Virtual Mentor		
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June 2001, Volume 3, Number 6: 177-218 Disparity in Health Care Delivery

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American Medical Association Journal of Ethics June 2001, Volume 3, Number 6: 179-182.

FROM THE EDITOR Deconstructing Disparity Audiey Kao, MD, PhD

"What brought you in today?" asked Dr. K.

"I have had attacks of lower abdominal pain for 1 year. The pain is located in the middle to right side of my lower abdomen," said Mrs. S, a 30 year-old, obese white woman who presents for her first office visit with Dr. K.

"Why have you come to see me today?" asked Dr. K.

"I have had attacks of lower abdominal pain for 1 year. The pain is located in the middle to right side of my lower abdomen," said Mrs. S, a 30 year-old, non-obese white woman who presents for her first office visit with Dr. K.

The only significant difference in these hypothetical clinical encounters is that one patient is obese and the other is not. The effect of obesity on clinicians' approach to patients with abdominal pain was recently assessed in a novel study by Wigton et al¹. The investigators were concerned that widely held beliefs that obese people are "lacking in self-control, lazy, and poorly motivated" might be found among health professionals^{2, 3} and that this stereotype would adversely affect their diagnosis and management decisions. Seventy-two 3rd- and 4th-year medical students were presented with video histories of simulated patients who presented with irritable bowel symptoms, but who differed in their body weight (normal versus obese). Based on this information, the medical students were asked how they would assess and manage these cases. Results of this study revealed no significant difference in diagnostic decisions and recommended management based on a patient's weight, except for those that were medically indicated, such as blood glucose and dietary counseling. However, the study revealed that medical students were less confident that obese patients would be able to comply with the nutritional and exercise recommendations, and they were less likely to want obese patients in their medical practice.

Despite its methodological limitations (such as convenience sampling and the hypothetical nature of the clinical encounter), this study sheds light on the complex and challenging issue of physician biases and its impact on medical decision making. But more substantively, the study reflects a much larger and ongoing inquiry into not only the medical, but social, economic, and political factors that contribute to the persistent disparities in health among individuals and communities in the US^{4, 5, 6, 7, 8}. In light of national and global disparity in health, this month's issue of the Virtual Mentor is dedicated to exploring and examining the variety of factors that lead to disparities in health among Americans and how physicians as professionals and as citizens can address this health crisis.

From an overall perspective, factors that maintain disparities in health and wellbeing fall into 2 broad categories: (1) health-related factors that can be modified by the health care system, and (2) factors such as poverty and illiteracy that require non-medical solutions to the social determinants of health disparities. A prime example of the latter, poverty, often results in a vicious cycle of health disparity that not only affects individuals but serves to concretize poor health across generations. Over this past decade, the percentage of individuals and families living below the federal poverty line has decreased significantly, and this is an encouraging sign. Yet, over this same period, the percentage of the US population still unable to afford health insurance, and millions more who have inadequate coverage. Efforts including the State Children's Health Insurance Program (SCHIP) and expanding coverage via tax credits are viable incremental solutions^{9, 10, 11}.

Ultimately, addressing the causes and consequences of social conditions such as poverty will demand participation and leadership from physicians in their roles as citizens of a civil society. We can give of our expertise to those in need, donate to charitable organizations, support those who advocate for effectual social policy, donate blood, register in a bone marrow bank, and always vote. Of course, this level of citizenry takes time, money, and effort, but as members of a society who are among its most affluent and well off, we must strive to live up to these obligations.

In addition to our responsibilities as citizens, we need to recognize how we may be contributing as physicians to inequities in medical care, and thus disparities in health. As noted in the above study by Wigton et al., evidence suggests that physician biases and patient stereotyping based on characteristics such as gender, race, appearance, and lifestyle may influence clinical decision making^{12, 13, 14, 15, 16}. Reflecting on my professional training as a resident during a time when a significant segment of the hospitalized population comprised AIDS patients, I can find instances of professional bias. Most of the patients I saw had contracted AIDS through intravenous drug use or unprotected sexual intercourse, and I can still vividly recall that, in my first month as an intern, one psychotic patient was intent on infecting the hospital staff with the HIV virus. Suffice it to say, I was ill prepared for this situation, and would be less than honest if I did not admit to moments of frustration and anger at these AIDS patients. Fortunately for the patient's care, an intern does what he or she is told, whether it's securing central venous access or drawing blood for cultures. Fortunately for my professional development, I had mentors who advised and reminded me that as physicians, it is our responsibility to care for, not judge, our patients. Now that I am an older physician, I realize that it is naïve to think that physicians are completely immune

to the prevailing stereotyping and biases that exist in today's society. Thus it is critical that, as professionals, we realize our flaws and failings as we strive to meet our professional ideals as healers and physicians.

