American Medical Association Journal of Ethics

March 2002, Volume 4, Number 3: 53-83 Givers of Care and Organs

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American Medical Association Journal of Ethics March 2002, Volume 4, Number 3: 55-57.

FROM THE EDITOR Unifying Medicine Audiey Kao, MD, PhD

What is the future of medicine in the public sphere, as expressed through its professional organizations? Will the profession continue to be just one of many competing interest groups, whose influence will continue to wane? Or is there a basis on which the professional organizations of medicine might assume a new position of moral leadership in American health care? This latter question is seldom asked, perhaps because the answer seems preordained by our understanding of the recent past and projection of that past into the future. Notwithstanding its direct stake in many health policy questions and its perennial ranking near the top of political contributors, organized medicine has become conspicuous politically by its marginality among a cacophony of players, demoted from center stage and seen as just another self-interested player.¹

To many scholars and commentators, the inability of medical professional organizations to transform themselves in the face of uncertainty and chaos seems intractable. With a less cynical critique of medicine's past, Rosemary Stevens, professor of history and sociology of science, argues that organized medicine's future in the public sphere greatly depends on the ability of physicians to develop and sustain relationships inside and outside the profession. Medical professional organizations can reclaim their public voice, she suggests, by leveraging their historical achievements in establishing clinical, educational, and ethical standards to create institutional discourse based on participatory power, rather than on the current conflict model of inter-organizational relationships.

While Stevens' organizational theory provides neither an exact roadmap nor a guarantee that the destination will be reached, organized medicine has come to an historical crossroads where its future credibility and influence will be determined. Organized medicine (for those who don't know) comprises the American Medical Association and the specialty, state, and county medical societies. To many observers, this federation of medical professional organizations is oftentimes less organized than its label implies. Confronted with member societies who have competing and conflicting interests and priorities, the federation's efforts to get doctors to agree on an issue calls to mind the cliche "trying to herd cats." Thus, it has become difficult for organized medicine to speak with one coherent and unified voice.

How, then, do we redesign organized medicine to better herd the cats? First, it must be noted that there are strong ties that continue to bind all physicians—our common heritage and shared experiences. As a profession, medicine has a history grounded in a set of ethical principles, and, while no code of professional conduct is monolithically accepted and comprehensively enforced, all those who enter medicine appreciate the importance of the profession's ethical underpinnings. Similarly, independent of time, geography, or specialty, medical students and residents share a process of socialization that prepares each generation of physicians. As an internist, I feel a certain collegial bond whenever I meet a new physician, and I hope and suspect that feeling is mutual. Any solution to reunifying organized medicine should draw upon these ties that bind us as physicians.

In my opinion, any intra- or inter-organizational solution that is meant to unify member societies requires clarification of professional medical organizations' roles and priorities vis-a-vis the interest of patients, physician members, and the profession as a whole. Patients and physicians share fundamental interests. Some mutual interests, such as protecting patient confidentiality and securing informed consent, are apparent. Other interests, such as efforts to reduce administrative burden and other hassle factors for physicians, may seem professionally self-serving, but from an important practical and patient-relevant perspective, frustrated and burned-out physicians are probably poorer communicators and less empathic with their patients.²⁻⁷

But what happens when the interests of patients and physicians conflict? When, for example, a physician's need for personal or family time coincides with a patient's need for the same time. Even when interests are not in direct conflict, professional medical organizations have to decide how to spend their time and resources among issues that may be more important to dues-paying physician members than to the profession as a whole or to patients and the public. Presented with these realities and choices, some have advocated for separate organizations—one that negotiates and lobbies solely for the interests of physicians and another that advocates on behalf of the profession in the public interest. In countries such as Canada and England that have single-payer systems, this organizational division of labor and responsibilities exists. In the US, with its multi-payer, public and private health care delivery system, an organizational solution designed to create a national collective negotiating unit for all physicians seems less likely to succeed. More importantly, though, a solution based on an organizational division of labor, while structurally "cleaner," undermines the ability of medicine to speak with a unified and coherent voice, and conveniently but artificially compartmentalizes pressing challenges that confront the financing and delivery system of health care in this country.

In keeping with our nation's political philosophy of checks and balances, an alternative, though messier solution (workable solutions are oftentimes messy) is a national physician organization that forces debate, discourse, and ultimate decision on important and potentially conflicting interests and priorities. In order to achieve this organizational resolution, leaders and members of the profession must decide

which interests among the primary constituencies of a national physician organization are paramount. Only after organizational clarity is achieved can more rational, but still imperfect, decisions be made when leaders are confronted with issues of resource allocation and conflicting interests. Only then, will organized medicine stand ready to speak with a unified and coherent public voice.

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IN THE LITERATURE
Ethical Medical School Applicants?
Samuel Huber

Lowe M, Kerridge I, Bore M, Munro D, Powis D. Is it possible to assess the "ethics" of medical school applicant? *J Med Ethics*. 2001;27(6):404-408.

Grades, summer jobs, MCAT scores, applications, interviews, and a little luck. All steps on the way to admission to medical school. In theory, jumping through these hoops suggests that the applicant is prepared to learn how to be a physician. Success attests to perseverance, interest, and ability to learn the prerequisites for the scientific side of medicine. But is there something else we should be measuring in applicants? Ethical behavior is essential to the daily practice of medicine, so should we assess student readiness to learn the specifics of medical ethics? Should we deny medical training to applicants who hold opinions that are incompatible with the core values of medicine in order to keep those students from doing harm as doctors?

