WHERE DOES THE PUBLIC GET ITS HEALTH INFORMATION?*

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W E live in what has been called the Information Age. All about us are more printed materials of interest to us than we can read, more television and radio programs than we can watch or listen to, and more new forms of electronic media than we can use. In matters of health, there seems to be an information glut. We are flooded by an overload of facts and opinions of varying validity.¹ Everyone agrees on the ideal of an informed public, yet how well is the need for reliable health information being met? What are people receiving? And from what sources? This is a complex subject with a vast number of facets.

HEALTH INFORMATION

Public health has now become everybody's business. When we talk about health information, we include disease and all those factors that may affect an individual's physical and mental well being—environment, lifestyle, stress, diet, and habits (smoking, alcohol, drugs).² AIDS is a recent addition to the list where information and education are being used to achieve behavioral changes.

During the past decade, there has been a substantial change in the interpretation of the health concept. The focus has been turning increasingly from "sick" to "health." The public, including patients, are recognized as partners with professionals in the health-care process; patient and public information and education are advocated as cost-effective mechanisms.³

These are not new concepts. At the 1961 National Health Forum, Dr. Leona Baumgartner, Commissioner, New York City Department of Health stated, "We are passing from a medicine in which you do something *to* the

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patient into medicine in which we must do something with the patient and in which he must do a lot more on his own....We have loaded people with health information, but they have not converted these facts into action. Today we must do more than scatter facts; we must communicate to get action, a process we have a great deal to learn about.'⁴

DEFINITIONS

While the word "information" appears in the title of this article, some of the information referred to is used in the sense of health promotion, health protection, health education, or disease prevention. Each term has a different implication. *Health promotion* is the process of advocating interest in health (e.g., use of safety belts, maintaining a healthful diet). *Health protection* is that activity in which control depends largely on manipulation of the environment (e.g., mandating childhood immunizations). *Health education* is any combination of learning experiences designed to effect voluntary adaptations of behavior conductive to health (e.g., smoking cessation). *Disease prevention* is intended to keep a specific disease from occurring.⁵ To make "disease prevention" work, the etiology of a given disease must be understood.

WHO IS THE PUBLIC?

There are several publics—people who consider themselves well, those who are at risk, those who are ill. There are children, teenagers, pregnant women, men with high cholesterol levels, adults who may be headed for glaucoma. Until we are able to reach all publics, all segments of the population, we shall never meet the goals set for a national consciousness for wellness in America, the 1990 Objectives for the Nation.^{6, 7}

WHO PRODUCES THE INFORMATION?

The producers of information are described here only to the extent that good new information comes about as a result of research and development, observation, analysis, synthesis, and serendipity, and is produced by the public and private sectors. One problem is how to distinguish the good that is produced from the uncertain.

WHO DISSEMINATES THE INFORMATION?

Everyone disseminates health information. Or at least, almost everyone. Generally we think of the mass media, voluntary organizations, health insurance companies, industry—especially the pharmaceutical and food companies for their ads and booklets—health fairs, self-help groups, libraries, schools, and health professionals. And, of course, neighbors, office mates, friends, and families offer advice.

Probably the largest source is the federal government, which is both a major producer and a disseminator of health information. While now there is a price tag on some of that information, much is still free. The government disseminates through federally supported clearinghouses, the public information offices of various agencies and institutes, the Government Printing Office, the National Technical Information Service, databases accessible through private sector vendors, and more. The information is disseminated to help prevent, control, and eradicate disease and to maintain health. The information is directed to several different publics, among them patients and their families, the media, and the general public. State and local departments of health also disseminate information.

From the vast numbers of disseminators, seven kinds are described here: physicians, television, print media, clearinghouses, schools and community health projects, libraries, and some relatively new uses of electronic media.

