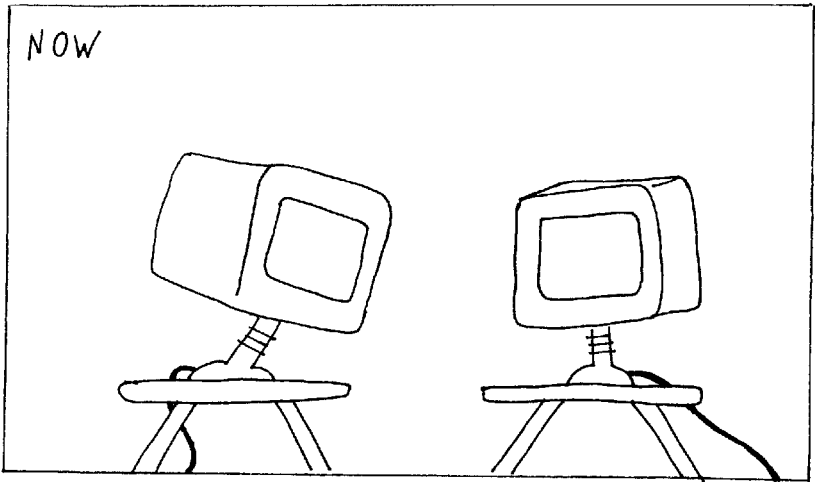


"I THINK THERE IS A WORLD MARKET FOR MAYBE FIVE COMPUTERS."
THOMAS WATSON, CHAIRMAN, IBM, 1943



"I FORESEE THE NEED FOR ABOUT FIVE HUMANS."

Providing Information to Patients

It can be argued that the largest yet most neglected health care resource, worldwide, is the patient or prospective patient. Most people could readily manage a number of common, important medical problems, such as sore throat and urinary tract infection, if provided with the clinical information necessary to do so. I don't mean to suggest that self-care can be accomplished by taking Hygiene 101 from the basketball coach in his spare time—or by studying Molecular Biology 401, with a discourse on the genetic determinants of immunological mechanisms. I mean good, solid, reliable, up-to-date, best current wisdom that virtually any literate person who wants to can understand.

Until recently, communication between doctor and patient was for the most part one-way—the doctor ordered and the patient was expected to obey. The “good” patient followed orders dutifully; the noncompliant (read “bad”) patient didn't. But times are changing; not as fast as we might like, but changing for the better.

It has long been my argument that doctors should give people sufficient information to enable them, or their designated surrogates, to

make enlightened decisions about matters of health and disease. People should know how they can best achieve and preserve good health and the good health of their families. They should know when a problem is not a medical problem—when, for example, the sadness that follows the loss of a loved one is healthy grief that will abate with time, and when it is clinical depression that could benefit from counseling or medication. They should know when to care for a medical problem themselves and how best to do this—for example, how to care for a laceration that is too small for stitches (lots of soap and water, no iodine).

People also need to know when it would be better to turn to others for help and how and where to do so. What are often the most difficult of diagnostic decisions typically get left to the patient—when to consult a doctor, which doctor to consult, and how to get in touch. When, for example, is the laceration big enough for stitches, and where should the stitching be done? In a medical emergency, people need to know what to do.

HOW DOCTORS TALK TO PATIENTS

Doctors can help people become better informed about matters of health and disease in a number of ways. The oldest and in many ways still the most effective medium is face-to-face communication. Dialogue between doctor and patient is the mainstay of clinical medicine. During the interpersonal encounter, the doctor tries to establish rapport, develop bonds of mutual respect and trust, collect information relevant to a patient's medical problems and general health, and communicate information for the patient's immediate and long-range use. In turn, the patient can explain his or her wishes to the doctor, and the two can work together to develop an approach to treatment consistent with both the patient's wishes and the dictates of medical science. Of course individual attention is not always possible, and when it is, it can be very expensive. Even in the best of circumstances, practicing physicians are faced with serious problems when it comes to dialogue with their patients. Clinical interviewing requires a large amount of time, and inadequate histories and insufficient counseling often result from limitations in time beyond the physician's control.

