

Virtual Mentor
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FROM THE EDITOR

Let There Be Light

Audiey Kao, MD, PhD

Recently, scientists were able to slow the speed that light travels to a near crawl. Using super cooled sodium atoms, Professor Lene Hau and her colleagues ultimately brought light to a momentary, but complete stop "It's nifty to look into the chamber and see a clump of ultracold atoms floating there. In this odd state, light takes on a more human dimension; you can almost touch it," Professor Hau reported in the Harvard University Gazette [1]. This extraordinary discovery shatters what was once considered one of the universe's great constants, the speed of light at 186,282 miles per second.

In our technology-driven society, such discoveries open the door to many practical applications. These include vastly more powerful computers and enhanced optical devices, as well as the possibility of more secure electronic communications that protect our medical, financial, and other personal information. At a more philosophical level, these enlightening experiments by Professor Hau fundamentally challenge our conception about the nature of our physical and biological reality, and force us to reexamine what we believe to be constant or inalienable in our everyday lives and society as a whole.

In the world of medicine, scientific advances and breakthroughs continually change how physicians learn and practice. But while the science of medicine is in constant flux, many believe that the art of medicine is based in large part on the fundamental nature of the patient-physician relationship. These fundamental features include the vulnerability that is created by illness and disease; and the information asymmetry between the lay and professional. Therefore, a physician's ethical and professional obligations are strongly shaped and dictated by the nature of the patient-physician relationship. But, what if these features of the patient-physician relationship are neither universal nor constant, how would this alter the physician's ethical identity and role when caring for the patient?

In this theme issue of the *Virtual Mentor*, we explore how advances in telemedicine, the Internet, and other emerging communication and computing technologies are challenging the fundamental conception of what constitutes a patient-physician relationship. To some, emerging technologies such as e-mail and the Internet provide patients with greater access to their physicians and empower them with readily retrievable health information. Few would argue that in rural and other underserved areas, a "virtual" relationship would be better than none at all.

But at the same time, others challenge the notion that an ideal therapeutic relationship can or should exist absent face-to-face contact, and are concerned that this physical distance between patients and physicians may accelerate a trend towards a more cognitive, less caring model of patient-physician interactions.

Beyond the implications of "virtual medicine" on the nature of the patient-physician relationship, these emerging technologies raise other issues such as the privacy and security of health information on electronic databases; a digital divide that further aggravates disparities in the health care system here and abroad; and new legal liability and economic reimbursement issues surrounding such activities. Thus, like the technologies of the past such as the telegraph, telephone, and television, new and emerging technologies in virtual medicine offer significant benefits, but also potential harms. Given our unprecedented reliance on technology today, our "love affair" with technological fixes must be balanced with the understanding that inherently human problems such as those in medicine cannot be remedied by technology.

With such rapidly changing technologies, the implications and consequences of "virtual medicine" are yet to be fully identified, let alone completely understood. We hope that this theme issue will shed some light on a technological evolution that will have revolutionary effects on how we learn and practice medicine. We expect that the ensuing online discussions will provide our readers with an opportunity to share their views and that together we can explore ways of addressing challenges when patients and their physicians interact and relate "online." As a little known philosopher once said, the path to enlightenment is, we hope, lined with lots of lamps - let there be light.

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Audiey Kao, MD, PhD is editor in chief of *Virtual Mentor*.

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CASE AND COMMENTARY

Responsibility of a "Virtual" Consultant

Commentary by Kayhan Parsi, JD, PhD and Audiey Kao, MD, PhD

Case

Peter, a six-year-old boy, was brought to the emergency room of a rural hospital complaining of severe pain in his right forearm. According to his mother, Peter was playing in the yard when he fell and landed hard on his right arm. Dr. Florence, who knows the family and has treated Peter occasionally in the past for bumps and bruises, performed an exam which revealed pain and mild swelling over his right forearm. No pain or loss in range of motion was noted in his elbow or wrist. An X-ray confirmed Dr. Florence's suspicion of a closed simple fracture of the right radius.

During the course of the physical exam, Dr. Florence also found areas of bruising on Peter's back and legs. In addition, the X-ray revealed evidence of a previous fracture in his right arm. Despite claims by Peter's mother that he is "accident prone," Dr. Florence suspected abuse, and considering the seriousness of asserting such a cause of injury, wanted to consult a pediatrician who specialized in child abuse cases. Since this community hospital was in a fairly remote area, video conferencing equipment had recently been installed to facilitate consultation between local physicians and specialists not available in this rural community.

Dr. Florence informed Peter's mother that he wanted her son to be seen by another physician through the means of the video equipment. Dr. Rhodes, a pediatric psychiatrist, was consulted because, if child abuse is suspected, immediate action including temporary state custody of the child may be required. As part of the virtual evaluation, Dr. Rhodes spoke with Peter and reviewed his X-rays. Given the limitations of the videoconferencing equipment, a physical exam including examination of the bruises could not be completed. Despite these technological limitations, Dr. Rhodes supported the initial concern about child abuse and recommended to Dr. Florence that Peter be taken into temporary state custody.

Questions for Discussion

1. Given the potential implications of suspected child abuse to the parents, should Dr. Florence, in making his decision, give Dr. Rhodes' recommendations the same weight as he would give a formal consultation?
2. If Dr. Rhodes' recommendation is considered to be more of a "curbside" than a formal consultation, what features would be required as technology advances for a "virtual" evaluation to be considered a "regular" consultation?

Kayhan Parsi, JD, PhD is a fellow in the AMA Ethics Standards Group
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The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.

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IN THE LITERATURE

Electronic Medical Records and the Internet

Keith Bauer, PhD, MSW

Mandl KD, Szlovits P, Kohane IS. Public standards and patients' control: how to keep electronic medical records accessible but private. *BMJ*. 2001;322(7281):283-287.

Throughout business, government, and academia, information management systems are converging rapidly with emerging communication technologies, resulting in unprecedented access to data and information, almost anywhere, and at any time. In medicine, personal medical records once kept in filing cabinets are now stored in computerized databases and transmitted to distant sites via the Internet and other technological means. More importantly, the "technical infrastructure" underlying the digital storage and transmittal system makes it possible to bring together disparate pieces of an individual's medical record that is tracked and identified by the equivalent of a medical social security number.

In this month's journal article, "[Public Standards and Patients' Control: How to Keep Electronic Medical Records Accessible but Private](#)," the authors argue that, beyond simply improving data accessibility and standardization, electronic medical records provide patients with greater control over their personal health information. For example, patients may be better able to access and correct inaccuracies in their medical records. However, with greater access to medical information, the privacy and confidentiality of patient health information is at potential risk. Therefore, the authors propose two doctrines to guide the development of electronic medical records in the Internet era. The first doctrine is that a public standard should be developed to regulate the storage and exchange of data, and groups including the AMA are striving to establish such policies; and the second is that patients should have control over who has access to their medical record information.

Questions for Discussion

1. Do you think the potential benefits of improved information flow and access to patient medical records outweighs the potential harms to patient informational privacy and confidentiality?
2. Should patients be able to alter their online medical records? Should they be able to note disagreements with what appears on the record? Should they have "read only" access?
3. Would patient access to their electronic medical record have either a positive or negative influence on the patient-physician relationship?

Keith Bauer, PhD, MSW is a fellow in the AMA Ethics Standards Group.