Michael Lowe and co-authors ask this question in a recent article "Is it Possible to Assess the 'Ethics' of Medical School Applicants"? The authors react to the recent conviction of a British physician for the murder of 15 of his patients by asking whether there is a way that medical schools could have identified him as morally unfit to become a physician prior to medical school. In this way, certain people could be excluded from the profession "before they cause harm." The authors systematically address different possibilities for measuring student ethics. They reject assessing ethical reasoning, moral reasoning, individual opinions on specific issues, and the use of vignettes. The authors suggest that screening for character traits consistent with certain personality disorders is a reasonable step to take in medical school admissions. They conclude that ethics should be measured in aspiring students, but that instruments need to be better defined and carefully validated before being employed in the application process.

Lowe et al begin their discussion with two premises. First, they claim that "ethics is the study of what we ought to do." Next, they assert that there are 2 types of factors that contribute to ethical behavior: those that can be taught and those that are innate. The authors decide that only innate factors should be tested before medical school. Other factors such as knowledge base, communication skills, and professional competence skills can all be taught in medical school, and, thus, it is unfair to require that premedical students already possess them. The authors then turn to how innate factors can be defined and measured.

Reasoning is a factor that contributes to ethical behavior. Ethical reasoning is dismissed by the authors as a logic game. Testing it will not yield useful information because students who are good at logic can also score well on this test. Kohlberg laid out a concept of moral reasoning in his theory of moral development, and others have elaborated on the concept in the form of validated tests. It has also been found that moral development can be improved by instruction as evidenced by increased reasoning scores. An important tenet of Kohlberg's theory is that moral reasoning is independent of the moral decisions that are made as a result. Since reasoning is detached from action in this way, the authors assert that it is neither fair nor informative to test aspiring students on their moral reasoning skills.

Next, the authors address asking students about their individual beliefs on specific topics. Although the authors do not acknowledge this, it is a common practice of medical school interviewers to ask students about their opinions on certain topics in ethics. The authors do not think that applicants should be rejected because of their individual beliefs. Furthermore, they point out that unsophisticated beliefs should be expected from students who have not yet developed them through instruction and experience. Similarly, the authors reject testing students using a vignette because it tests a single issue and asks for post-hoc reasoning, which is not the same as making a decision in real time.

Finally, the authors address character traits as indicators of the virtues associated with medicine. They cite a list of descriptors used by physicians to describe inappropriate behavior and attitudes observed in medical students, which includes "selfish," "amoral," "rude," "aggressive," "rigid," and "judgmental." The authors draw a link between these descriptors and traits listed in the psychiatric diagnosis of personality disorders. Since there is an overlap between DSM-IV criteria and moral judgments, the authors reject the movement to keep the two separate and conclude, "... we believe it is entirely appropriate to use some of the tools of psychiatry to investigate morality. A logical place to start is to screen applicants with standard questionnaires for the diagnosis of personality disorders."

A closer look at the personalities involved in unethical behavior reveals narcissistic traits, general disinterest in ethical behavior that could be akin to antisocial personality disorder, and uncritical following of instructions from superiors. This final trait is not linked to a recognized personality disorder, but is described as problematic nonetheless. The authors admit that screening for antisocial traits among highly intelligent applicants could be difficult and low-yield. They also admit that some degree of narcissism is beneficial in some branches of medicine. They say that what they are really looking for is some sort of tendency toward exploitiveness and shamelessness that turns self-confidence into a dangerous pathology.

The authors believe there is a moral imperative to screen for potential serial killers among medical school applicants in order to keep them out of the profession. They demand that any selection measure used for applicants be empirically validated and stick to testing sensitivity to moral issues (*not* competency in teachable skills). They concede that there are difficulties in defining unethical behavior in a testable manner, but remain convinced that this is a necessary exercise for the profession.

While this article raises important concerns about the character and judgment of people admitted to medical school, it leaves us with some unsupported claims and no particular direction for resolving the challenges presented. The premise that some components of ethical behavior are innate is a strong claim to make if the authors cannot identify any descriptive or measurable factors that fit in this category other than personality disorders. The potential for a discrimination or disability lawsuit is high with this sort of categorization, and the authors offer us little reason for accepting it. While a link between unethical behavior and personality traits is interesting, the authors back away from a convincing connection between traits and psychiatric disorders. Furthermore, blurring the distinction between "mad" and "bad" is something that should not be done lightly; nor should it be characterized as an area of agreement within psychiatric circles.

The intent of the authors is noble and well-founded. The profession does have a responsibility to ensure that its trainees are the best suited for the job, and medicine should take action to avoid as much unethical behavior as possible. Perhaps an ethics entrance exam is not the best way to accomplish these goals.

Ouestions for Discussion

- 1. Should we measure the character or ethical aptitude of medical school applicants? Does the profession have a responsibility to screen for "unethicalness?" Would the data tell us anything?
- 2. The authors claim that certain components of ethical or unethical behavior are innate; that is, inborn. If this is true, would it be discriminatory to reject someone on the basis of "innate" qualities? Is unethical behavior a disability?
- 3. Why shouldn't applicants be rejected on the basis of their individual beliefs? If someone is unwilling to change a strongly held belief that is at odds with the core values of medicine, why shouldn't he or she be barred from entry to medical school? (Examples: doctors shouldn't prescribe medication to people in pain; certain ethnic, socioeconomic, or gender groups don't deserve medical care.)
- 4. Medical school interviewers often assess individual ethical or moral beliefs informally and unsystematically. Is this a sufficient way to screen for potentially unethical physicians?

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STATE OF THE ART AND SCIENCE

Pharmacogenomics: Revolution in a Bottle?