I hope that by providing an opportunity for us to reflect on this complex issue, this special theme issue of the Virtual Mentor will help our readers better appreciate and understand the myriad factors that contribute to disparities in health. I call on my colleagues to apply our expertise and leadership not only as professionals but also as citizens of a civil society in addressing our nation's health disparities.

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CASE AND COMMENTARY Emergency Treatment for Patients Who Cannot Pay Commentary by Kayhan Parsi, JD, PhD

Case

Dr. Burnett arrived at DeFrancis to examine Mrs. Raphael. He confirmed her blood pressure to be the highest he had ever seen, 210/130, and he assumed that she had been hypertensive throughout her pregnancy. He estimated that Mrs. Raphael's baby weighed 6 pounds—less than normal weight. After stabilizing Mrs. Raphael's blood pressure, Dr. Burnett arranged for her transfer to David Ward Hospital, a perinatal facility better equipped than DeFrancis to care for underweight infants.

Ms. Harper then showed Dr. Burnett the DeFrancis Hospital guidelines regarding the Emergency Medical Treatment and Active Labor Act (EMTALA). EMTALA requires that patients diagnosed with an "emergency medical condition" or in "active labor" be treated at the emergency department where they present or be transferred, if they are in stable condition, to an emergency department better prepared to handle their medical emergency. Dr. Burnett refused to read the guidelines. He told Ms. Harper that Mrs. Raphael represented more risk than he was willing to accept from a malpractice standpoint. Moreover, he was concerned about reimbursement for taking care of Mrs. Raphael. Ms. Harper explained that Mrs. Raphael could not be transferred unless Dr. Burnett signed a form entitled "Physician's Certificate Authorizing Transfer." Dr. Burnett signed the form, and Mrs. Raphael was transferred.

On route to the hospital Mrs. Raphael delivered a healthy baby in the ambulance approximately 40 miles into the 170-mile trip. There were no outcome complications.

Questions for Discussion

- 1. Did Dr. Burnett fulfill his ethical obligation concerning treatment of indigent patients such as Mrs. Raphael?
- 2. Does the fact that Mrs. Raphael was a potentially high-risk patient make any difference in his ethical obligation?
- 3. In the absence of universal health insurance, EMTALA has become a safety net for uninsured patients who present at an emergency room. How well does this legal measure address inadequate care for the poor? What unintended adverse consequences can you foresee to this safety net role for EMTALA?

Kayhan Parsi, JD, PhD is a fellow in the AMA Ethics Standards Group

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 Physicians, Rural Practice, and Health Care Justice Keith Bauer, PhD, MSW

Bioethics refers broadly to the ethical issues and conflicts that arise in health care The shortage of physicians in rural areas is a longstanding and persistent problem for policy makers and medical educators who continuously face the challenge of devising effective means to meet the health care needs of rural residents. This is no small task, considering that rural areas are home to roughly 20 percent of the US population—approximately 50 million people—but only 9 percent of American physicians practice in rural communities. Rural areas have more primary care Health Profession Shortage Areas (HPSAs), which, in turn, have higher percentages of poor and elderly and persons with chronic diseases. From a health care justice perspective, this means that one of the least-well-off populations in the US—the elderly poor—is also one of the largest medically underserved populations.

Whether this population's inadequate access to medical care is unfair or simply unfortunate is subject to philosophical debate. What is not debatable, however, is that health care disparities in rural areas continue to worsen even as more physicians are trained in this country. In "Physicians and Rural America," Roger Rosenblatt and L. Gary Hart argue that limited access to medical services by many rural Americans stems primarily from the lack of health insurance and the tendency of health care professionals to live and practice in relatively wealthy urban and suburban areas. They also point out that more highly specialized physicians are less likely to live in rural areas and that, although more women are attending medical school, they are more likely than their male counterparts to practice in urban and suburban areas.