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AMA CODE SAYS

Medical Student Involvement in Patient Care: Report of the Council on Ethical and Judicial Affairs

AMA Council on Ethical and Judicial Affairs

Ask the Virtual Ethicist

Much to the benefit of patients and medical education, medical students are participating in patient care from the start of their medical education. Initially, students may be mere observers, but soon they assume more responsibilities, such as monitoring the condition of patients and even becoming involved directly in treatment. Patients and the public benefit from the integrated care that is provided by health care teams that include medical students and other trainees. Students' limited experience is counter-balanced by the supervisory structure of medical teams and patient care generally is enhanced by the involvement of medical students. Even so, some patients may prefer that students not be involved in their care. Others patients will value the opportunity to participate in the training of students in the context of receiving care in a teaching institution. This report elaborates on informing patients of medical students' training status and on ensuring patients' willingness to participate in student training.

Current practices in academic medical centers

In 1973, the Department of Health, Education and Welfare (DHEW) convened a Secretary's Commission on Medical Malpractice, which recommended that: "...the patient who is about to enter [a teaching hospital] should be told fully what to expect." Upon admission he should be given a statement explaining the educational aims and activities of the institution and told how students, interns, and residents will participate in his [or her] care." In support of the recommendation, the Joint Commission on Accreditation of Hospitals (now the JCAHO) promulgated the following guideline: "The patient has the right to know the identity and professional status of individuals providing service to him...this includes the patient's right to know of the existence of any professional relationship...to any...educational institutions involved in his care. Participation by patients in clinical training programs should be voluntary." Together, these statements make clear that it is inappropriate to assume that a patient is implicitly willing to participate in the training of medical students or other health professionals merely by being admitted to an academic medical center.

In the mid-1980s, investigators surveyed both medical schools and major teaching hospitals to determine whether policies had been implemented to comply with these guidelines. They found that a majority of hospitals did not specifically inform

patients of medical student involvement. A large proportion of medical schools' deans responded that their students received either verbal or written instructions on how they should introduce themselves. However, these instructions varied from students being required to introduce themselves explicitly as a "student," to encouraging students simply to clarify their status, to a small proportion that advised students to introduce themselves as "doctors."

The same researchers conducted a similar survey among third-year medical students to identify how they introduced themselves and obtained consent to treat patients. Results showed that a majority of students introduced themselves as medical students, without providing further clarification. A small proportion of students went further by stating that they were not yet physicians. In contrast, a similar proportion introduced themselves as "doctor." Finally, a considerable proportion of students alternated between these methods rather than using one method consistently.

In addition, the medical students were asked how they obtained specific consent to perform various procedures that were categorized in terms of their degree of invasiveness. These results showed that students were in fact reluctant to obtain consent for invasive interventions such as lumbar puncture or bone marrow aspiration. However, those students who were most forthright in introducing themselves and clarifying their status were more likely to obtain specific consent regardless of the level of invasiveness of the procedure. Some of the reasons students offered for not obtaining consent included that they considered themselves to be part of the medical team, that they did not want to be rejected by patients, or that they were concerned about the evaluation of their performance by house staff.

In a more recent study, results showed that although only a small proportion of medical students introduced themselves as "doctor," all had experienced being introduced by other members of the health care team as "doctor" and only 42% had corrected the information with patients. The authors explained that the deception may be due to the students' concerns that their clinical training would be compromised if the patient refused their care, but also because students were led to believe the practice was acceptable since staff responsible for their training perpetuated it.

Overall, these studies suggest that information that could be relevant to the patient receiving care from medical students often may be omitted. Some may be concerned that such disclosure may limit the opportunities students have to hone their clinical skills. This implies that the mission of the teaching hospital may be focused primarily on medical training, relegating other considerations such as respect for patient autonomy to a lesser role. Other explanations that have been put forward to explain this ethical lapse include: 1) the lack of coordination and the diffusion of responsibility between medical schools and teaching hospitals in implementing policies requiring students to obtain consent from patients to participate in their care; 2) relying on "blanket" consent to cover procedures performed by the medical team,

including students; and 3) medical educators' own reluctance to obtain informed consent in difficult circumstances, which sets a poor model for students.

Ethical considerations in the patient-medical student relationship The first encounters between medical students and patients are important moments in the progression of the students' ethical education. They should serve to integrate the theoretical foundation of medical ethics learned during pre-clinical education into the clinical setting and to promote the development of interpersonal skills, which students will rely upon throughout their career as physicians. In essence, medical students engage in a simple form of truth-telling that constitutes a first step in establishing trust when they introduce themselves as students and verify that patients agree to student participation in their care.

Clearly students will benefit from the experience they gain by practicing skills on patients. In return, it is believed that patients in academic medical centers also benefit from focused attention. The medical students' involvement provides patients an additional opportunity both to discuss problems and to receive information. For example, students have much more time to spend with patients when taking a medical history. However, some patients may feel uneasy about student involvement, a choice that ought to be respected. , Some patients may feel hesitant to state this reluctance to the medical student or another physician, particularly if they worry that such a refusal would adversely affect the care they receive. As a result, students and physicians should be especially sensitive to patient preferences in this area.

In one study, patient willingness to be involved in student training was measured by comparing one group of patients who were provided information about the program by non-physician patient-advocate-interviewers (PAIs) to another group informed by residents. Patients in both groups were told about the students' training level, the scope of the intervention to be performed by the students, the opportunity for patients to refuse to participate, and an expression of appreciation for the patient's cooperation. Overall, the patients informed by PAIs were more likely to understand that they were among the first patients to be seen by the students, to feel comfortable about being seen by students, and to appreciate the importance of their own role in medical education.

However, non-physician patient-advocates are uncommon and the task of informing patients about the role of medical students often is fulfilled by regular members of the medical team, or perhaps students themselves. As in many aspects of medical education, teachers and supervisors should lead by their example and, therefore, should be mindful of correctly introducing students to patients. Also, it is important to reassure patients that the quality of care they receive is independent of their willingness to participate in training. Ultimately, in an environment where patients are informed of the role of medical students, and where reassurances are given that student involvement is supervised, patients may find satisfaction by participating in training of medical students, similar to the satisfaction gained through participation in research.

In cases of emergency care, when the requirement for consent is waived and decisions are based on the patient's best interests, the participation of medical students should be evaluated judiciously. In situations where the patient will be temporarily incapacitated (e.g., anesthetized) and where student involvement is anticipated, involvement should be discussed prior to undertaking the procedure whenever possible. Similarly, in instances where a patient may not have the capacity to make decisions, consent should be obtained from the surrogate decision-maker involved in the care of the patient. Finally, state courts have censured physicians who have deceived patients in terms of their level of expertise, and liability has been imposed on undisclosed substitutions of surgeons.

Conclusion

This report focuses on the balance between the educational needs of medical students and benefits to society of medical training, and the obligation to protect the integrity of patients, to obtain patients' consent (oral or written) to student involvement in their care, and to refrain from using terms that may be confusing when describing the training status of the students. The report considers that medical students greatly benefit from clinical training and that their involvement can enhance patient care when undertaken with proper supervision. The important role that patients play in medical training is reflected in section 9 of amended Opinion 10.02, "Patient Responsibilities." However, the benefits of medical education should not undermine the obligation all medical providers share to respect patients and their right to understand and determine the manner in which they receive care. It follows that all health care professionals should identify themselves, their training status, and the purpose of their involvement. This obligation requires that medical students not deceive patients as to their qualifications.

