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Cybermedicine: How Computing Empowers Patients for Better Health Care

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Shortly after the Second World War, the eminent mathematician Norbert Wiener drew upon the Greek word kybernetes meaning pilot or governor, to coin the term cybernetics, which he defined as the science of communication between people and machines. More recently, the word cyberspace has been used to refer to the worldwide computer-based network that has so greatly enhanced communication between people and machines. As a derivative of cybernetics, cybermedicine is my word for the use of computer technology to enhance communication in the field of medicine and, more specifically, computing designed primarily to help the patient and clinician in the practice of medicine, computing that can improve the quality of medical care while reducing the costs and actually improving the relationship between the patient and doctor [1].

Good clinical computing is still more the exception than the rule, however. In spite of the great advances in computer technology, the patient, the prospective patient, and the doctor have yet to realize the full benefit of these machines. There are, of course, real dangers with the misuse of the computer, such as depersonalization, true dehumanization, and breach of privacy, and we must keep our guard up. On balance, however, the problem is not too much automation in medicine; the problem is *too little.*

During the 1960s, when I was at the University of Wisconsin, two lines of reasoning evolved in my mind. The first led to a philosophy that, in the vernacular of the times, I called patient power, arguing that patients who want to should be encouraged to make their own clinical decisions and helped to do so [2]. For centuries, the medical profession had perpetrated paternalism as an essential component of medical care, thereby depriving patients of the self-esteem that comes from mutual respect. The assumption was that the doctor knew best. Patient power questioned this. As George Bernard Shaw once wrote, Do not do unto others as you would that they should do unto you. Their tastes may be different.

My second line of reasoning led to the conclusion that the computer could be used wisely and well in the practice of medicine. This was controversial for its time, and those of us who were entering this new field were confronted by concerns about the computer in medicine under any circumstances concern about the potential encroachment of this new technology on the practice of medicine and the traditional rapport between doctor and patient. Would these machines result in the dehumanizing processes that had been associated with the Industrial Revolution? Would modern times destroy the art of medicine? The debate was frequently lively, and a commonly asked question was Will your computer replace the doctor? A rejoinder that I found useful and one still apt today, was that any doctor who could be replaced by a computer deserved to be.

It was at the University of Wisconsin in 1965, that my colleagues and I had the idea that we could program a computer to interact directly with a patient, to engage in meaningful dialogue, to explore medical problems in detail, and to do so in a personalized, dignified, and considerate manner an idea that had not been tried before [3]. There were theoretical reasons for pursuing this idea could the computer model the clinician as an interviewer? but there were practical reasons as well. The traditional time-consuming method of taking and recording detailed medical histories involves serious problems for the busy clinician, particularly in regions that are short on doctors.

I hoped that the computer-based interview would be helpful to the doctor in the care of the patient, that using the computer would be of interest to the patient (perhaps even enjoyable), and that pooled responses from many interviews would help us to learn more about the importance of the questions in the interview and to study the process of clinical interviewing. In the back of my mind was the idea that perhaps the computer could actually help patients help themselves.

We turned to the Laboratory Instrument Computer (LINC) for our study. This small, general-purpose digital computer was developed at MIT in 1962 by Wesley Clark and Charles Molnar, with a grant from the NIH; it was a pioneering machine, and in many respects was the forerunner of todays personal computers. It found widespread use in neurophysiology laboratories, where it could be programmed to study the nervous system of experimental animals. The LINC had a small memory and was very slow by todays standards, and there was a flicker on the screen that became increasingly noticeable as the number of characters increased. There was reason, therefore, to keep the questions short, but this electronically imposed succinctness had a beneficial effect on my writing.

The LINC was in great demand, and as a neurology resident with no status, I was given late night and early morning hours to program. Still, within a few months we had an allergy interview

written and working well. However, I found myself continuing to make revisions, and eventually I had to admit that I was procrastinating. It had been fun to talk about the computer and to argue with the skeptics, but to try it with a real patient *for the first time* that was another matter.