As a way of ameliorating disparities in rural health, the authors recommend that the medical education system do more to select and train physicians who are likely to choose rural practice and that Medicare and Medicaid reimbursement strategies be altered to provide economic incentives for practitioners in rural areas. If these measures prove inadequate, the authors also suggest creating more federal and state programs like the National Health Service Corps and adopting telemedicine technologies to extend the reach of physicians to rural areas.

Questions for Discussion

- 1. Is it fair to change Medicare and Medicaid reimbursement strategies so that they pay more for services performed in rural areas?
- 2. Is it fair for medical schools to selectively admit students who fit the profile of those more likely to practice in rural areas? If far fewer women than men

choose rural practice, is it fair to limit the number of women selected for admission to medical school?

3. In addition to educational and financial initiatives, the authors recommend the use of new information and communication technologies to overcome the geographical maldistribution of health care professionals in rural areas. Do you think that the use of telemedicine will undermine efforts to get physicians to locate to rural communities?

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STATE OF THE ART AND SCIENCE Genetic Disparity: Unfair or Only Unfortunate? Faith Lagay, PhD

Genetic information and gene therapies promise to complicate our understanding of disparity in both health status and health care. Genetic knowledge and technology will force us to consider which inherited conditions are "normal" and which deviations from "normal" constitute valid need for medical care. Implicit in this question are economic questions: To what extent does society owe a certain standard of health to all its citizens? To what extent should its healthier citizens subsidize care for the less healthy?

When health and character, skills and talents are thought of as inextricable aspects of who someone is, we pay little attention to just or unjust distribution. We are accustomed to the fact that some people are more healthy or gifted than others, and, unless nature has been particularly "cruel," the concepts of disparity and justice are seldom applied. When, however, the same health, skills, and talents are thought of as residing on discrete segments of DNA, it is easier to think about them as "parts," assets, or even resources. In the next move, we think about these assets and resources including health as something one should have. In this light, distribution is more likely to be viewed as just or unjust, fair or unfair¹.

Knowledge of our genetic make-up has already begun to test existing definitions of illness and health. Is a young adult with a mutation that leads to Huntington disease or might lead to breast cancer an entirely healthy person, a pre-symptomatically ill person, or merely, like everyone else, a potentially ill person? Does that person have a claim on medical services? The most widely used working definition limits "medical care" to those interventions employed to prevent illness, disease, and dysfunction, treat symptoms of illness, disease, and dysfunction if they occur, and restore function that is normal for a given individual's age and sex².

This standard medical model, as it is called, has been used to distinguish between needed medical services and optional or elective medical services. Decisions by both government and private payers about whether or not to reimburse expenses for a given medical service are generally closely tied to whether or not the intervention is considered to be a needed medical treatment, according to the standard medical model. Genetics will challenge this notion of medical need.

Even before the Age of Genetics, some distinctions were difficult to make; the effectiveness of a given therapy was often questioned, even though the need for

treatment was not, and the medical "need" for many psychiatric and plastic surgery procedures that could be linked, sometimes loosely, to "normal function" for one's age and sex was often disputed. Genetic information will blur these boundaries further, challenging definitions of medical need and treatment in ways that could easily create greater disparity in distribution of health care services. In the late 1980s, when discussion of the potential for genetic intervention was still largely hypothetical, the distinction between therapy and enhancement was invoked in the hope that the standard medical model would offer a means for distributing genetic services equitably. Gene therapy should be provided and reimbursed for disorders that created medical need. Other genetic interventions—so-called enhancements would have no claim on insurance or government coffers. Genetic enhancement would be optional and elective.

The distinction proved difficult to maintain. Borderline "hard" cases cropped up. Suppose it were possible to genetically enhance the immune system beyond what is now normal. Doing so would prevent illness and save treatment costs later on. Would that be therapy or enhancement? Would it be worthwhile for society to bear the cost of such treatment? Norman Daniels raised the hypothetical case of two young boys who will both be "short" by society's current standards³. One has a genetic deficiency in growth hormone; the other has no deficiency but 2 short parents, so his height is genetically influenced also. According to the standard medical model, society should provide human growth hormone in the former case but not in the latter, even though both youngsters will attain the same adult height without "treatment." Daniels maintained that it was better to adhere to the medical need distinction and negotiate the hard cases than to go forward without any standard at all.