Since the Second World War, advances in medical care have outstripped our ability to apply them, and pressures on health care systems worldwide have escalated. Doctors are pressured on one

hand by increasingly empowered patients, who understandably want and expect more personal attention, and on the other hand by parsimonious bureaucrats, who schedule more and more patients in shorter and shorter intervals. There is a pressing need, therefore, to seek new ways to enhance medical communication and thereby supplement the interpersonal relationship between doctor and patient. The idea is not to replace the doctor; the idea is to fill a void.

How then, can medical information be communicated in the absence of direct interpersonal communication?

Early Technology

Since early times, growth in population has been accompanied by innovation in communication, inventions that enhance the exchange of information between more and more people, but that do so at the expense of direct interpersonal conversation. Each invention, impersonal by its very nature, has in turn been subject to early criticism both by the well-meaning humanist, who objects to anything seen as having a depersonalizing influence, and by the well-meaning traditionalist, who opposes innovation on principle. It is likely that when that ingenious Sumerian who invented writing first pressed those cuneiform symbols into clay along the Tigris River some five thousand years ago, a skeptic standing nearby predicted with furrowed brow that people would soon stop *talking* to each other. Those who read *The Republic* in school will remember that Plato was very much opposed to theater as it was performed in ancient Greece. For him the portrayal of fictional characters was an ignoble pursuit that exposed audiences to the risk of corruption.

In more modern times, the telephone was written off prematurely: according to an internal memorandum at Western Union in 1876, the telephone “has too many shortcomings to be seriously considered as a means of communication. The device is inherently of no value to us.” The motion picture was also greeted with suspicion. The stage was by then a reputable medium (“legitimate theater,” as it were), but the movie, even as it gained in popularity, was deemed *common* and potentially harmful. To make a movie based on a book was a priori to debase the book. Parents worried about bad cinematic influences and meted out movie-going privileges with extreme judiciousness. Dorothy Parker likened the movie to sex, pointing out that while most enjoyed it, few would talk about it.

Radio had a similar history. “The wireless music box has no imaginable commercial value. Who would pay for a message sent to nobody in particular?” argued David Sarnoff’s associates in the 1920s, when he urged them to support radio as a commercial venture. Popular as it was to become, radio was late to be accepted publicly by the intelligentsia. *The Green Hornet*, *Captain Midnight*, *Terry and the Pirates*, and *Superman* (together with their comic book counterparts) were intermittently banned from middle-class households. Kids, of course, still listened—but did so with youthful subterfuge.

After World War II came television—lowbrow (boxing and wrestling were the staple programs) and frowned upon as potentially corrupting. As television broadened its scope and became increasingly available and popular, it was correspondingly chic among the culturati *not* to have television at home. There was a family in our neighborhood in the 1970s who did not have a set in their home. Mention of television in conversation with the parents elicited blank faces. The children, however, spent an inordinate amount of time in front of *our* set.

Movies and radio were by then regarded as legitimate art forms, particularly the earlier, pre–World War II films and programs. It was then acceptable to consider a movie *better* than the book on which it was based (*Elmer Gantry* and *The Godfather* come to mind).

The personal computer is the new medium on the block. And once again, prophecy was off the mark. “I think there is a world market for maybe five computers,” Thomas Watson, chairman of IBM, is purported to have said in 1943. But I am getting ahead of myself.

Medicine and the Printed Word

When Johannes Gutenberg invented the printing press in the mid-fifteenth century, he used his invention to publish the first printed version of the Christian Bible. His machine of course would have an enormous influence on secular communication, but the medical profession would be slow to adopt the printed word as a means of communication with patients. Patients were to be kept in the dark, knowing only what their doctors wanted them to know. Information in the hands of the patient could be dangerous, it was believed. When the doctor handed the patient a prescription it was written in Latin to *prevent* communication. Well into the twentieth century, medical articles in the popular press were treated at best with amusement by the

profession. This reluctance to go public with professional secrets is not unique to medicine. Most professions are protective of their information, which serves to differentiate them from the public. Scientists who write for the public risk criticism from their peers; only giants such as Einstein can write for the nonscientist without at least some risk of reprisal from the scientific priesthood. To this day, doctors who write for the public are vulnerable to the criticism of publicity seeking, of pandering to the public and jeopardizing the patient, for whom it is argued a little knowledge might be a dangerous thing. The concern that the public will not understand and will be misled is certainly legitimate, but it is sometimes expressed as a covert means of protecting the guild, rather than the public. There is valuable equity in the concentration of information within a profession.