PHYSICIANS

Poor communication. It seems obvious that the patient-physician interaction should be the primary source of health information tailored to the patient's specific problems, yet many studies of physician-patient communication have shown that doctors tend to underestimate their patient's desire for full information about illness and treatment. Physicians also tend to misperceive the amount of time they spend informing patients as well as the nature of the information that they do transmit.⁸ In interactions with patients that last about 20 minutes, physicians appear to spend a little more than a minute on the average. Perhaps that is one reason for an article in American Health titled "How to Talk to Your Doctor in 18 Seconds."9 One recommendation in that article: "If your doctor is unwilling to talk with you-or unable to communicate in terms you can understand-you can always find another one. (In a recent Harris poll, 30% of U.S. adults changed doctors for just those reasons.)" More than a quarter of a century ago this same problem was noted during the 1961 National Health Forum by Dr. George M. Wheatley, Medical Director for Health and Welfare, Metropolitan Life Insurance Company, when he stated, "A large percentage of patients are discontented because doctors don't tell them enough about their condition, fail to explain what the trouble is."⁴ So, although physician with patient is the best opportunity, it may not be the most effective.

Studies show that patients from upper or upper middle class positions received more physician time, more total explanations, more multilevel explanations, and less conflicting responses than did patients from lower middle class or lower class backgrounds. However, in the desire for information there was no difference between poorly educated, lower class patients and better educated upper class patients. Yet physicians misperceived this desire far more commonly for poorly educated or lower class patients.⁸

While physicians should be proficient as communicators and educators, modern demands for managerial and cost efficiency limit severely the time available for conversation with patients.¹⁰ Increasingly, and as noted for hypertensive patients, physicians routinely refer patients to other providers, such as nurses, nutritionists, or health educators for information and supplementary care.¹¹ It has been suggested that both the profession and the major payers should examine appropriate ways to achieve "a better balance between payments for cognitive as compared with technical services."¹²

Healthscope. In one outreach effort to improve understanding of health information, the American College of Physicians developed a program called Healthscope. Physicians show a carefully produced film in a community setting and answer questions from the audience. The College perceives the internist's role as helping the patient and the public to put the information shown in the film into perspective for himself "so that no one harbors unrealistic expectations about what medicine can do."¹³

Patient education. Patient education, which differs from health information, is directed toward a narrower segment of the population—people under medical care. This education is designed to obtain voluntary health behavior changes. In some states Blue Cross-Blue Shield, Medicaid, or commercial companies pay for the education.¹⁴

TELEVISION

The next area of major impact is television. Next to physicians, television has been the most frequently cited source of information about health. It may well be that daytime television serials, i.e., soap operas, are the largest source of medical advice in the United States.¹⁵

Bull. N.Y. Acad. Med.

The Bad News

The doctors. First, the physicians. The world portrayed on television hardly reflects the real world. Health professionals dominate the ranks of television professionals, with almost five times their actual proportions. An average viewer of prime time television sees 12 physicians and six nurses each week. Physicians are portrayed as miracle workers; they also appear to have a lot of time for each patient. They solve all problems, not just medical. They are authoritative, powerful, daring. They inspire an unrealistic sense of achievability and rate of success.¹⁵

Causes of death. On daytime serials the principal causes of death are homicides, car accidents, and heart attacks. "Four times as many women as men die of cardiovascular disease. Half of pregnancies result in miscarriages, and 16 percent in the death of the mother."¹⁵ This may be good story material but what subliminal message does this leave?

Characters and situations. Gerbner and colleagues¹⁵ found prime time characters healthy, relatively sober, safe from accidents, and slim at all ages, hardly ever need glasses, and rarely suffer impairment of any function. Television characters seldom take precautions against car accidents. In 283 situations in which commercials involved driving or use of a car where seat belts could be shown, the seat belts were shown or used in only 23%.