Recommendations

The Council recommends that the following be adopted and the remainder of the report be filed:

1. Patients and the public benefit from the integrated care that is provided by health care teams that include medical students. Patients should be informed of the identity and training status of individuals involved in their care and all health care professionals share the responsibility for properly identifying themselves. Students and their supervisors should refrain from using terms that may be confusing when describing the training status of students.
2. Patients are free to choose from whom they receive treatment. When medical students are involved in the care of patients, health care professionals should relate the benefits of medical student participation to patients and should ensure that they are willing to permit such participation. Generally, attending physicians are best suited to fulfill this responsibility.
3. In instances where the patient will be temporarily incapacitated (e.g., anesthetized) and where student involvement is anticipated, involvement should be discussed before the procedure is undertaken whenever possible. Similarly, in instances where a patient may not have the capacity to make

decisions, student involvement should be discussed with the surrogate decision-maker involved in the care of the patient whenever possible.

AMA Council on Ethical and Judicial Affairs is comprised of seven physicians, one resident physician, and one medical student. This report's consensus recommendation were adopted by the AMA House of Delegates.

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STATE OF THE ART AND SCIENCE

Toward Striking a Balance in Bioinformatics

Kenneth Goodman, PhD

One could make a very strong argument that information technology and genetics are the sciences that will have the greatest effect on 21st century healthcare. Although it is already clear that informatics is profoundly reshaping the health professions, we are only beginning to come to terms with the extraordinary risks and potential benefits of progress in the human genome sciences.

We need to determine what to make of the intersection of health informatics and genomics. Add in ethical and social issues, and we confront one of the greatest intellectual and practical challenges in the history of science.

Bioinformatics--the use of information technology to acquire, store, manage, share, analyze, represent, and transmit genetic data--has blossomed in the past several years. The term is most often used by scientists who sequence and otherwise analyze the genomes of humans and other species with computer technology. If we like, we can stipulate that bioinformatics also includes applications as pedestrian as using a personal computer to store the results of genetic tests ("Patient X has the BRCA1 gene"), as well as using intelligent machines to link physiological traits with a database in order to diagnose genetic maladies, predict clinical correlations, conduct research, and so forth.

Although bioinformatics raises many issues for human subjects research, we will confine ourselves here to more clinical concerns and group them under the label "clinical bioinformatics." (It is well to note, though, that once human genetic information is stored on a computer, it is much easier to study; in some cases the distinction between clinical and research issues will narrow dramatically.) Let us organize the ethical and social issues raised by clinical bioinformatics into the following categories: (1) accuracy and error, (2) appropriate uses and users of digitized genetic information, and (3) privacy and confidentiality.

Accuracy and Error

Health informatics has taught us that accuracy and error avoidance raise ethical issues that are often related to evolving standards of care. If there are emerging or established standards for database management, for instance, then a system that relies on a database will be more or less useful, reliable, and safe, depending upon whether or not the database is appropriately maintained, tested, augmented, and so on. The reason to link error and ethics is that errors, however unintentional, can

produce harm. Determining whether a harm constitutes a wrong is one of the main challenges of ethics. Our specific challenge here is to nurture the growth of an exciting new science while simultaneously ensuring that patients are not harmed or wronged.

Several current and future issues related to the accuracy of bioinformatics systems follow:

Risks to persons. To the extent that we can expect more and more frequent computer-aided discoveries of the genetic loci of human diseases, errors can pose or increase risks to public health and even the wellbeing of individuals. Patients may also be at risk when computers are used to predict the expression of future genetic maladies. The risks may be psychological and will likely vary depending on whether there is a treatment or cure for a given malady. The role of genetic counselors will loom large here.

Recanted linkage studies. Preliminary or unreplicated linkage studies are sometimes recanted or re-evaluated. Erroneous linkage analyses can throw colleagues off the track and, perhaps more importantly, cause unnecessary psychological trauma for individuals who fear they may be affected. In the case of purported linkages that correlate with race or ethnicity, there is the added risk of producing social stigma—perhaps especially in the case of neurogenetics and psychiatric genetics.

Meta-analysis. It is exciting to observe the emergence of meta-analysis in genomics. In this research technique, the results of previous studies are aggregated and reanalyzed by statistical software with the aim of achieving statistical significance or adequate sample sizes. This technique raises ethical issues by virtue, in part, of doubts about the quality of included data and the validity of inferences based on diversity of data. These doubts are important when meta-analytic results are applied to patient care.

Decision support. Even though diagnostic and decision support systems are well known to raise ethical issues in clinical medicine, there is as yet no critical analysis of decision support for genetic diagnoses in which, for example, clinical information, photographic material, pedigree, and gene localization data are analyzed by computers. The growth of genomic data bases and the increasing availability of genetic information at the clinical level suggest that decision support systems are a ripe source for ethical and social inquiry.

Appropriate Uses and Users

Questions concerning who should use clinical information systems and in what contexts have been shown to raise interesting and important ethical issues; we should expect that genetic data processing will elicit related concerns and pose new problems.

For instance, suppose a physician or nurse begins including genetic data in patient charts, uses those data to predict the likelihood of clinical manifestations and correlations, and employs those analyses to refer patients to genetic counselors. The first question is basic: Was this novel use undertaken with the patient's consent? Because genetic information can frighten or alarm patients in ways that other health and medical data do not, we need to ask whether the patients knew that genetic data was being gathered and stored for clinical purposes. In the absence of a treatment or cure for a particular genetic malady, it is not unreasonable for a patient to prefer not to know a genetic diagnosis or prognosis. Consent seems to be a crucial gate through which the physician or nurse must pass before using these data "for the patient's sake." The weight of valid or informed consent seems greater here - that is, in the area of genetics - than for more familiar kinds of clinical decision support.

To raise another concern, suppose that individuals' genetic data were being collected by governments, managed care organizations, or other third-party payers with the goal of shaping or adjusting risk pools or coverage eligibility. The difference between evidence-based actuarial calculations and discrimination can be very slight, indeed. To the extent that computers are used for these tasks, it will be essential for individuals, institutions, and society to decide on ethically optimized strategies for clinical bioinformatics applications.

Now we must ask who should use a genetic diagnostic or prognostic system. For example, does the possibility that determining health benefits raises a problem imply that bioinformatics tools should never be used by certain entities?

Consider that individual physicians, nurses, genetic counselors, or psychologists might use computer systems not only to improve patient care but also for less worthy purposes. Does it follow that certain users - in addition to uses - might be problematic?

One way to approach the question is to ask whether the user is employing a computer in a task not normally within his or her competence. In other words, if you are unable or untrained to perform certain tasks without a computer, then it is inappropriate to suppose that the computer can somehow imbue you with those skills. For instance, if a physician or nurse does not normally render genetic diagnoses, it is unwise to suppose that she or he acquires competence via the machine.

In fact, it is more than unwise - it is a patent mistake. Computers can improve our skills at many tasks but rarely, if ever, give us new professional skills or abilities. Therefore, an appropriate use of a genetic decision support system, for instance, will be to assist adequately trained professionals, not to replace them or to bring them "up to speed" in domains in which they lack basic skills.

This point must be clearly understood: Computers can be outstanding educational tools in bioinformatics as elsewhere, but there is a difference between acquiring a

skill and presuming its existence. We have learned from "ordinary" clinical computing that humans practice medicine and nursing but computers do not. This is a lesson well worth applying to bioinformatics.

Privacy and Confidentiality

The electronic storage of genetic information replicates a tension already familiar in health informatics: the tension between (1) the need for appropriate or authorized access to personal information, and (2) the need to prevent inappropriate or unauthorized access. Striking a balance between these two imperatives is an exciting but sometimes vexing challenge.

Privacy and confidentiality are potentially threatened when individual genetic data are maintained or transmitted using computers. The threats include bias and discrimination, personal stigma (as opposed to population or subgroup stigma), psychological stress, and tensions within families, among other risks. The difficulties posed by expectations of privacy and confidentiality are well explored in regard to the electronic patient record, but we do not yet know whether the inclusion of genetic data adds to or alters those difficulties.

