Patient Trust
By Norman Berlinger, MD, PhD

When I decided to switch careers and retire from my otolaryngology ear, nose, and throat (ENT) practice, I received a number of farewell letters from long-time patients. One of them came from the mother of a mentally delayed girl, Abby (not her real name), whom I had treated for about 15 years. In it she stated that she trusted me, and that was why she followed me when I switched practice locales. That is why she always asked me what I thought of other doctors opinions even though they were of different specialties. That is why she still calls me even now to evaluate the ENT care Abby is currently getting.

Why the trust? Her letter explained that on each office visit I always asked Abby how she was feeling and what was bothering her. Abby’s mother said that by always speaking with Abby first, despite her verbal disabilities, it seemed to be acting primarily in Abby’s best interests. I actually seemed to be Abby’s agent. Abby’s mother was critical of doctors who spoke only to her to find out how Abby was doing, an unfortunately common occurrence with mentally delayed patients, especially when I switched practice locales. That is why she always asked me what I thought of other doctors opinions even though they were of different specialties. That is why she still calls me even now to evaluate the ENT care Abby is currently getting.

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Research and Public Trust
By Jeffrey Kahn, PhD, MPH

A recent cover of Time magazine depicted a woman in a hospital gown crouching in a cage like a lab animal with the banner headline “Human Guinea Pigs.” Inside, numerous scandals at research universities were recounted, describing the shortcomings of researchers and medical centers carrying out clinical trials. They ultimately led to risky situations and inadequate information for prospective research subjects, the magazine says. Time’s conclusion was that people were put in harm’s way and that matters are only going to get worse without significant change.

At the same time, editorials in major newspapers are calling for additional clinical trials—for hormone replacement therapy for post-menopausal women, for drug testing in children, and others. They argue that a main lesson from recent studies is, to quote from the New York Times, “the importance of conducting clinical trials of medical treatments whenever feasible.”

How are we to make sense of the conflicting conclusions in each depiction of clinical research, making sure research subjects are protected on one hand while at the same time advocating additional studies with more people for more diseases?

One answer to the dilemma is to make some changes in federal research policy. Federal regulations have evolved
in today's busy practice. She trusted those physicians less because she suspected they might have been acting more as her agent. She thought Abby had important firsthand information to convey, and Abby was supposed to be the focus of the visit.

In the oath of Hippocrates trust is a central element in almost all the ethical obligations of physicians. Physicians must keep patients’ private information confidential, avoid mischief and sexual misconduct, and give no harmful or death-causing agent. Patients can expect that physicians will come to their aid even if it means putting the physician’s own health at risk, and they can trust that physicians will do everything in their power to help their patients. Osler Medical Journal reaffirmed the central role of trust by reminding physicians that medicine was a calling and not a business.

So important is trust that life is impossible without it. Even the most cynical of us must depend on it. Trust reduces complexity and the need to plan for innumerable contingencies. Trust allows us to take the necessary hundreds of daily risks—my brakes will not fail; my medicine is not bogus; my paycheck will arrive on schedule.

Recent national and world events have given us a new awareness of trust. Some authors claim that trust is eroding. They point to the abuses of Enron and Tyco executives, the sexual misbehavior of priests, and the stalemate in the Middle East, peppered with violence from both sides, as evidence of loss of interpersonal and institutional trust. In fact, last year Time magazine ran its lead story on the current crisis in trust, with the cover proclaiming, “You’re on your own, baby.” Conversely, others point to the terrorist attacks of 9/11 as a stimulus that is increasing trust, because we have realized again how dependent we are on one another.

This new awareness, grown from such events and the debates they generate, has finally focused attention on trust as the central element in the physician-patient relationship.