One review of research on alcohol use on television concluded that a youngster, too young to drink, will be exposed to 10 drinking acts on television during a day's viewing—and that was a conservative figure.¹⁶ When an alcohol-related event occurred in soap operas, it averaged a rate of about six per hour.¹⁷ Yet only about 1% of characters are portrayed as having a drinking problem or alcoholism.¹⁵

The viewers. Television tends to monopolize the free time of less educated, lower income groups.¹⁵ One study shows that these groups have the poorest opportunities for health and nutrition, yet are the most in need of valid information about health.¹⁸ A survey by investigators from Wayne State University School of Medicine found that only 30% of screen time devoted to health offered useful information; 70% of it was inaccurate or misleading—or both.¹⁹

Commercials. Although Gerbner et al.'s analysis of commercials aired during prime time and weekend daytime found that food advertising accounted for more than a quarter of such commercials,¹⁵ objective nutritional information appears to have been present in only 9% of these commercials. During a year, the average child viewer sees about 22,000 commercials; 5,000 of these are for food products, more than half of which are high sugar, low nutrition items.²⁰

The data produced by the studies suggest that television can help perpetuate unrealistic beliefs and values and unhealthy lifestyles.¹⁵ Why is this so? Where are the programs' medical advisors? According to one medical advisor, network standards and practices executives often take accurate medical information and transform it into misleading information. To eliminate things that might not be considered appropriate for prime time viewing, they often rely on old notions of what is or is not "wholesome." These uninformed notions as well as those of writers and producers often carry more weight than the expert medical advice.²¹ It will be interesting to see whether soap opera characters get AIDS and how that illness will be handled by television.

The Good News

There is some good news about television. In some situations the medium has produced beneficial health effects. The Stanford Heart Disease Prevention Program found that mass media campaigns could significantly affect behaviors that decrease risk factors associated with coronary artery disease. The mass media group showed a statistically significant increase in knowledge of coronary risk factors and a significant decrease in serum cholesterol level, systolic blood pressure, weight, intake of saturated fats, and number of cigarettes smoked per day.²² This, however, was a planned campaign, not an entertainment program.

Relatively new for television is the growing notion that viewers can call in and ask for advice on medical and psychological matters as they did on *Innovation*, WNET Channel 13's weekly series on science, technology, and medicine.²³ On Dr. Art Ulene's health information programs call-in questions were welcomed, and his segments on the *Today* show are carefully and authoritatively organized to deal with important questions and have provided good information. Television has also been a very popular medium for the local production and distribution of health promotion materials. Many hospitals are using closed circuit television for inpatient education.

The significance of television. Television's significance lies perhaps in its technical capacity to disseminate information. Television "... is the first medium to appeal to those whose normal sources of information are non-print sources, almost always word-of-mouth."²⁴ Several years ago one view

of the media led to the "hypodermic" opinion which held that once the message was injected, the audience was supposed to respond. In contrast, Klapper proposed that mass communication may not have a direct effect, but it does exert a significant influence through a variety of mediating factors.²⁵ While health education efforts using television rarely seem to meet the extraordinarily high expectations of health professionals, most of these television efforts do far better than even the most heavily backed advertising campaign. For example, a television based health education program aimed at an elderly population in New York City successfully induced 8% of its target population to participate in screening programs and follow-ups.²⁴

Improvements. People do want to know more. Yet the primary sources of news for most people, radio and television, have failed to keep up with the demand. The major reason is that there are just not enough well trained science journalists working in the broadcast media. In an effort to remedy this situation, WGBH in Boston offers Macy Fellowships in Science Broadcast Journalism.²⁶

PRINT MEDIA

For centuries print media have carried health information messages, some written directly for the popular press and some reported from professional sources. In 1986 more than 300 medical and science stories carried by the Associated Press and United Press International, about one each weekday and Sunday, were based on new scientific findings published in the *Journal of the American Medical Association, The New England Journal of Medicine*, and *Science. The Washington Post* and *The New York Times* ran several hundred stories citing these same three journals. Among the topics were dangers of cigarette smoking, spread of AIDS, and high salt content of many breakfast cereals.²⁷

People do want to know more. There has been a sharp increase in coverage of health information in newspapers and magazines. However, the communication of scientific and technical information to the public depends heavily on the knowledge and skills of professional who write them.²⁸ Articles in the press are often incomplete or do not accurately present information. Journalists give as reasons their need to meet deadlines and lack of space. They are also concerned with newness, drama, impact, and conflict, and for the most part have no background on the subject, nor do they necessarily want to obtain it.²⁹