Specifically, our objective is to determine if and in what way bioinformatics raises ethical issues that are distinct from ethics and genetics and, depending on what is found, either to adapt existing conceptual and pedagogic tools or provide new ones.

The key means by which we plan to meet these objectives are the successful development of ethically optimized guidelines (for organizations that maintain data bases, for IRBs, etc.) and model curricula in ethics and bioinformatics (for students and professionals).

Striking a Balance

The need for organizational policies, best-practice standards, and/or guidelines is widespread in the human sciences. Because the thrust of the proposed research is at the intersection of three vast areas of inquiry and practice - genetics, computing, and ethics - the challenge we face is extraordinary: Guidelines and standards often fail because they are either so broad or simplistic that they cannot adequately guide behavior, or are so specific or detailed that they are too inflexible to be useful in diverse and unexpected cases. There is therefore a need to strike a balance between these two shortcomings. Striking that balance would provide a very useful tool for organizations.

As to educational materials, it is worth observing that research ethics curricula usually overlook issues in bioinformatics. If we are correct in anticipating that the future of genetic research will be inextricably linked to information-processing technologies, then this oversight is, or will be, quite serious. Indeed, we may well conclude from our inquiry that there are larger nets to cast and that we should extend our emphasis on genetics to include all biology and medicine and the changes mediated by information technology.

Case 1: Genetic Information in Centralized Databases

Individual genetic information is increasingly stored in public, private and governmental health databases. The databases are or could be used for clinical practice, epidemiologic research, pharmaceutical investigations and other purposes. The World Medical Association (WMA) is drafting guidelines for the use of genetic information in such databases.

According to WMA Chair Anders Milton, "The public is rightly concerned about whether their right to privacy and confidentiality is threatened by these databases and whether information about them as individuals could be misused. Centralized health databases can make a tremendous contribution to the improvement of health. But the public's right to privacy and consent are essential to the trust and integrity of the patient/physician relationship and we must ensure that these rights are properly protected. Any guidelines must address the issues of privacy, consent, individual access and accountability."

Questions for Discussion:

1. Genetic information has been included for years' without clear regulation or rule - in electronic databases. If there were guidelines, should they apply to information collected retrospectively, prospectively, or both? Might it ever be too late for guidelines?
2. To what extent can informed or valid consent requirements be loosened if genetic information is anonymous or not linked to identifiable persons? How should the problem of racial or ethnic stigma be addressed in any guidelines?
3. Does - or how does - the purpose of a database have ethical consequences for its use? That is, does it matter if a database is (i) owned by a for-profit corporation, (ii) public health organization, (iii) government, etc.?

Case 2: Web-mediated Paternity Testing

Paternity testing has always raised difficult questions. Now, though, Web sites <http://www.dnanow.com/>, <http://www.genetestlab.com/>, and <http://dnatesting.com/> offer a chance to test a child's paternity - without the consent or knowledge of a woman or her child, a man or his (putative) child - or, indeed, a child, perhaps as adult, with a hair sample from whom what one site terms the "alleged father."

The companies offer genetic analysis of hair or buccal mucosa samples to determine paternity. A man might therefore complete an on-line form, submit a sample of his and a child's hair and, in a few days, learn via e-mail if he is the father. A woman unsure of which of several potential candidates is the father of her child might obtain a hair sample or samples and submit them along with her child's. If anyone has questions about the process, one firm offers the following: "For instant answers or advice, chat to a DNA expert online!"

A British Department of Health spokesperson was quoted in one report as saying of one vendor, "There is nothing illegal about the Web site. We are aware of concerns raised by advances in DNA testing and we are in the process of drawing up a voluntary code of practice on the way companies work."

Questions for Discussion:

1. The standard of care in genetic counseling generally requires pre- and post-test counseling for individuals and couples. Paternity is among the issues raised during such sessions, and couples or individuals are often warned that they might acquire information that could significantly alter or damage relationships. Web-based paternity testing diminishes or eliminates counseling and/or such disclosure, or provides these services via e-mail. Should Web-based testing be required to hew to standards elsewhere in genetic testing? How so, given that firms providing these services operate across international boundaries?
2. What kinds of caveats or disclaimers are appropriate for such Web-based services?
3. In the absence of laws that might regulate such Web-based testing, could voluntary policies or guidelines have an adequate effect?

Case 3: Errors in Genetic Databases

A molecular pathologist in California thought he had finally identified a gene he had been working on. He submitted it to GenBank, the public database that contains every published DNA sequence. GenBank can identify similar genes and so is useful in trying to infer a new gene's function. But the data base turned up more than 100 matches - a sign that something had gone terribly wrong. Indeed, each of those matches had in common a sequence that had been introduced by the commercial kit he had used to clone his gene.

The pathologist says he found the error "entirely by accident" and that "there's a huge number of public sequences that are incorrect."

Questions for Discussion:

1. We know well that databases are dependent on those who build and maintain them, and that database design, construction and maintenance raise ethical issues. What special issues are raised when databases store biological or health information?
2. Who should be responsible for errors in very large and/or complex databases? What is to be done when errors are perpetuated? An error might be caught or missed, have no effect or have a tragic effect - independently of the action that introduced the error. Does the consequence of the error have moral significance?
3. Is database size or complexity an adequate excuse for errors?

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HISTORY OF MEDICINE

Being There

Karen Geraghty

The following warning was issued through the *Lancet* regarding the use of telemedicine technology in the diagnosis and treatment of patients:

"The phrase 'medical advice' ... should imply that the recipient has been seen and examined ... so as to leave no reasonable doubt as to his illness ... and appropriate mode of treatment. In order to arrive at this degree of security ... it is commonly necessary and always advisable that a practitioner should be at the time in attendance on his patient Practice conducted [without direct contact with the patient] is no better than a name ... its systematic exercise even in trifles is at best the harmless shadow of a dangerous custom, and does not accord the true ideal of professional duty" [1].

The year is 1887. The technology that threatens the professional ideal of medical practice is the rudimentary telegraph.

By the end of the nineteenth century, communication technologies were opening new possibilities for the care and treatment of patients, as well as for more effective management of expanding medical practices. In 1876, a patent was issued to Alexander Graham Bell for the invention of the telephone and within months, physicians adopted the new invention as a means for treating patients over long distances. Public and professional opinion on the use of the device, however, was mixed. Although the physician was now more readily available to patients, the telephone encounter denied the physical contact so integral to the traditional model of the patient-physician relationship.