How does one define “trust-in-the-physician?” David Mechanic defines trust as competence, control, and agency. He believes that trust refers to a patient’s expectations that physicians will perform their duties in a technically proficient way, that they will assume responsibility and not inappropriately defer to others, and that they will make a patient’s welfare their highest priority. Ezekiel Emanuel adds two items to make the definition of trust especially relevant to the era of managed care. He includes communication, because good communication means the physician takes the time to listen to and understand the patient. He also includes compassion, because empathy enables patients to feel supported during periods of great stress. In short, trust is the patient’s perception of how well the physician fulfills his or her ethical obligations.

Trust is a prerequisite for medically effective care. A trusting patient will reveal potentially stigmatizing information about health-related behaviors such as sexual practices and substance abuse, or personal and revealing thoughts that are necessary to differentiate mental from physical disorders. Trusting patients also are more willing to accept treatment programs or prescribed changes in personal behavior that are difficult or risky.

Trust is a prerequisite for cost-effective care. Physician-patient relationships that are characterized by suspicion or distrust are likely to foster litigation and the expensive practices of defensive medicine. The absence of trust creates other substantial costs as patients seek second and third opinions, guard themselves from possible adverse outcomes, or disenroll from their current clinics only to start treatment all over at a new clinic.

Perhaps most important in both regards is that trust promotes patients to adhere to a physician’s advice. Over 800 studies of non-adherence have been performed over the past three decades. In fact, the National Institutes of Health (NIH) currently has 35 such studies underway. The results are enlightening. Non-adherence is largely unrelated to a patient’s socio-economic status or education. Only minor associations appear with the type of therapeutic regimen, the referral or appointment process, or disease characteristics. Rather, most research has found that patients typically follow only those recommendations they really believe in, as long as they have the ability to carry them out. In other words, they follow the recommendations they trust will have some utility and come from a trustworthy physician.

Non-adherence is a huge problem. About 38% of patients will fail to follow a short-term treatment plan, and about 43% will not adhere to recommendations for long-term treatment such as taking
Dr. Berlinger has an eclectic background in otolaryngology. As a practicing physician he has cared for patients in both private and university settings in the Twin Cities. Before being appointed a faculty member at the University of Minnesota’s Department of Otolaryngology, he spent two years at the National Naval Medical Center in Bethesda, Maryland fulfilling a two-year military obligation. He began his academic career there, as a professor at the Uniformed Services University of the Health Sciences, and a staff member of the Clinical Branch of the National Institutes of Health (NIH).

Dr. Berlinger also has extensive research experience at the laboratory bench. He was appointed as a staff scientist at the Sloan-Kettering Institute for Cancer Research, obtaining a National Cancer Institute Fellowship and several NIH grants. He investigated the role of reduced immune capacities in the genesis of cancer. Once appointed to the University of Minnesota, he moved his laboratory there and continued this and other cancer-related investigations.

It was the clinical experience at the University of Minnesota hospitals that fostered his interest in ethics. His primary clinical duties were to care for critically ill neonates and desperately ill bone marrow transplant recipients. On just about a daily basis, he was confronted with end-of-life questions and questions about medical futility and patient autonomy.

Dr. Berlinger changed careers last year and found a warm new home at the Center for Bioethics. In the Center, he does research about patient trust and its impact on medical outcomes. He has just finished writing a book about teen depression for HarperCollins, Out of Dark Waters: How to Recognize and Rescue a Depressed Teen, forthcoming. He was motivated by the conspicuous scarcity of resources allocated to this pervasive and devastating problem. He continues to write for the New York Times and various national magazines about medicine and science.

Selected Publications

BOOK CHAPTERS


ARTICLES


anti-hypertensive medications. Non-adherence is often not detected by physicians, even those with considerable experience. The human cost of non-adherence is considerable. Non-adherence can contribute to unnecessary diagnostic testing and procedures and can result in potentially harmful regimen changes, such as medication dosage increases. An intense national debate has focused on how to help more people afford costly medicines. Yet, there is an increasingly urgent problem of getting patients to take their medicines once they get them.