In 1946 came a turning point in medical publications for the public. Pocket Books published *Baby and Child Care*, by Benjamin Spock. Criticized at first by the American Medical Association and the American Psychological Association—for pandering to the public, being too permissive in approach, and definitely *not* representing Park Avenue pediatrics—Spock’s book so obviously filled a niche that it could not be stifled. It told how to care for a sick baby at 2 A.M.; it told parents when they could care for the baby at home and when to call a doctor, when to worry and when *not* to worry. Parents might not discuss Spock’s advice at a seminar on psychological theory or at a golf club social, but there was no way that *anyone* was going to wrest Spock’s book from their hands when their child was sick. It has been estimated that *Baby and Child Care* is second only to the Bible in total sales. Spock went a long way toward legitimizing the medical book for the public, and publications on self-care are now published in abundance, many even with the blessing of the AMA. The adage that “the person who treats himself has a fool for a doctor” is being replaced by titles such as *How to Be Your Own Doctor*.

Yet the published forum, like the lecture, is still a type of one-way communication. There is little provision for interaction with the author or lecturer. In addition, it can be hard to assess the accuracy of published material—particularly if experts disagree, which is often the case in the medical profession (more often than we care to acknowledge). When there is disagreement, whose advice does the reader follow? One cannot turn readily to the writer and ask for evidence. Still, a book can be kept close at hand, available for quick reference whenever needed, at any time of day or night.

As self-help books and articles on medical matters appear at an accelerating rate, their success creates a bewildering surfeit. The problem now is how to select the ones that can be trusted. And most of us cannot afford to house large libraries in our homes. Even when a good book is at hand, locating the desired chapter or page may be hard, even with an index and table of contents.

The ideal would be to have Dr. Spock in conversation in the living room. But to have his words of wisdom on the printed page, close at hand, is still a good alternative, impersonal as it may be. Books are portable and are usually replaceable if lost or worn out. The first-aid manual is here to stay, at least for the foreseeable future. Still, the health-minded reader can be left hanging with important questions.

The Airwaves

Perhaps recognizing the problems of books, a few doctors have turned to the airwaves, sometimes reluctantly and sometimes with zeal. As far back as 1936, CBS radio aired a fifteen-minute child health program, hosted by Dr. Alan Roy Dafoe, the physician who delivered the Dionne quintuplets. But radio and television are still basically one-way communicators over which the listener has little control. With medical topics, it is the producer and not the patient who schedules the programming. A diabetic in need of immediate advice is not going to tune in to a lengthy discussion of intermediary glucose metabolism on public television if a booklet from the American Diabetes Association is readily available on the kitchen shelf.

In some radio and television programs, however, the listener or viewer can converse with the expert over the telephone. This type of talk show is a response, I'm convinced, to the frustration evoked by one-way communication. People are restless by nature; they like to interact. They can take just so much of Pat Robertson without wanting to talk back. (If you're itching to talk back to *me* at this moment, you can use my e-mail address: wslack@caregroup.harvard.edu.) And sit-still behavior does not come naturally. The ever-proliferating cellular phone (ubiquitous on streets from Sydney to Paris to New York) is another example of the guy on the street talking back.

The audience participation talk show was invented, almost certainly, not by a clever producer but by an irate listener who demanded the opportunity to get a word in, albeit edgewise. Sports and politics, the first call-in topics, still dominate the airwaves, but medicine has

found its dial-in niche, whereby doctors can give specific advice to callers. On midday television in Boston, Timothy Johnson takes “house calls” on medical matters, Tom Cottle counsels troubled callers on psychological issues, and Alexis Beck gives advice on nutrition. In San Francisco, Dean Edell offers medical common sense on both radio and television call-in shows. Helpful as these programs may be, however, they still serve mainly as forums of general interest, rather than solutions to the specific medical needs of patients. The waiting time for callers is long, often as long as the time in the physician’s waiting room, few callers get on the air, and airtime is short.