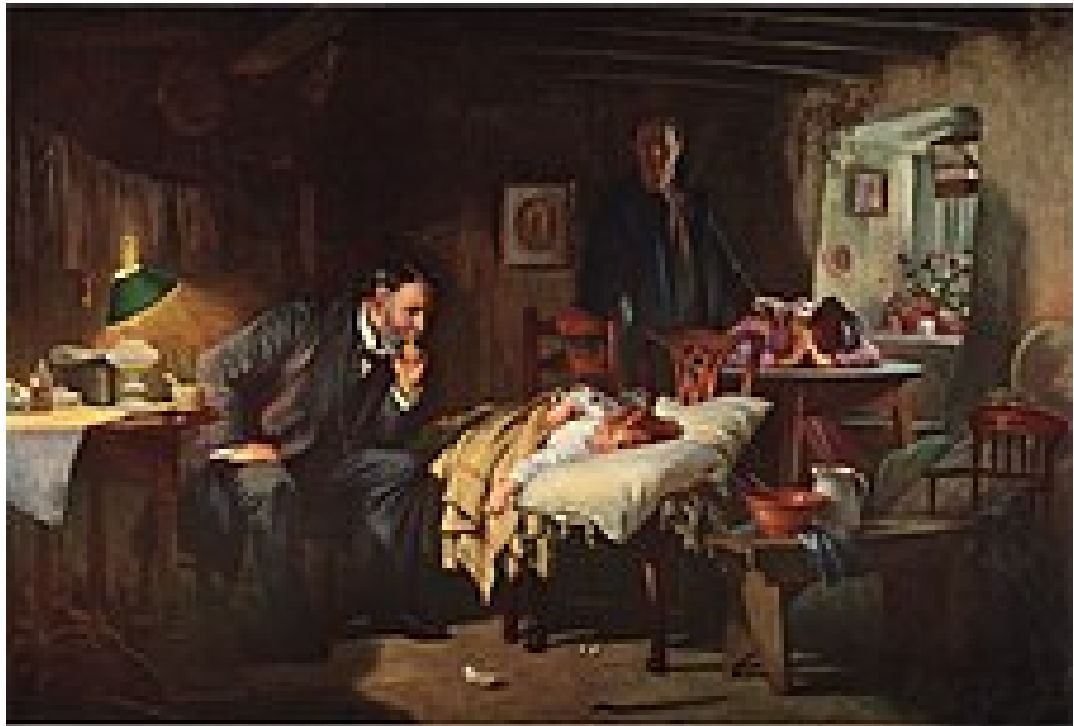
Several medical journals enthusiastically reported the experience of a physician in Cincinnati, who was awakened:

"during the night by a summons through his telephone to go at once to the house of the caller, who stated that his child had croup and was coughing violently. As the house was several distant miles, and the doctor very tired, he requested the father to hold his child for a few moments before his telephone. This was done, and the practised ear of the physician at once convinced him that there was no fear of true croup. After informing the father of this, and giving the necessary directions regarding the management of the patient, the doctor again retired. When he saw the

infant the next morning, all symptoms of *laryngismus stridulus* had disappeared, and the child was apparently quite well" [2].

JAMA however, reported a similar story that provoked a different reaction from a worried parent:

"A St. Paul doctor ... was requested over the wire to visit a sick child two miles away the other night, and not wanting to go, prescribed over the 'phone and went back to bed. On making the call the next day he found the patient doing very well under the care of another doctor, and went back with a change of mind regarding the usefulness of Professor Bell's invention" [3].



Sir Luke Fildes. *The Doctor* (1891)
Image courtesy of the *National Library of Medicine*

The professional ideal of medical practice, unarticulated but challenged by these two stories, can be illustrated by Sir Luke Fildes' famous portrait *The Doctor*. Although painted in the waning years of the nineteenth century, well before the technological innovations of the twentieth century made the house call obsolete, there is already something wistful captured in the portrait—something intangible that—while not yet lost—themselves to slip imperceptibly away.

The child lies desperately ill while the parents huddle in the background, fearful, helpless and grief-stricken. There is nothing more the physician can do medically to save the child. Why, then, is he still there? He can only keep vigil—watching as the girl's delicate breath grows ever more shallow.

Now picture a different scene—one with the physician's chair empty, and the two distraught parents clutching a telephone receiver.

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ART OF MEDICINE

Back to the Future

Audiey Kao, MD, PhD

On April 1924, when *Radio News* published a cover story titled, "Radio Doctor - Maybe," it offered readers one of the first glimpses into what medicine and the patient-physician relationship might (or should) look like in the future. Like most predictions, this glimpse into the future of "telemedicine," while fairly successful in foreshadowing new technologies in medicine, was predictably more myopic in understanding its full impact on patients, their families, and their physicians.

The image on the *Radio News* cover depicts a young boy sitting on the edge of his bed, with his tongue sticking out, as he stares into the monitor of a sophisticated device: a radio equipped with interactive video transmission and several medical instruments. At the other end of the connection, as represented in the monitor, a physician peers into the patient's throat, while simultaneously listening to his heartbeat through a stethoscope applied to the boy's chest.

On a scientific level, the *Radio News* cover is quite remarkable, considering it appeared before most of the technologies it represents became available. The multimedia platform depicted in the image was probably identified as a "radio" because that was the only communication device with a name and function that would ring familiar to a general readership of that era. In fact, the device was more like a television than a radio. In 1924, the television, as we know it, would not be tested for another 3 years, and videoconferencing, which is now increasingly used in patient-to-physician and physician-to-physician telecommunication had not even been invented. The stethoscope depicted in the image foreshadowed the variety of diagnostic, monitoring, and other medical instruments that are routinely employed today in telemedicine.

On a social-psychological level, the predictive accuracy of the *Radio News* cover was invariably limited by the norms and expectations of that era. For example, the doctor in the image is a white man because the medical profession had few women and even fewer minority practitioners at the time. Accentuated by the artist's use of warm colors, the image also attempted to capture the humanizing aspects of "house calls" which were still common place in the practice of medicine at that time - a doctor visiting a young patient dressed in his comfortable clothes surrounded by loved ones in a familiar environment.

While the benefits of house calls have undoubtedly been romanticized by both the lay and professional communities of today, this image reminds us that technology is neither good or evil; its impact often depends on how it is applied by individuals, communities, and society. In the case of telemedicine technologies, the electronic house call portrayed in the illustration does hold the promise of providing good medical care, especially to those who are less mobile, live in remote communities, or are simply too ill at the close of life. However, these technologies remain at this moment still an approximation of a face-to-face interaction between patient and physician, and while this proximate clinical encounter may take place in real time, it is still less than real and robust.

In the "Back to the Future" movie series, Marty McFly and Doc Brown traveled back and forward in time to right the wrongs of their actions and choices and those of others. Fortunately or not, none of us has a time-travelling DeLorean. Thus, when we contemplate medicine's future - a time when physicians care for their patients through electronic media - it is critical that we choose to employ technologies that promote not only the science of medicine, but, more importantly, the human and caring qualities of medicine embodied by the house call.

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PERSONAL NARRATIVE

"Sorry Daktari, the Phones Are Not Working Today, Maybe Tomorrow"

Robert Davidson, MD, MPH

I came to Africa believing that telemedicine technology was going to be a big part of the future of medicine. It seemed like the perfect way to link developing countries with modern medical centers around the world for consultation. I was optimistic that the technology would reduce the need for medical evacuations to countries like South Africa or the United States for sub-specialty consultations not available in country. The reality, however, is quite different. With the exception of the Internet, on which I will comment later, virtual medicine and telemedicine have had limited impact in Eastern Africa.

Hardware Alone Doesn't Do It

When I was asked to contribute to this month's theme topic, I tried to do my homework. I reviewed the two major referral hospitals in Nairobi, a regional medical hub, to find out what kinds of telemedicine technology were being used. The large private hospital is using essentially nothing. The administrator says he gets at least one salesman a week trying to sell him technology, but the unavailability of the bandwidths necessary for transmitting data makes it impractical. The other major hospital has developed more applications. It is part of the Aga Kahn Hospital System with support from the Aga Kahn Foundation and ties to the Aga Kahn Hospital in Saudi Arabia, a major teaching and research institution. The Nairobi affiliate has several direct communication linkages including an MRI scan machine in Nairobi that sends the images to Saudi Arabia for interpretation. The Chief of Radiology was very proud to show me the equipment. When I asked him how often he used the linkage, he chuckled and said he doesn't. The data from the MRI is so massive that it takes hours to transmit via telephone. We both knew how impractical this was as the ability to keep a good long-distance connection from Kenya for longer than ten to fifteen minutes is rare. Another great idea but impractical with the current communications infrastructure.