Nonetheless, the print media are helpful. For example, the National Health

Screening Council for Volunteer Organizations stimulates health fairs—a week long, community health education and screening service. The Council reported that through the use of radio, television, and print it " 'reached over 75 million Americans with health messages...'".³⁰

FEDERAL HEALTH INFORMATION CLEARINGHOUSES

During the past 15 to 20 years the Department of Health and Human Services has funded the development and operation of numerous health information dissemination systems, often in the form of clearinghouses. In general, clearinghouses collect and process information, respond to inquiries, and disseminate information. Many maintain computerized databases. Major clearinghouse activities involve responding to the public's requests for information and for specific documents.^{31, 32}

Depending on the type of request, clearinghouses may respond with standard kits of information or other materials such as biblio-profiles, brief state of the art reports with a comprehensive bibliography. The information clearinghouse of the new National Institute of Arthritis and Musculoskeletal and Skin Diseases currently mails monthly more than 10,000 copies of a booklet on osteoporosis prepared by the Institute.³³ People learn of this booklet through articles in the mass media and request them.

Most federal health clearinghouses aim their services at a particular audience. Because of limited funding and staffing, or because other organizations may have been designated to respond to a particular audience, some clearinghouses limit their services to specific groups. In some cases, for example, the National Health Information Clearinghouse, the audience may be as broad as the general public. Other clearinghouses may serve primarily highly specialized practitioners in specific settings. On the average, clearinghouses serve about 50,000 requests a year, most from health professionals.

Clearinghouses practice outreach through other health related organizations, health fairs, professional meetings, and announcements in journals, but they are limited by budgets and scope in what they can do. Some of the 34 or more topics in which there are clearinghouses and information centers are: alcohol, arthritis, cancer, cholesterol, diabetes, digestive diseases, drug abuse, family planning, high blood pressure, and smoking and health.

SCHOOL HEALTH EDUCATION AND COMMUNITY HEALTH PROMOTION

Schools. Schools and communities are also major sources of health information. In primary and secondary schools throughout the country, health education programs address many topics: disease prevention, health risk reduction, nutrition, smoking. One example of such a program is the consortium of the New York public schools, the New York Academy of Medicine, and the corporate community, which has produced an innovative interdisciplinary curriculum to bring comprehensive health education to inner-city children. The project, called "Growing Healthy in New York," is a program for grades K through 7.³⁴ Among the topics covered are growth and development, nutrition, consumer health, and drug use and abuse. Most likely, information on AIDS will be considered for inclusion.

Communities. Community health projects are conducted throughout the United States. They include worksite hypertension, smokeless tobacco education, prevention of teenage pregnancy, teenage substance abuse, and more. In 1986 197 projects were submitted for consideration for the Secretary's Health Promotion Awards.³⁵ The Centers for Disease Control's Center for Health Promotion and Education is a prime mover in the encouragement and initiation and support of both school health and community health education programs.

LIBRARIES

A traditional source of information is the public library. As indicated in the earlier section on physicians, patients often have questions that remain unanswered or even unasked in the doctor's office. Some of these questions land at the desks of reference librarians. An analysis of 817 reference requests processed by four Cleveland area libraries during a three month period in 1981 revealed that more than 50% were health related.³⁶ However, this finding was not supported by another study done in Houston, Texas.³⁷

Increasingly, the shift in social attitude toward health hazard appraisal, risk of reduction, and health maintenance is reflected in the percentages of questions, comparatively small as yet, that libraries—medical and metropolitan public libraries—receive on the subjects of physical fitness, exercise, nutrition, and prevention. Increasingly, however, the library—public and hospital—is called on to coordinate health information access at a local level. A number of formalized consumer health information programs have been organized in such cities as Los Angeles, Cambridge, Syracuse, Cleveland,

and Tulsa. Many librarians now serve as focal points for the dissemination of health information in the community.³⁶ Their activities include application of selection criteria for articles for the public: accuracy, currency, point of view, audience level, scope of coverage, organization, style, and format.³⁸