It seems only intuitive that patients who trust their physician likely will adhere to a prescribed pill-taking regimen more than suspicious or distrusting patients. Surprisingly though, this question has never been addressed scientifically. That is why I undertook this kind of project myself. I am currently working with the University of Minnesota's Department of Family Practice to determine in a large clinic population whether the degree of patient trust correlates with adherence to an anti-hypertensive regimen, and whether adherence can be corroborated by evidence of better blood pressure control. The data are being gathered now, and results should be available in several months. Adherence is the single most significant clinical problem in the management of patients with essential hypertension.

Trust is fragile. It can be wounded or destroyed in just one encounter with a physician, if the physician, for example, gives incorrect advice or advice that contradicts that from the last office visit. This is most unfortunate in that trust develops only iteratively. It is built slowly with the aggregation of positive experiences with a particular physician. Lack of trust leads to suspicion. When the suspicion develops into distrust, the relationship is over.

Emerging structures of care present significant challenges to the development of trust. A truncated encounter with a physician decreases the amount of time necessary to develop trust. These encounters are increasingly impersonal, being dominated by specialization, technology, and bureaucracy. Modern medicine may be marked by fewer expressions of caring and humaneness, while the increasing use of e-mail by both patients and physicians may provoke patient worries about confidentiality.

The patient has become more of a consumer. Some patients are beginning to feel that they must be on guard in the medical marketplace, believing that managed care is on a collision course with the ethical aspects of professionalism that engender trust. Rewarding physicians for lowering costs would seem to decrease trust, especially among patients with insufficient financial resources. Patients wonder whether a managed care organization is able to guarantee an essential degree of professional autonomy.

Curiously, some bureaucrats believe trust is a barrier. They believe that patients should be aggressive seekers of information rather than rely on trust. Better medical structures will arise, they say, pointing to the fact that, after all, this country was founded on distrust. However, these proponents of patient activism may have forgotten that in complex and technical areas, patients may base decisions more on trust than on informed choice.

Center News

The Center for Bioethics is pleased to announce that the Center’s Director, Jeffrey Kahn, PhD, MPH, has been named the first holder of the newly endowed Maas Family Chair in Bioethics.

The chair was created with a lead gift from the Maas Family Foundation. Significant support from Fairview University Medical Center, the Permanent University Fund, and a number of estate donors has been instrumental in realizing the vision of Shelley N. Chou, MD, PhD, a former Dean of the Medical School, who was a founder of the Center for Bioethics and initiated the chair campaign.

Carl Elliott, MD, PhD, and Jeffrey Kahn, PhD, MPH, have been appointed as Elected Fellows of the Hastings Center.

Bonnie LeRoy, MS, CGC, Director, Genetic Counseling Graduate Program, University of Minnesota, received the Natalie Weisberger Paul Award from the National Society of Genetic Counselors. The award is given annually to a genetic counselor who demonstrates exceptional lifetime leadership qualities in the profession of genetic counseling.

See the Center's website at www.bioethics.umn.edu for Bioethics courses offered Spring Semester 2004.
Federal regulations have evolved to require inclusion of historically underrepresented groups in clinical trials... to require inclusion of historically underrepresented groups in clinical trials—chief among them women and underrepresented minorities—under the argument that the changes increased these groups’ access to the benefits of research. But such protections, including requirements for informed consent, confidentiality or adequate representation apply only to studies funded by the government or that will end up having their data submitted to the Food and Drug Administration. Most research universities voluntarily agree to apply these standards to their federally funded and non-federally funded research, but such agreement is not universal and does not apply to the many other entities that engage in research. A growing list of lawmakers have suggested that federal law be modified to require that all research on human subjects be covered by federal regulations, regardless of the source of funding.

The sources of funding have additional effects on research. Even if research regulations covered all research, one of the soft spots in oversight has been managing the potential for financial conflicts of interest. Some watchdog groups have argued that financial stakes in the outcome of research by both researchers and institutions are at least partly responsible for some of the recent scandals. Rules from the government as well as professional groups are coming, promising to set higher standards for what financial relationships will be allowed.