I then talked with the medical unit at the U.S. Embassy in Nairobi. The regional physician also chuckled and said they have a great set up with lots of "neat toys" like derm scopes and naso-pharyngeal scopes and a big two-way audio-visual broadcast unit. However, they cannot use them because the telephone system capability renders them useless. So, the reality is that the technology developed in modern countries is fascinating, but useless without a communications infrastructure to support it. I have time this morning to write this segment because the telephones in this section of Nairobi have been out for three days. "Sorry

Daktari, the phones are not working today. Maybe tomorrow." This stops any e-mail connection with the medical units of the other countries I support. We have no Internet access without telephones. I can try the cellular phone network but have no confidence it will work. In fairness to other countries in Africa, Kenya seems to have a particularly poor communications system. For instance, in South Africa, the telephone system as well as several cellular networks blanket the country and serve it well. However, South Africa is not an underdeveloped country. It is the classic problem of the haves and have-nots. The South African medical care system is excellent and really does not need telemedicine linkages for consultations but the country has the infrastructure to support it.

The Mixed Blessing of Internet Access

The Internet, however, has had a much more dynamic impact in Eastern Africa. At least when the phones work, I am able to access a tremendous data base of information. The need for reference textbooks is virtually no longer existent. I can get the information including patient information handouts faster from the Internet than paging through outdated reference books. This access is also available to the volunteers, which is a mixed blessing. They often use the information access to self-diagnose or at least gather a lot of information. A typical encounter with a volunteer might start with, "Hi Doc. I want to talk to you about X disease." I have learned to start with asking what they already know because often they have several printed information sheets from the Internet and are here to "check out" what I know. Usually this works well and the information is helpful to the volunteer. However, there are some hidden problems with this unlimited access to medical information. For example, medications are readily available from the local chemist without prescription. We have had problems with volunteers self diagnosing, often incorrectly, and starting on an inappropriate or dangerous medication.

Another problem is inaccurate and biased information on the Internet. I recently had an excellent example of this. The Peace Corps follows the World Health Organization recommendations for malaria prophylaxis and uses mefloquine [Larium]. This is a somewhat controversial drug with side effects. I do not want to get into the debate on mefloquine in this article. Maybe we can do a future segment on controversies in medicine. However, recently a volunteer came in with information from the Internet to prove to me that mefloquine was dangerous and the Peace Corps should not use it. I read over his data and found it very different from the known published studies on the side effects of mefloquine. I challenged him on the source of his data and he supplied the Internet address. We logged on together and I was shocked. The Web site was a litigation law firm in the United States which was using the Internet to solicit sign-ups for a class action suit against the makers of Larium. It was a frightening Web site with inaccurate information and lists of anecdotal horror stories about mefloquine. I asked him if he trusted this information, and, after discussing it for awhile, he agreed that it was biased and unreliable. I gave him the data from the few good controlled studies on mefloquine and asked him to review them and then come back to talk with me. He has not

returned. I just hope he trusts me enough to continue taking his prophylaxis, as I sure do not want to treat him for malaria.

Access to the Internet is expanding throughout Eastern Africa. Cyber cafes have become quite common and are coming down in price. In Nairobi, a typical charge would be 100 shillings or about \$1.25 for the first five minutes and 20 shillings a minute thereafter. Even many rural villages are gaining access to the Internet. The United States and other countries are supporting Internet access in the schools. The Peace Corps volunteers have been in great demand to teach information technology and they report how great it is to see young students really turned on by what the Internet offers. My wife and I keep in touch with family and friends in the States almost entirely by e-mail, and a colleague here at Peace Corps is using the Internet to work on a Masters in Nursing from an American nursing school and finds it excellent. The Internet certainly reduces the feeling of isolation so common in third world countries.

So, the Internet has and will continue to have a tremendous impact in Eastern Africa. Much of this is very positive for the country and its people. But not all. The use of telemedicine technology, however, is more of a dream than a reality until the communication infrastructure catches up. Hopefully, the telephones here start working again in time for me to submit this segment of my journal of experiences in Eastern Africa. Happy surfing.

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PERSONAL NARRATIVE

Telemedicine: Assisted Self-Treatment at the South Pole

Sara Taub, MA and Kayhan Parsi, JD, PhD

It has been said that the death of one person is a tragedy whereas the death of a million is a statistic. Putting a single human face on suffering inevitably makes it more real and compelling. For instance, the Baby Jessica story in 1987 had an entire nation and world glued to television sets to watch the rescue of the little girl in the West Texas well. More recently, the story of Dr. Jerri Nielsen, the South Pole physician who treated her own breast cancer with the assistance of telemedicine technologies, created enormous media interest. Yet the AIDS epidemic which has killed untold numbers of Africans and affects an estimated 1 in 20 in large portions of sub-Saharan Africa, has only recently stirred much media interest here in the US, generating, at long last, a recent *Time* cover story.

Dr. Nielsen's story contains all the elements of a compelling drama: a sacrificing physician in the remote environs of the South Pole, supportive and caring colleagues, technology that enabled health care professionals in the US to treat the doctor's breast cancer, and a daring rescue by US Air Force pilots who whisked Dr. Nielsen away from the bitter cold of the Pole to treatment in the US.

Even before her experience with cancer, Dr. Nielsen's story was dramatic. Leaving behind the remains of a bitter divorce and estranged from her children, Dr. Nielsen fled to the South Pole to confront new challenges. After reading an ad by the National Science Foundation for a physician To join a research team at the South Pole, "I felt a prickling sensation up and down my skin," she recalls in her new book *Ice Bound: A Doctor's Incredible Battle for Survival at the South Pole*, "like the kind of physical excitement a child feels at the sight of a bicycle under the Christmas tree . . . I believe in geographic cures - they allow you to throw all your cards in the air and see where they land . . . then pick them back up and deal them again." Facing grim weather, lack of sunlight, and primitive surroundings, Dr. Nielsen served as the resident physician for the other "polies" with whom she worked. By March of 1999, however, when the South Pole station had already been closed off from the rest of the world for the next several months, Dr. Nielsen made a frightening discovery: a 5½-cm lump in her breast. E-mails were exchanged. Physician colleagues in the US knew that they needed to examine a biopsy. But who would perform the biopsy? Fate produced an unlikely "surgeon;" one of her colleagues, a welder, practiced on various fruits and vegetables before performing the needed biopsy on Dr. Nielsen, under her guidance.

The availability of telemedicine technologies opened up precious opportunities for Dr. Nielsen and her colleagues to treat her incipient breast cancer. She credits one of her fellow "polies" for setting up the necessary equipment to transmit information regarding her case: "We sent samples twice, because the first samples were stained with antiquated stains left over from the Navy and they didn't work. The telemedicine system was developed at the Pole by my girlfriend Lisa. She used equipment we had on hand, a camera, a microscope, and a computer, and rigged up a system to use the Internet to transmit the pictures. (She's pretty smart!) [1]"

It soon became obvious that even with an electronic connection to an oncologist in the United States, Dr. Nielsen did not have the supplies necessary to treat herself. Air-dropped chemotherapy drugs, while they brought hope, did not change the growing consensus that the physician-turned-patient needed to leave the station. In addition to her physiological responses to her disease, a frightened Dr. Nielsen was losing her strength, memory, and morale as a result of the treatment and the atmospheric conditions.