The time came, however, when it was now or never. I approached a medical intern and asked if he could select a patient for me. He was tired; he had been up all night, and the thought of being replaced by a computer had a definite appeal. He suggested a patient, an older man who was recovering from a heart attack and was now up and about, getting ready to go home. I went to his room, introduced myself, told him the general idea of the project, and asked if he would give us a hand. He said hed try anything once, and he walked with me to the medical sciences building, where the LINC was housed. Fortunately, there was a free hour at lunchtime for us to try our first interview. He sat down in front of the machine; I turned it on, spun in the program from tape, turned down the lights in the room (the dim characters on the screen were easier to read in the dark), pressed the start button, and stepped back to observe.

The tapes churned, and HAVE YOU EVER HAD HIVES? appeared on the screen. The characters flickered, the lights on the console flashed on and off, and the LINCs speaker emitted an eerie, high-pitched sound. We had the computer but its owners were still doing a cat brain experiment, and on the other side of the Sheetrock partition, people were walking in and out, and a cat was meowing. It was reminiscent of Kafkas *Castle* or Koestlers *Darkness at Noon.* Clearly, these were not optimal circumstances for *any* medical interview, let alone one conducted by a computer.

Yet my patient seemed oblivious to his surroundings. He got going at the keyboard, responding appropriately to the questions, and soon it was clear to me that he was having fun and there was rapport between man and machine. He laughed out loud at some of the comments from the computer. Some I had intended to be funny; some I hadnt. And he talked out loud to the machine, sometimes in praise and sometimes in criticism. Of course, he never would have said this to me face to face, a doctor with a white coat and a Bakelite nametag. It was apparent to me that perhaps for the first time in his experience as a patient, he was in control of the interview. Here was patient power at work [4].

Heartened by our early results, we pressed on with further studies of computer-based medical interviews in our laboratories at the University of Wisconsin and, more recently, at Beth Israel Deaconess Medical Center in Boston. Our programs have addressed a wide variety of medical and psychological problems. And in our experience, and the experience of most others who have studied dialogue between patient and computer, concern about the computer as a depersonalizing influence has been unfounded. Most patients who have had the opportunity to talk to the computer have found their experience to be enjoyable, interesting, and informative.

The next step in our studies of patient-computer dialogue was to use the computer as a patients assistant. It has been my premise all along that the largest yet least used health care resource, worldwide, is the patient or prospective patient and that the interactive computer can be used beneficially to enlighten patients and empower them in the health care process, thereby improving the quality of care while reducing the cost. When the forces of supply and demand dictate it, patients do very well in managing medical problems. If, for example, the biochemistry of insulin were such that a child with juvenile diabetes needed only one insulin injection per year, it is likely that an academic endocrinologist in a teaching hospital would give the injection, and at considerable expense. But the need is typically twice a day, and it is the parent or older child who gives the injection at home, with admirable skill. There is no other way. And there are a number of common important medical problems, such as headache, sore throat, and urinary tract infection, that patients could manage themselves if they were provided with the clinical information necessary to do so. We have developed interactive programs for patients with such problems and found them to be highly effective when used in our experimental clinics.

I used to dream of what I called the interactive Benjamin Spock, a computer-based program in the home that would offer advice and suggestions about prevention of medical problems, as well as diagnosis and treatment when such problems arose. The program would also help people to seek and use health-care facilities in an enlightened manner, and participate as partners with clinicians in medical decisions. The idea was not to replace the doctor. The idea was to fill a void. Patients make medical decisions for themselves all the time, such as when to go to the doctor. My dream was that the computer would be available to help people make these decisions in a more knowledgeable and enlightened manner.

Now, with more and more PCs available to more and more people, and the technology of nationwide and worldwide communication over the Internet, this dream is becoming a reality. Web sites offer a wide range of health-related information. For the most part, such information is presented in a noninteractive, didactic manner. But I am confident that more and more interactive programs will be available to address the individual needs of patients who use them, and we are working to develop such programs. And more and more patients are communicating with each other and with their doctors over the Internet, to their mutual benefit.

As with all health-related literature directed to the patient, readers must be wary of the source of information on the Internet and seek second and third opinions. Misinformation is there along with the useful and well founded. But the information is there in abundance and its accessibility is unparalleled in the history of civilization.

It is heartening that the costs keep coming down. Most middle-income families can now afford a personal computer with a modem. Computer-based telecommunication can be expected to evolve the ways calculators have, which now almost everyone can own. The computer may have started out in the hands of the elite, but it is now available to more and more people; it is becoming democratized as well as democratizing

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