WHEN PATIENTS TALK WITH PATIENTS

In 1935, Bill W., a recovering alcoholic, found himself in Akron, Ohio, the victim of a failed business venture. Fearful that he might have a relapse, Bill had a remarkable insight—if he wanted to help himself, he should find and help another alcoholic. He found Dr. Bob, an alcoholic physician, and helped him to stop drinking. It was there, in Akron, that Bill W. and Dr. Bob (neither of whom ever drank again) founded Alcoholics Anonymous, the most successful approach to alcoholism ever devised.

Bill W.’s insight, that one’s own experience with a medical problem can be used to help someone else with the same problem, and that in doing this, one is also helping oneself, is at the heart of all successful self-help and medical support programs. Only an alcoholic can fully understand the experience of alcoholism. Only a woman who has undergone a mastectomy for breast cancer herself can fully understand what is in store for another woman with the same diagnosis. Only the parents of a toddler with diabetes will know what this entails—the blood tests, insulin injections, meal planning, and day-to-day living, at home and in the outside world. And in communicating their experiences to help others, these people are putting their problems to good use in what I think is the most durable form of altruism—helping yourself by helping others. Sadly, the self-help programs in their early days were sometimes treated with scorn by the medical profession. But doctors are coming to realize, however belatedly, that all of us—patient and clinician alike—can benefit from the principle that patients and their families are an invaluable resource for one another. This is enlightened self-interest in the best sense of the term.

Initiated not by clinical experts but by people who share the same problem, symbiotic communication has seen remarkable growth over the past sixty-five years. More and more, people are sharing their problems and their strategies for coping, both formally and informally, one on one, in groups, forums, books, and pamphlets, and on radio and television. The wise doctor knows when *not* to intrude on such beneficial communication.

ON-THE-SPOT INSTRUCTION

It is helpful to differentiate between information that we need to commit to memory and information that is readily available through external sources. In the classroom, where great emphasis is placed on memory, external sources of information are suspect. Teachers worry about the handheld calculator or the use of crib notes during an examination. Outside the classroom, however, memory is less important. If information is on hand whenever needed—for example, how to start the furnace, how to place the jumper cables, or, on a more esoteric level, how to calculate the area under a curve—there is little need to memorize. There are even good reasons not to rely on memory.

Rapid, reliable recall is not always a strength of the human mind, for all its marvelous attributes. It is often safer to read instructions than to rely on memory, particularly when the information is important but rarely used. Paradoxically, if the information is often used, this too can result in errors. When the familiarity of a protocol leads to boredom, the mind tends to wander. When the stakes are high, as in the cockpit of a commercial airplane about to take off, the copilot reads a checklist to the pilot, even though the pilot knows the panel by heart.

And so it is in medicine, at least for the patient if not the doctor. Doctors tend to be obsessed with memory (knowing it all can be a matter of pride), although less so than in days gone by. But patients do not need to memorize medical information. They just need to have it handy. Better to have the first-aid manual readily available than to commit its contents to memory.

ENTER THE COMPUTER

The essence of the computer, in contrast to the book, play, movie, radio, or television, is its ability to *interact*, to converse with its user one on one. As a prescription for the patient, the computer can be pro-

grammed to simulate one-on-one conversation, but with the collective wisdom of many doctors.

The idea of a patient “talking” to a computer was hotly debated at its inception in the radical decade of the 1960s and is still controversial. This is understandable. Novelty is unsettling. It is hard for us to assess the potential, for good or for bad, of a new idea. This is true in virtually all walks of life—the arts, the sciences, the professions, and the marketplace. Good ideas are often thwarted. As Machiavelli observed, “The innovator makes enemies of all those who prospered under the old order.” (Not all those with enemies are innovators, of course.)

And so it has been in medicine. On one hand, bad ideas are often promulgated. Carcinogenic X rays were once used to treat normal thymus glands, ringworm, and acne; tonsillectomies were routinely performed under general anesthesia in healthy children; and the operation to remove the frontal lobes of the brain (prefrontal lobotomy) was a common treatment for mental illness. On the other hand, René Laënnec was ridiculed for his invention of the stethoscope (it separated the doctor’s ear from the patient’s chest), and Ignaz Semmelweis couldn’t convince his fellow Viennese obstetricians to wash their hands before delivery.

And so it has been with the invention of the computer and its introduction to society and medicine.