Faith Lagay, PhD

Pharmacogenomics applies information about the human genome, gene sequencing technology, and molecular biology to drug design. At first glance, the technology seems not to present the same sort of harrowing ethical dilemmas we have come to expect from genetic knowledge and technology, such moral conundrums as parental right to select offspring traits or determining whether it is ethical to fertilize and implant an embryo in hopes of conceiving a tissue donor baby to save an existing child. Instead, like all advances in drug treatment, pharmacogenomics will bring with it higher cost and, thus, concerns about equitable distribution of health care. Like all gene-related technologies, it will reveal more about us and challenge the current procedures to protect the confidentiality of the additional information. The social justice and policy problems embedded in those 2 outcomes are grand in scope and correspondingly difficult to resolve. In the end, pharmacogenomics may be part of a revolution in personal identity as well as in how we pay for medical care in the U.S.

The potential benefits of pharmacogenomics are considerable. Applying knowledge about an individual's inherited response to drugs to the design and development of commercial pharmaceuticals holds the promise that drugs may one day be tailor-made to each person's genetic makeup. The products of this "rational drug design" technology would replace current drugs that are intended to serve the entire patient population. These blockbuster, one-formula-fits-all, drugs, typically work for only 60 percent of the population at best. More worrisome and costly than their ineffectiveness is the instance of serious adverse drug reactions (ADRs) that are responsible for 100,000 deaths a year in the U.S. and cost society an estimated \$100 billion a year.

The Promise of Pharmacogenomics

Pharmacogenomics expands upon a progenitor science, pharmacogenetics, which dates from the 1950s when researchers first noticed an inherited tendency in the way people react to drugs. An individual's reaction to a particular drug depends, in large part, upon whether the drug's target cells have the proper receptors for the chemical compound being delivered and how the individual metabolizes the drug. Ultra-rapid metabolism of a drug can cause it to be ineffective, and slow or non-metabolism can result in the accumulation of toxic amounts of the drug in the body. Genes control both these factors—receptor binding sites and enzymes involved in metabolism.

Before it was possible to isolate the genes involved in the synthesis of given metabolic enzymes, appearance and family relationship were the main clues to the presence of inherited or genetic factor in reaction to drugs. Early pharmacogenetics investigators focused on the broadest and most obvious categories of inheritance and relationship: ethnicity, geography, language, and race. This approach revealed, for example, that 5 to 10 percent of people from Mediterranean and African ancestry lack the glucose-6-phosphate dehydrogenase enzyme and thus risk breakdown of red blood cells from more than 200 drugs. Testing for drug sensitivity was by trial and error. The drug was prescribed, and then the patient's urine was examined to check the rate of the drug's metabolism.

SNiPs

The science of connecting drug reaction to genes took a great leap forward with the discovery and use of SNPs (pronounced snips) in the late 1990s. On their way to sequencing the entire genome of 3 billion base pairs (purine and pyrimidine bases bound together to create the "rungs" across the now-familiar double helix) scientists kept coming upon instances where one member of the base pair differed from the expected. Of the 4 bases that DNA comprises—adenine, cytosine, guanine, and thymine—adenine generally bonds with thymine, and cytosine binds with guanine. About every 1,000 or so base pairs, scientists observed a mistaken pairing: a guanine paired with a thymine, for example, instead of with a cytosine. These single departures are SNPs, "single nucleotide polymorphisms." What makes SNPs helpful is that certain SNPs are found sprinkled throughout the population, so that by looking at the DNA of individuals who share a certain inherited condition, drug reaction, or susceptibility, researchers can sometimes identify a shared SNP. (To be helpful, the polymorphism must be shared by at least 1 percent of the population tested, so the promise that pharmacogenomics will create drugs tailored to each individual is a slight exaggeration.)

Enough DNA samples taken from enough people make it possible to connect drug toxicity and ineffectiveness to SNPs, with 2 results. First, genetic tests can identify those who would have serious ADRs before they receive the drug. Second, drugs can be designed to work effectively but non-toxically on those who have ADRs to the one-formula-fits-all blockbuster drugs. Step one has already begun. For example, a set of enzymes called CYP34 metabolizes about 50 percent of all common drug compounds. Searching for SNPs that control these enzymes, pharmacologists at St. Jude Children's Hospital in Memphis discovered 2 SNPs that "quash" production of active enzymes. "People who carry either one of the culprit SNPs metabolize drugs more sluggishly than do people who harbor other versions of the gene". Those in the field predict that testing for most enzyme-related drug reactions and resistance will be available within the next 5 years and that rationally designed drugs will be available in the next 7 to 12 years.

Pharmacogenomics: At What Price?

The question of resource allocation comes up whenever public money is spent for research and development. That question is less an issue in pharmacogenomics

because pharmaceutical companies have, understandably, jumped on the technology, many of them merging with biotech companies that suddenly see a profitable product in the near future for the first time.^{8,9} It might seem that drug companies would be less interested in products that work on only a portion, 40 percent, say, of the population; that such products would bring in only 40 percent of the revenues. But a drug guaranteed to work on the 40 percent for whom other drugs are ineffective or cause harmful side effects will return a steady revenue at a premium price.

Chances are good that pharmaceutical companies will also spend less in gaining FDA approval to introduce new pharmacogenomically produced drugs to the market. Clinical trials can currently cost upward of \$250 million per drug, most of it spent on phase III.² After phases I and II have demonstrated, respectively, the candidate drug's safety and efficacy on several hundred people, phase III verifies those results on 5,000 to 10,000 people. With pharmacogenomically designed drugs, adverse responders and non-responders will be identified in phases I and II, so that phase III participants can be far fewer in number—only those whose genetic tests show they will respond favorably.⁹

While this advantage will reduce the amount pharmaceutical companies must invest in bringing a new drug to market, the savings may not be passed on to patients. As mentioned, the guarantee of effectiveness will draw top dollar on the market. Adding to overall patient expenses will be physicians' desire to guard against ADRs and lost treatment time due to ineffective drugs by ordering DNA tests. These currently cost about \$500, though that is expected to come down. The topic of DNA testing raises not only patient cost but also the threat of compromised confidentiality of patient information.

