raw data tabulated as information. It would be a start, but we should go much further.

For example, I should like to see tabulations by the interval between the patient's admission to the hospital and the last visit of the patient to a physician, by living arrangements at home (that is, whether the patient lived alone, with another responsible person, or in a multiperson household), by use of cardiac drugs at the time of admission, by presence of other chronic diseases, and by case-fatality rates.

Information of this kind starts to become useful in understanding the needs of individual persons and populations but to be really influential it has to be turned into health "intelligence." For example, if age-sex standardized rates show that patients admitted to the hospital with cardiac failure who have not seen a physician for more than a year stay twice as long as those who have seen a physician, or if the age-sex standardized case-fatality rate for patients in hospitals of 50 beds or less is twice that for those in hospitals of 500 beds or more, the policy analysts will begin to get some insight into the workings of our health care arrangements and to the possible benefits of improved referral arrangements or even regionalization of hospitals.

To achieve this level of utility, information needs to be recast, analyzed, and presented so that those responsible for policy analysis and decision making can understand and appreciate what and where the problems are. Later they should be able to evaluate the impact of changes on the problems by measuring what has changed and how much it has changed. "Intelligence" about the system is substituted for information and for raw data; in other words, the military notion of "intelligence" should be applied to the management of our health services.

Statistical systems in this sense constitute the core of our social memory and our collective experience, the term, according to Oscar Wilde ". . . that everyone gives to his mistakes." How else can we benefit from our mistakes as well as from the pluralism and diversity of health care arrangements in this country? How else can we choose, how else can we know how to intervene, support, encourage, or stop specific services or practices. How else can we identify high-risk groups who need special forms of care or follow-up? As in the case of the elephants, what is the value of a memory, if you do not have anything worth remembering?

In summary, we need a posture of leadership and of decision making at Federal, State, and local levels that recognizes the need for clear enunciation of health policies, based on the analysis of "intelligence" generated by information systems designed by well-trained health statisticians and health care administrators. All this should be under the aegis of the coordinated Federal-State-local health statistics systems and must include the creation of strong State centers for health statistics. Both survey and record systems should be related through mechanisms for approving the design and installation of systems and for controlling their quality. Provisions should be made for the adoption of uniform terms, definitions, and classifications that are either advocated or required in much the same fashion that the uniform reporting of births, deaths, and other vital events has progressed in this country. Uniformity will not be achieved overnight but a start can be made.

Priorities for Data Collection

Some features of health statistics can be defined by six terms that start with the letter "P" —six "P's" for "priorities." Above all, I believe that our health information systems should be problem-oriented, that is to say that they should be focused essentially on the problems that patients and populations present locally, regionally, and nationally to our health care systems.

They should be person-related, so that, with due protection for confidentiality, individual persons can be identified and, where appropriate, events, such as their hospital admissions or physician contacts, can be linked within practices, institutions, health care systems, and perhaps within communities and, for some purposes, even regionally or nationally.

The data should be population-based so that the determination of denominators related either to enrolled populations or to geographically defined populations will permit demographic standardization of the data as the principal means of making comparisons. There is perhaps no need to emphasize to statisticians that data should be period-explicit and place-specific, but it may be important to emphasize that all requests for data should be characterized by extreme parsimony. Ask only for as little data as needed now and only as much as can be fully justified today.

If some of these points were more widely appreciated by those responsible for development of health information systems throughout this country, more progress would have been made in less time. There is nothing new or secret about these matters. They have been the subject of reports and discussions sponsored by the World Health Organization (*12, 13*).

In summary then what are the priorities for data? To my way of thinking, the single most useful and most readily available information base for improving the health care arrangements in this country would be through the universal requirement that all hospitals—general and mental, short-term and long-term, private and public

—install and participate in a regional hospital discharge abstract system.

Florence Nightingale pointed out 120 years ago that only when we know the characteristics of the patients and their clinical status, and when we have some measure of hospital efficiency, usually reflected in budgets, costs, or charges, can we compare the accomplishments of one hospital with another or of all hospitals within a community with those in other communities. It is the single most powerful method of examining the work of hospitals in relationship to their effectiveness and their efficiency.

The second priority should be assigned to developing information about ambulatory medical care; at this level, the bulk of medical practice occurs, and it is the arena of greatest concern to the consumers. The problems of primary medical care, the use of physician surrogates and allied health personnel, and the organization of services, as well as the objectives of medical education, can be sensibly debated and decisions made only when data on ambulatory medical care are available at national, State, and local levels. Progress in this field has been made but much more needs to be done.

I would also give high priority to the development of management information systems for health maintenance organizations. It is the concept of the enrolled population and of responsibility for the management of the health care problems of this defined population combined with incentives for prudent use of resources that is likely to have the greatest overall impact on both the care of patients and the costs of medical care.

With all of these developments of course the National Health Survey through its continuing household interviews, the National Health Examination Survey, the National Hospital Discharge Survey, and selected ad hoc surveys should be continued. It is only through these methods that we have measures of the needs of populations that permit comparisons between users and nonusers or between enrollees and those not enrolled in health care systems.

My final priority is reserved for urging increased financial support and large-scale improvements in the training of health statisticians. We urgently need a larger cadre of professionally trained health statisticians who are familiar with the operations of health care institutions, with modern principles of communications science, management science, and information systems as applied to large-scale social and industrial enterprises and who are also familar with contemporary thinking about health care organizations and problems. If we could double the ranks of health statisticians, we could evolve a national health intelligence system that could exert more constructive influence on our health care system than the mere provision of more money and more physicians.

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