ELECTRONIC METHODS

Dial access telephone lectures. In the early 1970s the University of Wisconsin, with the help of the Regional Medical Program of the National Library of Medicine, developed a community-health tape library that physicians could access by telephone. Parts of the tape libraries were restructured into telephone dial access systems (Tel-Med and Health Line) with three to five minute taped health messages on a variety of medical and health related topics for the consumer. While there is a sizeable volume of data on the frequency of use of the system, there appears to be little evidence of its effect on users' knowledge, attitude, health behavior, and use of health care facilities.³⁰

The doctor's house call via computer. Another method is the doctor's house call via computer. St. Silicon's Hospital and Information Dispensary sounds like the title of a new television series. Actually, it is the name of a project of the Department of Family Medicine at Case Western Reserve University School of Medicine. And it is a computer that makes house calls. A description appeared in *Vogue* and other magazines and in *The New England Journal of Medicine*.^{39, 40}

Anyone with a modem-equipped home computer, or with access to a computer terminal, can direct medical questions to the staff at Case Western. The questions are answered by a board-certified family medicine physician faculty member, usually within 24 hours. The creation of St. Silicon was unintentional. The project was started as a communication system for physicians within the hospital's clinical units. After a while, the phone number got out, and people began to call with their personal medical questions in the hope that a physician would answer. So the faculty began to develop the system as a medium for community health education.⁴⁰

The system was made as user friendly as possible, with sample menus and help screens. The heart of the system was the medical clinic, subsequently nicknamed "Doc-in-the-Box." The physicians who monitor the system and answer questions are instructed to do no diagnosing or treating, but to give general information in response to the queries. In the second week after installation of the new system, it received over 100 calls a week. For the four months prior to submitting the article, 233 calls per week came in on a system with a single phone line. St. Silicon also offers "Dent-in-the-Box," an electronic dental clinic, and "Shrink-in-the-Box" for emotional problems.

About one third of the callers were medical professionals wanting to use various other features of the system. The rest were members of the public who have asked over 500 medical and 100 dental question through the system in just over one year of operation, new questions currently arriving at the rate of about 20 per week.

The kinds of questions people ask include ones they have forgotten to ask while in the physician's office such as the side effects of a prescribed medication. Others are questions people think are too trivial or too costly to take to a doctor, or that they are reluctant to ask face to face.

Limitations of the system. Perhaps the chief limitation of St. Silicon is the socioeconomic selection factor. To use this system, one must have access to a microcomputer or a computer terminal with a modem. An analysis of the 1,287 users registered in the system at the time the article was prepared revealed that they are predominantly white, male, and professional or white collar people in their late 20s. This population appears to have needs for health information not met by existing programs. And if this motivated, educated, literate population has trouble meeting its needs, what about the less educated, the nonliterate? According to industry analysts, this keyboard population will grow as home computers become cheaper, as more students who are growing up with computers enter adulthood, and as modem-equipped computers become increasingly prevalent.⁴⁰

Databases. Thousands of databases are now online, many of them biomedical or health related on which one can search for information.⁴¹ Some contain drug information, such as Consumer Drug Information Full-Text with information on more than 200 of the most frequently prescribed drugs comprising over 1,000 brand-name products. Others include birth defect information, a directory of health information resources, toxicology data, etc.

An innovative, relatively new database is the Combined Health Information Database (CHID) on BRS Information Technologies (a national database vendor) and BRS After Dark and BRS/Saunders Colleague. CHID is the product of a consortium of clearinghouses and databases of the U.S. Public Health Service. It includes such databases as AIDS School Health Education, which contains the full text of articles and reports, for example, the Surgeon General's Report on AIDS. CHID also contains databases on arthritis, diabetes, digestive diseases, health education, health information, and high blood pressure. CHID subfiles may be searched separately, in groups of the subfiles selected, or totally as CHID. As of May 1987 there are eight subfiles on CHID with more than 30,000 abstracted items reflecting patient, community, worksite, and school health education and health promotion resources—programs, curricula, policies, materials, audiovisuals, and more.⁴²