The swipe card containing every person's genomic identification is still beyond technology's reach, but it won't be for long. With new correlations continually being made between SNPs and diseases, drug sensitivity, and other susceptibilities, it seems sensible and economic to test individuals just once and keep all the information on file. This presents a nightmarish challenge to patient confidentiality and one that physicians and policy makers will have to solve soon. Physicians will have to determine how to manage the information that DNA tests will reveal to patients about themselves and their family members. Still, they cannot be expected to explain to each patient the basics of genetics, genetic probability, and the prognoses of diseases the patient doesn't yet have, if indeed he or she ever will. Acquiring informed consent for DNA tests and determining what resulting information a patient does and does not want to know will be a daunting task. Perhaps genetic counselors will find a role here. Whoever ends up doing the educating, patients or their insurers will pay.

The second level of confidentiality—who besides the patient has access to the information—should be a matter for policy, to my mind, policy that severely restricts access to patient records. It makes no sense that physicians should be

burdened with the practical hassle (not to mention the dubious ethics) of maintaining isolated or shadow files so that employers and insurers cannot view DNA test results. Instead we must decide, as a society, what any third party—employers, insurers, schools—have a right to know. In my view, the answer should be "almost nothing." The support for my argument entails a restructuring of the way insurers do business and make profits, replacing the individual risk and "actuarial fairness" foundation with one rate for all who are covered. This would amount to a huge upheaval in a large segment of the corporate sector, but one no larger than the change the health care sector has undergone in a mere 2 decades.

While costs to patients will go up, pharmacogenomics could well reduce the economic cost of missed work and low productivity. The reduction will come from fewer ADRs; less lengthy drug treatment periods for patients; greater effectiveness of drugs (reducing the toll of disease on the body), and an increase in the number of illnesses that drugs can treat effectively.¹

Conclusion

Viewed alongside such attention-getting dilemmas as genetic enhancement of embryos, pharmacogenomics seems like a gentle giant. But it could signal the need for sweeping policy changes. First, it will lead to an explosion in DNA testing, for once drug sensitivity testing is available, it will become a standard against which negligence can be measured in cases of severe or fatal drug reactions. Secondly, physicians will have to work out means for educating patients about genetics and preserving confidentiality of their records. At the same time, the cost of DNA testing (on which physicians will insist for the reason just given) and the high price of more effective, safer drug therapy will drive up expenses. These challenges to confidentiality and affordability should force policy makers to address insurance discrimination (for those have insurance) and the just distribution of health care to all members of society (including those who do not have insurance). If it achieves these ends, pharmacogenomics will be good medicine indeed for the nation.

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HISTORY OF MEDICINE Learning to Listen Karen Geraghty

It happened the other morning on rounds, as it often does, that while I was carefully auscultating a patient's chest, he began to ask me a question. "Quiet," I said, "I can't hear you while I'm listening".\(^1\)

That physician has not shushed a patient, silencing questioning sounds from the lips while focusing intently on the muffled thumps from the stethoscope? Technical listening is a skill that has advanced medicine tremendously in the last 2 centuries. If the staff of Aesclepius was the symbol of ancient medicine, the stethoscope undeniably has become the symbol of modern clinical medicine. While perhaps the most basic of diagnostic tools available to the contemporary physician, this deceptively simple rope of tubing and metal symbolizes the history, style, and content of modern medicine.

At the beginning of the 19th century, the value of percussion in physical diagnosis was recognized by Auenbrugger and Corvisart, leading to advances in the diagnosis of lung and heart disease. Laënnec enhanced the clarity of chest sounds with an innovative solution to the problem of listening to the chest of a stout but bashful young woman. He rolled a tube of papers and placed one end to her chest and one to his ear, thus both preserving her modesty and creating the first rudimentary stethoscope.

Despite its pervasive use in the 20th century, initial use of the stethoscope was slow to gain acceptance by physicians and patients alike. Physicians were wary of relying on information conveyed through instruments and of introducing devices into the physical exam that might interfere with their communication with patients. Patients were suspicious that stethoscopes might reveal more personal information than they intended their physicians to know. Use of the stethoscope likewise required a complete reorganization of how medicine was taught and practiced:

To learn the sounds of disease and their association with anatomical lesions required access to a large number of patients, the presence of colleagues who could teach auscultation, and autopsy facilities to check bedside judgements. All of these could be found in a hospital. . . . As Laënnec wrote: 'It is only in a hospital that we can acquire, completely and certainly, the practice and habit of this new art of observation".²

Once it was accepted as a common element of the physical examination, use of the stethoscope ushered in the era of technological medicine and with it a new way of listening to the patient. Technical listening requires a very specific focus,

indicated—but not of course, exhausted—by the minute but decisive change, whereby the question: "What is the matter with you?," with which the eighteenth-century dialogue between doctor and patient began...was replaced by that other question: "Where does it hurt?"³

While the first question elicits the patient's perspective in defining the problem, the second question clearly shifts the responsibility to the physician. Use of the stethoscope, along with the increasing technological innovations of the 20th century, soon threatened to drown out the patient's voice in the clinical encounter. The challenge that this shift posed to the patient-physician relationship did not go unrecognized. At the turn of the century, long before the bioethics movement of recent decades, physicians were cautioned to treat the "patient as person, [by considering] the patient's personal history and social situation in diagnosing and treating organic disease".⁴

Yet despite the forewarning, technological advances coupled with the increasing reliance on the objective data of statistical evidence and measurement came to dominate the clinical encounter. The incongruity of the physician's admonition to the patient in the quote at the beginning of the article clearly captures the paradox of the contemporary clinical exchange—with its focus on the objective symptoms of the body, rather than on the subjective accounts of the patient's experience.