There is no question that the availability and use of sophisticated computer technology helped save Dr. Nielsen's life. Hardware, though, is not enough. Without a technologically savvy colleague, an on-site physician - Dr. Nielson herself - and the willingness of her team members to train and cooperate in unfamiliar care-giving, the South Pole rescue story would have been far less satisfactory.

Even after the successful biopsy and some chemotherapy, Dr Nielsen needed to be evacuated from the South Pole - an undertaking that proved very ambitious, since weather conditions at that time of the year almost preclude the descent and landing of an aircraft - and cost a significant amount of money. Again, we confront the limits of technology and its many possibilities. The heroic efforts put forth to save Dr. Nielson lead us to reconsider the Baby Jessica phenomenon and the wealth of human, financial, and technological resources we are willing to mobilize once we put a human face on suffering.

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PERSONAL NARRATIVE

Through the Patient's Eyes: The X Factor

Audiey Kao, MD, PhD

Intel Corporation chairman Andrew Grove considers how the X Factor - the impact of information technology on business productivity - may affect medicine. In his 1998 piece for *JAMA*, Dr. Grove tells how, following his 1995 diagnosis of prostate cancer, he researched his illness on the Internet and decided the course of treatment he preferred. He foresaw that e-mail could end the telephone tag game between patients and their physicians and that physicians would soon create their own Web sites. "The potential benefits of the X Factor in medicine," Grove declared, are "tremendous for patients as well as for physicians."

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PERSONAL NARRATIVE

Through the Physician's Eyes: The Patients (Internet)-Physician Relationship

Clarence H. Braddock III, MD, MPH

"Hey doc, my son got this stuff off the Internet. I was looking at it and wondering, how come I'm not taking this medicine?"

I smile, taking the printed pages from Mr. S, then look down to see what he's found. Quickly scanning this printout from an arthritis support group Web site, I see a discussion of chondroitin and glucosamine for osteoarthritis. My mind races; do these substances work? I recall a recent Grand Rounds on osteoarthritis, the speaker mentioning the data suggesting a possible benefit, and breathe a mental sigh of relief. "Mr. S," I say, "there have been some studies on these two supplements for patients like you, and some show that they do help. But not all experts agree, and we don't know some of the possible harms. "Also," I continue, "it's hard to know if the stuff you buy is the right potency, since these are not regulated by the Food and Drug Administration."

Another crisis averted. With each passing day, my anxiety about the next Internet printout rises. Next time, it may be a treatment that I know nothing about. How soon will my patients know more than I do? What will they think if I don't know the latest development? Is the information they read even accurate?

As the number of Internet-based resources for medical information rises, more patients enter the clinical encounter with unprecedented amounts of information. Ranging from diagnoses of illnesses to new and untested treatments, this information challenges the physicians' traditional role of holder of all medical knowledge, and thereby potentially undermines an age-old source of medical authority. At the same time, when patients do obtain, read, and process accurate medical information in advance of the clinical encounter, it can enhance their ability to understand the clinical decisions that lie ahead, potentially solidifying their role in medical decision making and strengthening the patient-physician relationship.

Physicians can easily feel threatened by these developments. Our own medical knowledge and judgment are called into question. We may feel defensive, needing to justify our reliance on more accepted approaches to diagnosis and treatment. Our skepticism about new and untested clinical developments is questioned. Yet this need not be so. Physicians can and should use their patients' interest in medical

information as an asset, allowing discussion of the sources of this information to increase the patient's knowledge and forging a stronger therapeutic alliance.

How can physicians encourage the positive side of increased patient access to information? It is important to see patient interest in learning as an invitation to discuss their conditions. Try to find parallels in the medical diagnosis that mirror the patient's own interpretation of his or her illness. It is important to make the distinction between the patient's interpretation of the illness and our diagnosis of disease and, at the same time, to understand the relationship between them. Our clinical diagnoses are translations of the patient's real-life experience, and in respecting the patient's version as legitimate, we foster the therapeutic relationship.

Similarly, by demonstrating a respectful rather than scoffing attitude toward the patient's sources, one can convert a potentially adversarial discussion into a more collegial one. When patients share their sources of information, they are also demonstrating trust in us and giving us insight into their thinking. What do they really think of our diagnoses and treatment recommendations? These are questions for which we need answers; they hold the key to fostering patient adherence to treatment regimens. We can make the patient feel comfortable by acknowledging that they are not taking their medications, or that they are taking alternative treatments outside of our prescribed plan. These situations also offer an opportunity to give patients advice about finding reputable sources of medical information. We can ask them about their sources, and along the way suggest sources we know to be providers of good quality information.

What should we do if the patient challenges our advice? Occasionally, patients will hold strong views on medical diagnosis or treatment that are diametrically opposed to the physicians. This can create conflict and tension. The ethical dilemma for the physician intensifies when the basis for the patient's views seems to be inaccurate information from outside sources. Such situations are not really new, but because the Internet makes such information sources increasingly ubiquitous - not to mention unregulated and potentially misleading - the physician may see strong disagreement as a way of meeting an ethical obligation to prevent harm. These situations underscore the importance of maintaining trust and open communication, even in the face of disagreement. Any chance that we might have to help patients see that their strong views could turn out to be harmful rests on our ability to foster trust. Patients must feel confident that we know what we're talking about, can acknowledge our own uncertainty, and are acting in their interest rather than merely upholding medical authority.

Furthermore, as patients become more knowledgeable, it becomes ever important for physicians to remain up-to-date on medical developments. Critically reading the biomedical literature, attending continuing medical education conferences, and conferring with colleagues are all parts of the life-long learning, a core part of our obligation to maintain professional excellence.

Overall, then, Mr. S.'s question had a positive effect. It caused me to think more carefully about how he processes medical information, and to understand the influences, including, very obviously, the opinions of his son, on his views about his illness. I also was reminded of the importance of keeping myself up-to-date (boy, was I glad I had attended Grand Rounds that week). Finally, I was grateful that Mr. S. thought enough of our relationship that he was willing to call me "on the carpet" for what he thought might be an omission in his medical treatment, for this afforded me the opportunity to address his concern, and in so doing lay another brick in the foundation of our therapeutic alliance.

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VIEWPOINT

Tailoring Telemedicine to End-of-life Needs

Audrey Kinsella

End-of-life care service needs vary enormously according to patients' circumstances; and meeting these needs using conventional care services can be trying. According to published findings by researchers in the Dartmouth Atlas of Healthcare, oftentimes hospice and end-of-life care service delivery is based not on medical concerns but on provider preferences (i.e., logistics and consequent difficulties). Telehealth tools and services (that is, healthcare tools and services that have communications features) may have the potential to bridge the problem of access to desired care, however.

Tele-tools and Services for End-of-life Care

There is a growing range of telecommunications-ready tools that can help to ameliorate some trying situations at end of life. Starting with the very ordinary household telephone and broadening out to full-scale telehealth workstations and to smart housing devices or entirely wired rooms are some possibilities for extending care. However, few if any telehealthcare tools are designed specifically for end-of-life patient needs. The challenge for practitioners is therefore two-fold.

1. The tools must be identified, first of all, and their features and capabilities scrutinized by physicians so that they can be used correctly and effectively with end of life patients.

To this end, "Tomorrow's Tools," a segment of the Last Acts Web site which is devoted to issues in end of life care, can be a helpful start [1]. Each quarterly installment of "Tomorrow's Tools" features a topical emphasis with a targeted, annotated bibliography, details about new technologies in the "Today's Toolbox" segment, and comments from a panel of recognized experts on potential uses and value of the topic at hand. The February 2001 topic is "Smart Houses: New Ways to Get Patients the Care They Want." Earlier topics have included "Machines that Talk ... and Talk Back;" "Video 2000;" and "Self Care ... Now!?"