Theorists soon recognized a more serous flaw in the therapy-enhancement distinction—the consequences its implementation would have. If enhancement were not reimbursed and only the well off could afford enhancement, a "genobility" would result⁴. "Not only will the rich have more money than the rest of us," said philosopher Thomas Murray, "they'll be taller, healthier, better looking, and smarter"⁵. Some social intervention seems called for to prevent such an exacerbation of disparity in health-related opportunity. Can we restrict enhancement, even for those who can afford it? Should society be expected to compensate for all differences in distribution of natural assets, for each individual's good or bad luck in the natural lottery?

Recent thinking about whether and to what degree society and its individual members should bear the burden of correcting inequalities in the distribution of natural assets is summarized in From *Chance to Choice: Genetics and Justice*, published last year⁶. Its authors outline 2 positions on the question, which they call the social structural view and the brute luck view. The former view holds that society satisfies its obligation to provide equal opportunity when it compensates for defective social structures such as discrimination on the basis of race, gender, physical disabilities, and so on, that affect health care. Yes, the distribution of

natural assets is unequal, but it cannot be said to be unfair or unjust; one's bad luck in the natural lottery is just that, bad luck, and society has no obligation to provide, at its own expense, remedial treatments or accommodations.

The other model—the brute luck view—maintains that people's opportunity should not be limited by circumstances over which they have no control. This view supports the notion that there can be genetically based conditions that limit people's opportunities though they may not, strictly speaking, be conditions that create the need for medical services as stipulated under the standard medical model. And society should incur the cost for correcting the unfortunate, unequal distribution of natural assets that impede one's ability to pursue opportunities. The brute luck view endorses the goal of freeing humans from opportunity-limiting effects of misfortune in general. But differential distribution of attributes and talents accounts for diversity and provides the basis for valuing the natural gifts that some are born with. One must wonder how and where the brute luck model draws the line between opportunity-limiting effects and special natural talents.

As is proving to be the case in so many aspects of genetic knowledge and technology, the questions being raised are not new. Rather they give new urgency to issues that our society has not resolved. They force us to confront deeply contentious matters of individual versus social responsibility and to define what exactly our constitution intended when it guaranteed its citizens equal opportunity to pursue happiness, a pursuit promoted or inhibited in large part by health status.

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American Medical Association Journal of Ethics June 2001, Volume 3, Number 6: 191-193.

MEDICINE AND SOCIETY Feeding Health Disparities Kayhan Parsi, JD, PhD and Sara Taub, MA

The title of a 1997 Errol Morris film "Fast, Cheap & Out of Control" could aptly describe the abundance and ubiquity of low cost, nutritionally challenged food in the American landscape. Drive down any highway or turn the television to any commercial network and you'll soon be bombarded by slick ads inducing you to dig into the latest product for mass consumption. We've all heard the old adage that you are what you eat, but can it be said that you become what you watch?

Television programming and advertising appear to play a role in promoting unhealthy eating habits, sometimes playing on age and cultural stereotypes to coax viewers into buying foods that provide more comfort than nourishment. This perception has been recently reinforced by a study conducted by University of Chicago researchers who concluded that television shows and advertisements geared toward African Americans feature more obese characters and sell more high-calorie foods and beverages than other programs. The researchers studied four sitcoms that star African American characters and are popular with African American audiences—*Moesha, The Parkers, Malcolm and Eddie,* and *The Jamie Foxx Show.* They also examined four sitcoms without African American stars that are popular with general audiences—*Friends, Frasier, Jesse,* and *Stark Raving Mad.* They came up with the following results:

- 27 percent of the actors on the African American-oriented shows were overweight, compared to 2 percent on the general interest shows.
- 4.78 food commercials aired per half-hour in the African American-oriented shows versus 2.89 in the other shows.
- 31percent of commercials during the African American-oriented shows were for candy and 13 percent were for soda, compared to 11 percent for candy and 2 percent for soda in the general interest shows¹.