The bottom line is if we don’t do a better job of protecting subjects, then the most important commodity in research will be lost—the trust of the public. Without trust, patients won’t participate in research, and the public won’t agree to spend tax dollars on it. The truth is we want the benefits that medical research has to offer and we want it without biases that may affect safety. It is possible to have both, but not without the research community making sure research is performed with the highest ethical and scientific standards.

A system of compliance is important, but as a fail-safe measure rather than as the first line of defense of the rights of research subjects. Instead, conscience ought to take priority over compliance, and with that shift will come all-important trust.

Ethics and Public Health: Model Curriculum Released

A new free resource on ethics and public health is now available. Ethics and Public Health: Model Curriculum is the product of a collaborative effort among the Association of Schools of Public Health (ASPH), the Health Resource Services Administration (HRSA), and The Hastings Center, with additional support from the Robert Wood Johnson Foundation. The concept for the model curriculum grew from a rising interest in the ethical, legal, and social aspects of public health policy and practice. With this interest came a demand for the teaching of ethics in schools of public health and in professional public health settings, and for the resource materials to support it. The curriculum is intended as a resource to enhance and encourage thoughtful, well informed, and critical discussions of ethical issues in the field of public health.

The project brought together teachers of ethics in public health, other content experts, and representatives of the government and the public health practice community. The curriculum consists of self-contained units or modules, each written by a leading expert, and each containing similar resources—an analysis of the ethical question, several case studies with commentary for discussion, resources for further study and research, and the like. The project was led by a four-member working group, and aided by assistance from professionals at ASPH:

Bruce Jennings—The Hastings Center
Jeffrey Kahn, PhD, MPH—Center for Bioethics, University of Minnesota
Anna Mastroianni, JD, MPH—University of Washington School of Law and Institute for Public Health Genetics
Lisa Parker, PhD—Center for Bioethics and Health Law, University of Pittsburgh

The entire curriculum or individual modules can be accessed at www.asph.org/document.cfm?page=723. For information, or to order a hardcopy of the curriculum, email: MStadtler@asph.org.
Recent Faculty Publications

**BOOK**


**BOOK CHAPTERS**


**ARTICLES**


Guest Editors—Josephine Johnston, Carl Elliott

Johnston J, Thomas M. Summary: The Science of Genealogy By Genetics (pp. 103-108).

Johnston J. Case Study: The Lemba (pp. 109-111).

Parfitt T. Constructing Black Jews: Genetic Tests and The Lemba–The ‘Black Jews’ of South Africa (pp. 112-118).

Azoulay K. Not An Innocent Pursuit: The Politics of a ‘Jewish’ Genetic Signature (pp. 119-126).

Zoloth L. Yearning For The Long Lost Home: The Lemba and The Jewish Narrative of Genetic Return (pp. 127-132).

Dula A, Royal C, Secundy M, Miles S. The Ethical and Social Implications of Exploring African American Genealogies (pp. 133-141).

Baylis F. Black As Me: Narrative Identity (pp. 142-150).


Palsson G, Helgason A. Blondes, Lost and Found: Representations of Genes, Identity, and History (pp. 159-169).

Sabir S. Chimerical Categories: Caste, Race, and Genetics (pp. 170-177).

Parfitt T. Place, Priestly Status and Purity: The Impact of Genetic Research of an Indian Jewish Community (pp. 178-185).
Calendar of Events

**Feb 2**
Dianne Bartels, RN, MA, PhD, will speak on “Ethical Challenges in Genetic Health Care,” at the Alliance of McLaughlin, Research Institute and Benefits Healthcare, Great Falls, MT. For information, call 406-455-3631.

**Feb 4**

**Feb 5 & Feb 28**
2/5 Jeffrey Kahn, PhD, MPH, will speak on “Ethics, Art, and Biotechnology.” 2/28 Steven Miles, MD, will participate as part of a panel “What is Human,” as part of the Gene(sis) exhibit “Contemporary Art Explores Human Genomics” sponsored by the Frederick R. Weisman Art Museum, Minneapolis, MN. For information, call 612-625-9494.

