H.R. Warner

Professor Emeritus,
Department of Medical Informatics,
University of Utah,
Salt Lake City, Utah, USA

Preface

Patient-centered Systems

The arrival of the information age has already empowered many computer users in a variety of ways that significantly effect how they manage their lives, and we are still just at the beginning. As a result of easy access to medical information through a personal computer connected to the Internet, some of these people are now in a position and may want to assume much more responsibility for their own health care. Will it result in an improvement in health care? How will this change the role of the medical professional? In this preface I will reflect on where we, as professionals in Medical Informatics, have come, and where we are going in this process of empowering the patient with the tools of modern information technology.

What are the forms in which we might provide access for a patient to medical information that might have a positive impact on her or his health? Some of these include:

1. direct access to medical knowledge,
2. access to the patient's own medical record,
3. direct entry of data into the medical record,
4. better access to the best available health care,
5. convenient tools for management of an individual's own health care expenses.

Access to Knowledge

The world's medical literature is available on the Internet at no charge through programs such as PUBMED from the National Library of Medicine. By accessing this, a patient may become informed about his or her own disease, including available treatment options. The physician then may be expected to be equally well informed in order to give useful advice at the time of the consultation.

Evaluation of information in the literature by a layperson, however, may be difficult and may lead the reader to erroneous conclusions. Most lay people lack the experience needed to interpret the results of a scientific study and to recognize which conclusions drawn by an author are valid based on the evidence presented. Even some practicing physicians struggle with this problem. Review articles represent one solution where full text is available on line. Expert systems to help the patient with this task may be another solution in the future.

Computer-based expert systems designed specifically for lay people such as "Medical House call" [1] present another source of knowledge to interpret a patient's complaints and to answer medical questions. Such programs, however, have not proven

to be very popular when sold as stand-alone systems for use on a personal computer. Access over the Internet may prove to be more attractive.

As in accessing medical literature, the user of an expert diagnostic system must be able to express a medical concept (symptom, sign, etc.) in medical terms that the system can understand. If this cannot be done, the expert system will not be able to give the user a valid response, such as an appropriate differential diagnosis, prognosis, or treatment suggestion. A key aspect of any form of medical education must deal with learning the language of medicine. A challenge for future research in Medical Informatics is to find ways to solve the language problem for all people seeking medical advice.

Lay people may now access on the internet genetic information regarding the mode of inheritance of more than 10,000 diseases using a program developed by Victor McKusick called "Online Mendelian Inheritance in Man"(OMIM) [2]. In addition, technology is also available to assess an individual's gene complement and quantify the risk of many diseases. For some people knowing what diseases may await them as a result of their gene complement may not be desirable until effective preventive or treatment options are available.

Patient Access to Medical Records

As a patient assumes more responsibility for her or his own care, the record that documents that care should be accessible to the patient. This implies that all the vital information needed for decision making be integrated to reflect events occurring in hospitals, physicians' offices, pharmacies, laboratories, other sites where care occurred and even phone and e-mail encounters. Just sharing one's medical records with another doctor, clinic or hospital is a real change for most physicians and often meets with resistance. Sharing the patient record with the patient will be an even bigger adjustment for most physicians and will require convincing them that the benefits to all parties justify the required effort and perceived risks. Here again, the usefulness of this record to the patient may be limited by his or her ability to understand medical concepts and the language for expressing them as well as mapping them onto larger diagnostic concepts that in turn relate to treatment and prognosis.

Computer-based Acquisition of Data Directly from the Patient

Experience at the LDS Hospital [3] clearly demonstrated that patients could respond to questions posed by a computer-administered history program of their present illness with answers to questions from which a computer program could make a correct diagnosis 65% of the time. However, some patients answered "yes" to too many questions and caused the expert system to suggest some unlikely diagnoses. Warner Slack [4] found that some patients preferred to confide in the computer because they perceived it as being "non-judgmental". Such involvement of the patient in the data acquisition process will be much easier with tomorrow's technology such as speech recognition and natural language understanding and may significantly expedite the exchange of information that is an essential part of the delivery of health care.

Access to Best Available Health Care

A physicians' phone and email directory is available on an intranet at the large Partners Healthcare System in the Boston area. It has already proved to be very helpful to physicians, nurses, and management, but is not yet available to patients. In the future, systems like this may also contain information on each physician in the form of data supplied by patients regarding their satisfaction with the physician's past services. Such a system would further empower the patient by allowing the patient to contribute to grading the physician's services after each visit [5]. Patient satisfaction certainly represents an important measure of the quality of health care.

Patient choice among treatment options is already facilitated using multimedia presentations for conditions such as breast and prostate cancer. Evolving high-speed communication using the Internet will make these methods of patient involvement in their own medical decisions even more attractive.

Management of Health Care Expenses

The evolution in the USA from fee-for-service to medical insurance and now managed care has overwhelmed the patient with paperwork and made it very difficult to know what to pay to whom and when to pay it. Expert systems that incorporate guidelines could not only advise both patient and physician about insurance coverage for services as they are ordered and the claims are submitted, but could also eliminate much after-the-fact communication and delays in resolving payment issues. The positive impact on convenience for all parties and potential for reduction of overhead cost in the health care system should motivate us to move in this direction.

The key to success of any new information system is in the motivation of the intended user. Often the user's response is hard to predict until the

system is built and actually put in operation. Just how far patients will choose to go in taking advantage of information systems to control their own health and understand what is happening to them may depend on how clever we are in building these tools and how wise we are in how and where we introduce them.

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Address of the author:
Homer R. Warner, MD, PhD
Professor Emeritus,
Department of Medical Informatics,
University of Utah,
Salt Lake City, Utah 84132, USA
e-mail: hrwarner@aol.com