Ironically, with the increasing reliance of physicians on more sophisticated and powerful technologies, use of the stethoscope—once the gold standard in a physician's physical examination—is falling out of favor among the new generation of physicians.

It is a common scene at teaching hospitals today: young doctors ignoring physical examination to the chagrin of their supervisors. At one time, keen observation and the judicious laying on of hands were virtually the only diagnostic tools a doctor had. Now, they seem almost obsolete. Technology like ultrafast CAT scans and nuclear imaging studies rules the day, permitting diagnosis at a distance. Some doctors don't even carry a stethoscope anymore.⁵

In the quest to reach ever-greater percentages of statistical certainty, the new generation of physicians is shying away from subjective observation, wary of relying on the evidence uncovered by their own senses and the unquantifiable descriptions by patients. "Fear of lawsuits is partly to blame, but the fear of subjective observation is stronger. Doctors are uncomfortable making educated guesses based on what they see and hear".⁵

The stethoscope, viewed with skepticism as a means for making a good physical diagnosis a century ago, is in some circles now viewed with skepticism as being too subjective to produce a physical diagnosis with a high degree of statistical certainty.

In a highly technical environment where uncertainty is unacceptable, the remarkable developments in diagnostics and therapeutics, while advancing the state of 20th-century medicine, have nonetheless created a chasm between the physicians' clinical orientation toward disease and patients' experiences of illness. While physicians of the 19th century tended to listen to patients at the expense of the information provided by technical enhancements, 21st-century physicians could be charged with the opposite problem. They are being called upon to learn how to listen to patients' subjective accounts and to incorporate them into the technological framework of clinical medicine.

Most patients who experience illness symptoms develop an explanatory model. More frequently than physicians realize, these attributions involve serious and potentially life-threatening medical conditions. Only a minority of patients spontaneously disclose or "offer" their ideas, concerns, and expectations. Often patients suggest or imply their ideas through "clues." Active listening is a skill for recognizing and exploring patients' clues. Without this communication skill, patients' real concerns often go unrecognized by health care professionals.⁶

The challenge for contemporary physicians, therefore, is to balance and reconcile the patient's subjective account of illness with the objective information about the patient's body produced by technology. The stethoscope, in spite of its simplicity as a diagnostic tool, represents—perhaps now more than ever—the ideals of the patient-physician encounter. Born of a physician's consideration for the feelings and experience of his patient, the stethoscope represents the benefits of technology while exemplifying, literally as well as metaphorically, the intimate and crucial link between the patient and physician. Skillful listening by the physician through the stethoscope reveals the hidden language of the body. The stethoscope also serves as a reminder that learning to listen skillfully to the language of the patient's concerns and experience should be just as important.

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VIEWPOINT Used Parts Faith Lagay, PhD

Two-thirds of the bodies donated at death to help others are used for tissue—principally bone and skin—rather than for organs.¹

Donations from one body can be used in as many as 400 procedures.

Corneas, portions of the mandible, heart valves, saphenous veins, and patellar tendons can be transplanted directly to the same parts of the recipients' bodies from which they were harvested in the donors' bodies.

Bone from the iliac crest (pelvis) is used in hip and spinal surgery.

Tissue from 3 sources—costal cartilage, thigh muscle fascia, and Achilles tendon—finds its way to the knee for repair and reconstruction.

Rib segments are used in mandible reconstruction and skull repair.

Hearts unsuitable for transplant may supply aortic and pulmonary valves, and pericardial tissue may be used to replace damaged dura around the brain.

The use of recovered skin (about 4 square feet per body) is so lucrative in cosmetic surgery that burn units have difficulty procuring as much as they would like for therapeutic grafts.

Parts of femur and fibula are most versatile. Chopped, grafted, ground to powder, chemically treated, or tooled into dowels and screws, they can supply materials "for everything from dental work to spinal surgery".¹

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Faith Lagay, PhD is the managing editor of *Virtual Mentor*.

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VIEWPOINT Writing "The Gift" Chris Fusco

When journalists have opportunities to escape their newsrooms and report stories first-hand—to spend days, weeks, or even months with their subjects—they usually chomp at the bit to take them. In most cases, I would, too. But this story was personal. It was August 17, 2000, when my childhood friend Mark Mucha told me that he had liver cancer and might need a living-donor transplant to save his life. Four of my friends and I ended up on the short list to be Mark's liver donor, and, after nearly 4 months of waiting, I was selected. Adding to the drama was that Mark was a new dad, and that my wife Jennifer was 8 months pregnant with our first child when Mark and I went into surgery on December 12, 2000. We were both 28.

My editors at the *Chicago Sun-Times* and I recognized the "story value" of my being Mark's donor early on, but the subject didn't really come up until after I was singled out to do the operation. It's one thing to thrust oneself into a story as an impartial observer. It's another to be one of its main characters, and to ask family and friends to put their lives on display. My bosses realized this, and they didn't want to be pushy. At the same time, they knew this was a once-in-a-lifetime opportunity to place a reporter not only in an operating room but on the operating table. Luckily for me, Mark and his wife, Kelly, embraced the idea of my writing our story. They felt that if the transplant allowed Mark to get his life back, they would do everything possible to raise awareness about organ donation and cancer research. A story in the *Sun-Times* only would aid that cause.

The problem was that this story did not have a happy ending. Mark died on March 25, 2001, after a series of complications that included my liver failing him and a second transplant not working, either. Besides the grief of losing him, I questioned if I wanted to—or if Mark's family would let me—tell our story, which had more twists and turns than anybody could have anticipated. Back at work about a week after Mark's death, *Sun-Times* Metro editor, Don Hayner, called me into his office. He guaranteed that nobody at the newspaper would think any less of me if I didn't do the story. But he also made a very logical argument about why I should consider writing it. "We only tend to write about things like this when they go well," Don said. "This one didn't, and I think the public can learn something by reading about it." With Kelly's blessing and cooperation from everybody involved in Mark's case, "The Gift: A Transplant Journey" appeared in the *Sun-Times* in late December 2001.