**Feb 12**
Carl Elliott, MD, PhD, will speak on “Better People Through Better Technology?” at the Mayo Clinic, Rochester, MN. For information, call 507-538-1511 or email: aaker.janice@mayo.edu.

**Feb 25**
Carl Elliott, MD, PhD, will speak on “American Medicine Meets the American Dream,” at the Institute for Advanced Study, Princeton, NJ. For information, email: donie@ias.edu.

**Feb 1**
Steven Miles, MD, will speak on “Preparing for Dying,” at Plymouth Congregational Church, Minneapolis, MN. For information, call 612-623-9267.

**MAR 9-12**

**MAR 13**
Jeffrey Kahn, PhD, MPH, will speak on “Little Cells, Big Issues–The Ethics of Stem Cell Research,” at the Annual Meeting of the Wisconsin Society of Science Teachers, Appleton, WI. For information, email: Webmaster@wsst.org.

**MAR 13**
Dianne Bartels, RN, MA, PhD, will speak on “Stem Cell Research,” at St. Patrick’s Catholic Church, Hudson, WI. For information, call 612-624-9440.

**MAR 13**
Jonathan Kahn, JD, PhD, will speak on “Privacy and Community” at DePaul University College of Law, Review Symposium, Chicago, IL. For information, call 312-362-8000.

**MAR 19**
Jeffrey Kahn, PhD, MPH, will speak on “Stem Cell Research: The State of the Policy Debate,” at Kansas Health 10th Ethics Conference, Wichita KS. For information, email:charrison@kansashealthethics.org.

**MAR 26-28**
Steven Miles, MD, will speak on “The Legacy Value of Post-Genomic Research and the Interests of African Nations,” at the 2nd Annual Conference of the African Genome Initiative “Genomics & African Society,” Cairo, Egypt. For information, email: genome@hsrc.az.za.

**APR 19**

**APR 23**
Jeffrey Kahn, PhD, MPH, will speak on “Ethical Issues in the Use of Pre-Implantation Genetic Diagnosis,” at the 3rd Annual International Bioethics Forum “Who Knows? Who Needs to Know?” BioPharmaceutical Technology Center, Madison, WI. For information, visit www.btc.org.

**Great Conversations**

**“Bioethics in the National Spotlight”**

March 23
Jeffrey Kahn, PhD, MPH, in conversation with Harold Shapiro, PhD, will speak on “Interface of Bioethics, Public Policy, and Scientific Research,” at the Ted Mann Concert Hall on the University of Minnesota West Bank campus. For information, call 612-625-5760.

**Elder Learning Institute Bioethics Series**

March 25 - May 13
Center for Bioethics faculty will participate in an eight week lecture series on the University of Minnesota campus. The series will address current issues in bioethics. For information, call 612-624-7847.
Center Faculty & Staff

**CENTER FACULTY**
- Jeffrey Kahn, PhD, MPH
  *Director and Maas Family Chair in Bioethics*
- Dianne Bartels, RN, MA, PhD
  *Associate Director*
- Debra DeBruin, PhD
- Carl Elliott, MD, PhD
- Jonathan Kahn, JD, PhD
- Joan Liaschenko, RN, PhD
- Steven Miles, MD
- John Song, MD, MPH, MAT
- Maryam Valapour, MD
- Susan M. Wolf, JD

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- LeeAnne Hoekstra
- Candace Holmbo
- Karen Howard
- Jacob Larson
- Christiana Reese

Announcing New Center Reading Packet

*Ethics of Organ Transplantation*

The Center for Bioethics, with support from the Starr Foundation, has developed a new educational reading packet, on the ethics of organ transplantation. The packet highlights key ethical, legal, and social issues. It includes valuable on-line resources, and a glossary of terms. This packet is available on our website at [www.bioethics.umn.edu](http://www.bioethics.umn.edu) or can be mailed upon request. For more information about this and other Center reading packets, please contact Ariel Abbott-Penny at abbot035@umn.edu or 612-624-9440.