DISCUSSION

Deficiencies in health information. In a relatively short time we have come a long way in providing health information yet we still have a long way to go. In 1975 health education of the public was called the missing link in the evolution of health services. An article in the *Journal of Medical Education*⁴³ cited some deficiencies in health information as it is too often presented, and many of these are still relevant 11 years later. At that time, health information was found to be:

based on analysis of what consumers either need or want to learn; (c) presented without opportunity to translate theory and information into practical applications; (d) presented in unimaginative or unnecessarily technical style; (e) inadequately related to life style, cultural background, environmental condition, and existing health services in the community, and (f) often in conflict with other messages.⁴³

The author wrote that, at the very least, the public needs a detector of bad information. We also know that a higher level of health information literacy is required. While some of this is now being taught in school and community health education programs, television, for example, is a double edged sword: it is both a source of information and misinformation, and the poorly educated are more likely to believe the misinformation than are the better educated.

Yet even if not misinformation, there is often conflicting information with the public bombarded by reports of dangers and boons to health. Topics range from pathologic processes such as osteoporosis to environmental situations as in radiation hazards. A recent letter to the editor in *The New York Times* complained that we have had physicians' opinions and research results that run counter to information given previously, that physicians cannot get their stories straight. The letter asks whether there should not be an effort by the medical profession to establish a clearinghouse on health findings.⁴⁴

Some questions and needs. What information do people need to help them to live healthy lives? Are they getting that information? If so, at what cost? If not, what is the cost? How well is the need for reliable health informa-

tion being met by those marketing the health concept? Can we be confident that appropriate information is being made available nationwide, not just the controversial? What systems and priorities exist to guide who should get what information? What systems would be best? What will they cost? What alternatives exist for each of these processes?

We know from literacy level tests and experience that the level of the information is often too high. Much health related information still is difficult for even well educated patients and their families to find and to understand. And we know that a large proportion of the population reads poorly or not at all. There remains a need to teach patients and communities how to obtain health information, how to evaluate it, and how to use it. And further, as Bazelon wrote, "To improve health in the broadest sense, society as a whole must make choices despite uncertainty. To choose rationally, however, society must be informed about what is known, what is feared, what is hoped, and what is yet to be learned."⁴⁵

Evolving a strategy based on these questions and needs means that there should be a new look at information and its role in the total health picture. We are being forced to do that now to get AIDS information to the public.

Recently, the American Medical Association published a "Health Policy Agenda" that includes recommendations for health information and education in meeting public health care needs through health professions education and in communication among the research community, the media, and the public. Among the recommendations are: that self help and mutual aid groups should be promoted as useful components of health promotion and disease and injury prevention. Another is that studies should be conducted on how well research news is disseminated by the media to the public, and should be evaluated to determine the effectiveness of health information and education efforts.⁴⁶

CONCLUSIONS

Much of the public wants health information. However, much of what they, we, get is difficult to find, incomplete, conflicting, misleading, and hard to understand. If individuals are to accept their roles as decision makers in health, they must have easier access to useful information—and the demand for this information grows daily.

There is also a need to teach the public to ask the right questions and to provide better public information about the possible implications of courses of actions and about situations where as yet there are no answers.

One of the continuing problems is that the public does not understand how science works, how answers are obtained, and that these answers may be a long time coming, to say nothing of the national expense in producing them. The public and health professionals alike must also understand ways to change lifestyles and habits and ways to promote behavioral change.⁴⁷ Messages must be clear and motivating. And in the end we must also recognize that there are differences in human values that may not be able to be reconciled. Many organizations have recognized these issues and are attempting to deal with them.

By examining the issues on diffusion of health information, this symposium is certainly a milestone along the way to understanding the problems, and, as a result of our discussion today, new strategies may be laid out. The topic warrants the best thinking of all of us—it is surely one of the nation's and the world's highest priorities.

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