Writing the story proved difficult both emotionally and technically. I went through a 2-foot-tall stack of medical records, spoke dozens of times with Mark's surgeon and other medical experts, corroborated dialogue with friends and family, and delved into a controversy about whether too many adult-to-adult live-liver surgeries are being performed too quickly. There were days when I felt like quitting, but all the work paid off.

"The Gift" sparked nearly 800 e-mails, letters, and telephone calls to the newspaper. One was from an emergency-room nurse who wrote that the story "has been circulated to all of the staff as a 'must read.' Thank you for reminding me why I became a nurse, and why I continue to do it in the face of sorrow, sadness and pain." Another person wrote, "I was moved by this story so much that, even though I said I would be a donor and filled out donor cards in the past, I never signed the back of my license—until this morning. Thank you for making me believe." Still another, "I truly believe the story will change *Sun-Times* readers throughout the United States the way Sept. 11 did. God willing, maybe this story will surpass Walter Payton's efforts 10-fold with organ-donor transplants. We all have to again re-think our priorities in life."

I have never gotten such heartfelt responses to anything that I've written. Equally gratifying was that calls to the state's organ-donor hotline doubled during the two weeks following the story.

In hindsight, I'm glad that I wrote "The Gift," and that so many people walked away from it enriched. It is heartening to know that newspapers can still make a difference in readers' lives. I'm glad Mark's son Jake and my son Ben years from now will be able to read the story and know what true friendship is all about. At the same time, I'd give anything for the situation . . . and the story . . . to never have happened. For Mark and me to be getting ready to take our boys to their first White Sox game this summer. That would have made a great story—the kind that lives on in one's memory, not in the newspaper.

Chris Fusco has been a staff reporter at the *Chicago Sun-Times* since September 2000. Before that, he worked at the suburban *Daily Herald*, where his beats included transportation and politics.

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PERSONAL NARRATIVE

Through the Caregiver's Eyes: In Hushed Tones

Diedre Martin

My husband died on a perfect winter's day in Los Angeles. Steady rains the previous day had left the air damp and faintly smelling of flowers and grass. The sun, slow to burn through the clouds, made surfaces sparkle with a combination of rainwater and dew. Replenished by the water and cool temperatures, the abundance of flowers seemed brighter, more colorful than usual. At the time of my husband's death, the sun had warmed the day and cleared the sky of grey, replacing the somber color with an intense blue and a few flat, white clouds to break its evenness.

Inside our home, Alan's body lay in perfect stillness. He died a few minutes before noon, and over the next hour close friends gathered to wait with me for the arrival of the men from the mortuary. Friends sat or stood in the family room, talking among themselves in hushed tones. In the adjoining room, I sat on the bed next to my dead husband and listened to their muffled conversation, occasionally picking out a word or two. Their familiar voices comforted me as did the birds singing outside the window and the sun that warmed the room and made it bright.

I watched Alan's chest, hoping for a sign that the labored breath I had heard for the past months would return for a moment or two. I remembered when I first noticed the changes in his breathing. I awakened to a pause, an absence of sound. It was a silence that frightened me. I found myself waiting, counting the seconds until I heard the familiar, greedy intake of air. Alan's pattern of breathing deteriorated slowly over the weeks. I marked our remaining time together by the growing silence between those ragged sounds.

Observing his body, I marveled that Alan was handsome, even in death. Who, I wondered, had changed his position from the one where he had taken his last breath to the serene pose he held now?

A car door slammed, returning my attention to the window and the world outside. Two strange men, dressed in dark, businesslike suits and crisp, white shirts, climbed the 42 steps to our front door. Both wore their hair short and neatly styled. They looked young—too young to be the ones to take my husband's body away. My memory finds them physically unattractive, but now I wonder if I am recalling them accurately.

I have forgotten what, if anything, they said to me as they entered the bedroom, but I do know, they handed me a number of papers to sign. Without bothering to read them, I scribbled my name and the date at the bottom of each page. They moved away from me and positioned themselves on either side of our bed; then, with no apparent signal, they lifted Alan's long limp body to the center of a white sheet and began to wrap him in it. Unable to speak, I slipped in front of one of the men, took the sheet from his hand, and reached over my dead husband to take hold of the other side. My abrupt movement might have startled them, but I felt it was my place to wrap Alan in his white shroud, covering his face, his body, for the last time. Having completed the task, I stepped away and watched.

A metal cart, used to transfer the dead to the funeral home, stood next to our bed. On the cart lay a thick, black plastic bag. A large, metal zipper extended down the length of the bag, open, ready. In one swift movement, the men transferred Alan's body from the bed to the metal cart. As soon as his body was centered on the opened bag, they began to zip it shut. It was at that moment I fled from the house, running down the old brick steps, escaping the awful sound of the zipper and the disappearance of my husband.

By the time I reached the bottom of the stairs, I was breathing heavily. My hands hung awkwardly against my sides as I stopped to catch my breath. I was confused and agitated and felt out of place in my own neighborhood. Minutes passed. Breathing became easier. I realized I was waiting for the men to carry his body to their black van.

The front door of our home swung open, and the 2 men from the mortuary carefully guided the cart down the stairs. It reminded me of a long, narrow laundry cart on oversized wheels. I searched for the outline of Alan's form, but it was hidden somewhere deep within the cart. Gone was the body I knew better than my own. I tried to visualize my own back but couldn't, for I had never really seen it, not fully, not as it really is. But I knew his back, his body, every curve and blemish, and felt a part of me had vanished within that cart.