Telecommunications-ready or other communications tools that have been focused on to date in "Tomorrow's Tools" include: pre-programmed infusion pumps to deliver pain medication and for hydration and other patient needs. Another range of tools is video technologies that deliver medical directives from any number of clinicians, or for purposes of providing information, solace, and reminders using a show-and-tell approach. Using video, there can be an immediacy of contact - even if the clinician is off site - which is not possible with conventional care to address

end-of-life patients' individual needs. However, as noted by Stephen Spann, MD, who uses video technology for teaching purposes, presenters must learn about video technology's capabilities to use it productively and effectively. Doing so will help physicians to overcome two significant barriers: distance, and infrequent or inadequate communications [2].

2. The second challenging task is matching the appropriate tool with specific patient need or needs.

While end-of-life care patients are as diverse as the population in general, certain qualities are distinctive. They are more fragile, yet the majority wish to spend their last days not in hospitals but in their own homes. If the patients are out of the institutional setting, then there is all the more reason for physicians to locate tools that can ease their patients' transitions at the end of life, ones that are usable by the patients and their family caregivers as well as by home care/hospice nurses. The value: new tools can help physicians to communicate more often and as-needed with end-of-life patients in alternate care settings.

Among the decisions to be made when trying to match tools with patient needs is patient attitude toward using new tools. According to Chris Frank, MD, who manages rehabilitative care in a palliative care unit, independence and the need for self care are important considerations for some patients even at the end of life [3]. Dr. Frank says: Loss of control is one of the most challenging consequences of illness for many people. This is true when considering decisions about medical care, living situations, and extent of treatment, and it is also a major issue for people in the more day-to-day aspects of life. When people need to rely on others for activities of daily living, it commonly causes distress and depression. Most people strive for independence throughout their lives, and independence may be an even more important issue for dying patients. Self-care routines become important since they provide a way for the individual, often in collaboration with their caregivers, to dictate what is important to them in their daily living. It offers autonomy as well as predictability which increases the chances that they feel in control [4]. Enabling patients to continue somewhat with their familiar routines, as well as they are able, may be one of the key features of value of new tools introduced at the end of life.

"Smart" or pre-programmed sensors and other electronic tools can assist in achieving this end. Take a very common consideration at end of life, incontinence and possible ensuing difficulties with bedsores. It is currently possible to program blankets, mattresses, and other mainstays of the patient's bedside with higher tech tools that can time and sense the need to alert patients to empty their bladders and/or alert them or their caregivers to turn the patient or otherwise change position [5]. Beepers, phone calls, and other telecommunications tools used for this commonplace application provide patients at the end of life with increased communications (and ultimately, greater comfort) as and when needed.

Conclusions

A significant problem with introducing technologies in end of life care is the perceived reticence (by physicians, nurses, and patients) toward using high technologies in this highest touch of all care delivery scenarios. Key to the technologies' acceptance is physicians' ensuring that the selected tools are appropriate for use by end-of-life care patients and their family caregivers, and that patient needs can be addressed by means that will extend access to, not replace, hands-on clinical care [6]. Once we're over that hurdle of accepting the idea of technology's use at end of life, it will be an important step for physicians to become involved in development and design of focused tele-tools to ensure usability and that needs are met. To do so, physicians should take the initiative and work with device manufacturers to educate them about end of life patient needs.

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VIEWPOINT

The Digital Divide

Audiey Kao, MD, PhD

- An ad in California seeking riders for the Pony Express read: "Wanted. Young, skinny, wiry fellows. Not over 18. Must be expert riders. Willing to risk death daily. Orphans preferred." From April 3, 1860 to late October 1861, the Pony Express provided the fastest mail delivery between St. Joseph, Missouri and Sacramento, California on a trail length of nearly 2,000 miles. More than 180 men were known to have ridden for the Pony Express, and the fastest of these men once delivered the mail in 7 days and 17 hours. The Pony Express was officially ended on October 24, 1861 after the completion of the telegraph.
- More than two billion e-mails are sent and delivered nearly instantaneously each day in the United States. In a survey of over 15,000 physicians, 69 percent of respondents use e-mail for personal communication, but only 3 percent send e-mail to patients [1].
- The majority of adults ages 18 to 59 (55 percent) who have Internet access on a home computer use this technology to get health or medical information; as compared to getting information on entertainment, sports, and hobbies (78 percent) or making investments in stocks and bonds (19 percent) [2].
- Adjusted for computing power and speed, computer prices have fallen several fold in the last 5 years, but a digital divide still exists among individuals based on race, education, and income. White Americans have greater access to the Internet or e-mail at home than African Americans (57 versus 38 percent). Those with some college education are more likely than others (65 versus 41 percent) to have Internet/e-mail access. Individuals earning \$50,000 or more have greater access to the Internet (72 percent) than individuals earning between \$30,000 and \$50,000 (50 percent have access) and individuals earning less than thirty thousand dollars (31 percent access) [2].
- The medical use of e-mail is projected to increase, given patient demand and potential cost savings for medical practices, but many legal, ethical, and economic issues remain surrounding its appropriate uses [3-6]. For example, many argue that documented informed consent should be a prerequisite for e-mail communication between physicians and patients, but no standards for obtaining that consent currently exist. Protecting the privacy of e-mail communications between patients and physicians is another serious consideration, as is the question of whether physicians who use e-mail to

communicate with their patients should be reimbursed for that form of consultation.

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VIEWPOINT

Jay Sanders, MD: Telemedicine Pioneer

Faith Lagay, PhD and Kayhan Parsi, JD, PhD

If any single physician's name has become synonymous with the nascent field of telemedicine, it is that of Dr. Jay Sanders. Like any pioneer Dr. Sanders helped define a new frontier that few have seen or crossed. Telemedicine, he says in simple terms, "uses technology to deliver medical services to the point of need" [1]. The power and potential implied in that brief definition, however, give telemedicine the ability to redress the concerns of accessibility, cost, and quality in medical care. Believing that such systems promise to promote more equitable delivery of health care by lowering cost and reducing other barriers that block access to care among rural and low-income families, Dr. Sanders has become not only an advocate but an activist for the cause.

Despite growing acceptance and adoption of telemedicine, there remains no shortage of challenges. These include the high costs of system design and set-up; insurance reimbursement for telemedicine services; licensure regulations that restrict physicians from practicing in states where they are not licensed; liability matters (suppose an indistinct image leads to misdiagnosis?), and privacy concerns.

But Dr. Sanders is convinced that these obstacles can be overcome. To improve rural health care in Georgia, he designed a system employing interactive voice and color video and telecommunication systems coupled with telemetry that connects some 60 hospitals across the state to a central hub. Doctors at the hub examine and treat patients at the multiple satellite locations. He also initiated an "electronic house calls" project at the Medical College of Georgia thereby offering patients the opportunity to be cared for in their own homes or in nursing homes. Although equipment and start-up costs run into the six figures, hospitals participating in the Georgia-based program have not only improved the quality of patient care, but achieved it with greater efficiency [2].

A graduate of Harvard Medical School, Dr. Sanders directs the U.S. telemedicine initiatives to the G-8 nations and is a founding member of the American Telemedicine Association. The author of numerous articles and a recent book, *Telemedicine: Theory and Practice*, Dr. Sanders also serves on several editorial boards including *The Telemedicine Connection* and *Telemedicine and Virtual Reality*.

As a pioneer advocate and activist in the field of telemedicine, Dr. Sanders has trail blazed a new frontier for physicians and the medical profession, one for which we recognize him as a role model in medicine.

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