They moved quickly past me, and I am almost sure one of them mumbled his condolences. The legs of the cart collapsed against the van's floor as the entire contraption was shoved into the windowless back section. Then, almost simultaneously, both of the van's heavy metal doors met at the middle and slammed shut. The harsh sound initiated an unpleasant sensation that ran through my body like a fine current of electricity, causing an internal trembling that left me weak.

As they drove away, I experienced the first wave of grief. The emotion proved stronger, more powerful than anything I had ever felt before. It washed over me, taking the life I knew with it, changing me forever.

Trading Los Angeles for Milwaukee

For 20 years Alan and I lived in California. Initially, we planned on staying just until we finished school. But we kept extending our stay until eventually we realized it was our home. Most of those years were spent in Los Angeles, a city we learned to love, a place where many of our closest friends lived, where we enjoyed our careers, and where our daughters were born. When their father died, Kathryne was 8, Alexis, 5.

Two years after Alan's death, the girls and I left Los Angeles and moved to Milwaukee. I grew up in Chicago, which is only 100 miles south of Milwaukee, and I had formed a positive impression of the smaller city. Milwaukee offered the cultural benefits of a large city without the disadvantages. But there was one more benefit to Milwaukee: I would not be reminded of Alan wherever I turned.

Hospice and a New Beginning

Once the girls and I had settled into our new home, I explored the possibility of performing community service as a hospice volunteer. Alan had died at home with the help of hospice, and I was indebted to each person who made that possible: nurse, social worker, volunteers who kept open the 24-hour help line, and home aide workers who assisted Alan with his showers when physically I was no longer able to do it. Even though I was young, strong, and determined to honor Alan's wish to die in his own bed, without the support of home hospice the last month of Alan's life would have been even more difficult than it was for Alan and me.

I learned that it takes more than a committed person to care for the dying, and like most people, I was unschooled in this type of care. The Los Angeles home hospice workers provided me with the guidance I needed to ensure the best possible environment for Alan to die at home.

During the final months of Alan's life, I was his primary caregiver—a job that involved all hours of the day and night. Our family was assigned an intelligent, kind nurse who specialized in end-of-life care. Theresa was Alan's tireless advocate and my patient teacher. With her as my guide, I learned how best to attend to his needs, making him comfortable and ensuring his safety. Alan did not want to spend his remaining days in a hospital bed; he wanted his own bed and to sleep next to me. It was Theresa who showed me how to arrange his pillows so he could sleep more comfortably. By rearranging them every couple of hours, I learned how to relieve the pressure on Alan's back, sometimes even easing the effort it took to breathe. Periodically, he had to take IV medication. It was she who gave me the confidence to check the lines, switch the bags of medicine and fluids at the correct intervals.

Grateful for her quiet support when our family needed it, I felt I would show my deep respect for her by volunteering my services to hospice. After the first year in our adopted city, I began community service as a hospice worker. I never imagined it would be a journey lasting 6 years.

Saint Anne's Hospital

In Milwaukee, several hospice organizations accept volunteer workers. After touring them, I finally selected an established, well-run unit at an inner city Catholic hospital. Located in a neighborhood predominantly African-American and Orthodox Jewish, it draws its patient population not only from the surrounding area but also from a loyal group of older people. This group, at one time, lived close to the hospital but now travels from all parts of the city to return to their old neighborhood for medical care. The hospital serves both the poor and the well-to-do.

St. Anne's Hospice Unit is sandwiched between 2 very active wings of the hospital—the east wing, devoted to patients needing short-term rehabilitation, and the west wing, dedicated to oncology patients. Unlike any other area of this busy hospital, the hall that leads to the hospice rooms is quiet. Absent is a sense of urgency. There isn't the bustle of technicians, nurses, and doctors entering and leaving rooms, checking charts, and discussing a course of action for a patient. No one has to dodge a wheelchair carrying a patient to treatment, diagnostic tests, or scans—no one here requires them. That part of the patient's hospital life is over. This part is peaceful and quiet.

All these things I learn over time. But on this first day, when the sixth-floor elevator doors open, I step out into the St. Anne's Hospice Unit, a nervous but determined volunteer.

Diedre Martin lives with her two daughters in Milwaukee where she writes and works with members of a documentary film company.

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PERSONAL NARRATIVE

Through the Student's Eyes: Respecting a Hero's Wishes

Draganas Gastevski

Nearing the peak of Mt. Pelister in southern Macedonia, I stopped to look at the radiant yellow sun directly above head. I gave myself a moment to take in the beauty of the feathery clouds in the rich ocean of sky. While absorbing my surroundings, I looked down to see the village built at the base of the mountain. The tiny ceramic roofs glowed fiery-red under the hot July sun. Among those little ants was the house where a dynasty began.

Pando Gastevski was born in October of 1922. He was married by the age of 18 in the usual arranged manner. He soon created the initial fork in the new tree with his first son, Simo. Immediately after, war broke out. Pando fought bravely with the Yugoslav resistance until his capture by the Germans. He spent the next 2 years in a death camp in Bulgaria. Many of his comrades lost any glimmer of faith. To Pando, the light of freedom glowed like a strip of burning magnesium. He organized a revolt that would aid the escape of over 15 men. The Germans, not willing to accept defeat, tore through the mountains with behemoth tanks and trucks in search of the sickly, dried up men. A 6-month pursuit followed. The escapees made it to safety only by the goodness of the communities they passed through.

Pando continued his family life with the birth of his second son, Lazo. He also took the popular vote to become mayor of several villages. When Lazo was still an adolescent, Pando decided that a new canvas would be needed to paint the rest of his family's story. He set off to Australia and then to America in what would become a 10-year journey. In the end, Pando went back to Yugoslavia with enough money to bring his wife and second son to America.

Today, Pando is a grandfather twice over, with great-grandchildren from Simo's only son, Goce. With Pando's victories and success has come one of his greatest hardships, old age. He is now 79 years old, suffering from diabetes, high blood pressure, arthritis, congestive heart failure, and the difficulties associated with each of these illnesses. Pando had the desire to take one, perhaps last, trip back to his homeland with his grandson, Dragan. His fragile dreams suddenly shattered with the development of gangrene in his little toe. His somewhat uncontrolled diabetes had decreased blood flow to his feet, making the chances of a good immune response almost as easy as attaining world peace.

Pando was immediately admitted to the hospital. The surgeons and doctors concluded that the best treatment would be amputation of the leg "merely" at the upper thigh. Pando's son, Lazo, immediately called on *his* son, Dragan to come home to help. Upon receiving the news, I rushed home from college as fast as I could. As long-standing interpreter and pre-med student, I was sent by my family to get the whole story from the doctors. In all of my attempts, the only information I gathered was that it was safer to amputate the entire leg rather than just the foot. In the end, with the support of researched medical advice, I challenged the surgeons' decision to amputate the entire leg. The resulting surgery only removed 2 toes, leaving Pando independent enough to continue living his life. As a future doctor, I see myself wanting to treat patients to better their health. Immediately, I begin to consider my grandfather's case and the point at which we must stop treating patients in order to respect their dignity and happiness.

At first, the news of a broader amputation had sent Pando into shock. This brave military commander, mayor, pioneer, and family man had been brought up in a culture that stressed his role as the leader of the household, the root of our growth in this new country. I was the first one to tell him of the doctors' decision. He told me frankly that he would rather put a bullet in his head than to live the rest of his life as a cripple, always begging for help to go to the bathroom. I was, of course, used to his brute chivalry. Before his hospitalization, my mother and I had shared the responsibility of driving him to doctors. In the beginning, Pando would allow us to go in with him and listen to the doctors' prognoses. Upon returning home, we would tell him that he shouldn't have that chocolate because of the doctor's orders. Pando would tell us that we misunderstood the doctor, because the doctor had apparently told him to have one piece of chocolate per day. This trend of contradiction persisted until Pando became angry and refused to let my mother enter the examining room with him. We continued to note him satisfying his sweet tooth and his resulting high blood sugar. Any attempts to confront him, however, have always ended with him swearing that he was doing what the doctor told him.

Is this a case of simple anger, or is it a respectable leader of a clan facing humiliation as a result of the difficulties at this point in his life? I might also think that his occasional forgetfulness could be to blame. My family and I have tried many times to persuade him to go on insulin or do more exercise. Every time, he has put up a brick wall of resistance. Is it time for us to dig trenches and reenter combat? As a medically oriented student, I believe it is my duty to help those around me, especially my family. But in considering this issue, I begin to question whether it is even worth fighting with him. If my family pulled out all the artillery and fired upon him, he would forever resent us for our insolence and demoralizing acts against the head of the dynasty. In all of this consideration, I am not able to draw up a clear ending or decision. My attempt to weigh strict medical care against personal freedom keeps stabilizing at a certain point: Does Pando achieve a higher level of overall happiness if we let him do what he wants? At my young age, I am not yet sure what the meaning of life is. I do, however, know that a general aim of man is to have the highest levels of happiness and satisfaction throughout life. My

grandfather has gone into Hades and has come back to level the land for his family with his own fists. As a leader, he has created a foundation for growth in our villages in Macedonia, and most of all, for his own dynasty. After all that he has been through, I attach particular significance to the fact that his first mention ever of ending his life comes in answer to a doctor's diagnosis. I leave this considerable narrative pondering the same thought with which I entered: What should doctors and families do when one who has lived a hero's life, or *anyone* for that matter, refuses strict medical care?

Draganas Gastevski is a biology major psychology and neuroscience minor at Loyola University who intends to enter medical school upon graduation this year. Dragan has a strong interest in medical ethics and has worked as a public health counselor over the past year.

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PERSONAL NARRATIVE

Through the Patient's Eyes: A Valentine Story

FR Burdette

When it became apparent that the solution to my drooping eye and ongoing eye infections was surgery, I was ready to schedule it for the earliest possible date.

That would be February 14th, Valentine's Day. Valentine's Day hadn't been special to me for years. I didn't have any Valentine obligations. Neither Hallmark Cards nor Russell Stover's Candies, nor florists—nor anybody else—had profited from me for some time. I was a cynical Valentine Scrooge as it were. Still there was something about scheduling that day that seemed peculiar, strange, ironic—I didn't know quite what. But I went for it.

When they rolled me into the operating room I was somewhere in the twilight zone. I had to be able to open and close my eyes on demand but not to wrestle the knife from her long delicate young fingers. I joked with her not to make me look any younger than about 40. I don't remember whether she promised not to remove more than one quarter of a century or not. I do remember her drawing lines on my eye lids for the knife to trace.

Later I became conscious of a young male voice speaking softly to her, encouraging, supporting, agreeing as she removed some of the excess folds of my right upper eyelid. I asked where this coach had come from as she tightened and shortened my lower lid, but there was only soft laughter as she reattached the lower, and upper lids in the corner of my right eye.

The left eye was simpler. It didn't take long just to remove part of the upper eyelid and suture it back together. Then the young male came up alongside me. I think he made eye contact but I only remember seeing one black eyebrow beneath a blue surgical cap as he explained he was her husband—an ear, nose and throat man—and that he liked to come watch her when his schedule permitted so that he could learn to improve his own plastic surgery skills.

It sounded like a love story to me.

FR Burdette lives, writes, and walks the seawall in Galveston, an island off Texas, in the Gulf of Mexico.

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