Dr. Anjali Jain, the University of Chicago pediatrician who headed the study, commented upon the disparity: "One could say this is an accurate reflection of African American reality, but on the other hand it might also be viewed as an ideal. It might help overweight people to feel less stigmatized, but on the other hand it might give them the message there aren't any adverse health consequences to being overweight" ². This is not to suggest that overweight people should not star in television shows. On the contrary, people of all sizes and shapes should figure in programs that claim to offer viewers a "slice of life." What is at issue is the message

conveyed when people who carry excess weight are portrayed almost invariably as happy individuals who have no health complications to worry about from their weight. A similar phenomenon occurs in film, where characters often smoke but seldom experience the health consequences associated with the habit. Obesity becomes a condition associated with only positive attributes that people will aspire to attain despite the health risks it raises in reality—a message further reinforced by the interspersed commercials that push for the consumption of "junk" foods. The concerns here are no different from those raised by ad campaigns that showcase emaciated women as ideals of beauty that girls will want to emulate.

Appearance-related preoccupations—poor body image and social stigma—deserve to be addressed in conjunction with excess weight. It is not appropriate, however, to discuss weight only in terms of aesthetics when its implications for health are significant. The Department of Health and Human Services' *Healthy People* 2010 finds overweight people at increased risk for several diseases that include: high blood pressure; type 2 diabetes; coronary heart disease; stroke; gallbladder disease; arthritis; sleep disturbance (apnea); respiratory problems; breast, prostate, and colon cancers; and depression³.

In a country where more than 100 million adults are overweight⁴ and obesity in younger children has been called an epidemic, it is time for the health consequences of obesity to be emphasized and addressed. Public education about nutrition and the importance of exercise is key to preventing and controlling problems of excess weight. To be involved in this public health initiative that has direct impact on their patients' well-being, physicians will need to have adequate knowledge in nutrition. Along with teachers and other community leaders, health care providers can play a significant role in helping people develop a balanced diet and integrate exercise into their daily routine. As Former Surgeon General Dr. C. Everett Koop, founder of "Shape Up America!," notes: "While there are obviously some costs involved, the result in terms of reduced health care expenditures will far exceed the dollars spent"⁵. Why has there not been more outreach in this public health area—with efforts similar to those extended in the battles against tobacco, alcohol, and violence? By using its resources to teach the principles of health-promoting lifestyles, the health sector could help reduce the number of overweight people and, in turn, reduce expenses associated with treating health complications of obesity.

Although, excess weight is a problem across the population, studies report that it is more prevalent among certain groups—particularly low-income African American women who face not only cost and neighborhood safety barriers to shopping for products that promote healthy living habits, but also tend to be more tolerant of obesity⁶. This observation brings us back to television programming and stereotypes. Dr. Jain says: "In some ways, the TV findings may just reflect reality, but I think it also plays a role in creating that reality. The chicken-and-egg argument is definitely there"⁷.

Along with ethnicity and culture, education influences consumption patterns. Younger and less educated viewers may be more influenced by what is shown and sold on the airwaves. Seeing healthy and happy obese characters as well as commercials for junk food may undermine educational efforts to improve dietary habits. This is where physicians have a responsibility to educate patients about nutrition and counter the plethora of images in the culture that promote poor dietary habits.

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HISTORY OF MEDICINE Physicians and the Obligation of Charity Care Audiey Kao, MD, PhD

As American health care services have become increasingly expensive, the persistent question of how to manage the financial aspects of caring for the poor has become more urgent. In 1847, when the American Medical Association published its *Code of Medical Ethics*, physicians were encouraged, as a duty to the public, to provide limited, gratuitous services to the poor:

Poverty, professional brotherhood, and certain of the public duties referred to in the first section of this article, should always be recognized as presenting valid claims for gratuitous services ... to indigent circumstances, such professional services should always be freely accorded ¹.

This duty of providing charity care had been a hallmark of the virtuous physician since the early Middle Ages, and over time had been incorporated into the gentlemanly ethic of the *noblesse oblige*. However, even by the time that the AMA *Code* formalized this duty in the mid-nineteenth century, several social factors were beginning to coalesce which would transform health care simultaneously into a commodity to be bought and sold on the market as well as a public good—and even a right—expected by citizens from their government. In the 150 years that followed, physicians would be called upon to mediate this tension between health as an expensive commodity and health as a social good. The question of how to care for the poor landed squarely in the center of this conflict which would come to define the context of medical practice into the year 2001.

The American medical profession emerged in the wake of the euphoria and aspirations of the Revolution. Political autonomy was in its infancy in the newly liberated colonies, and American wariness of the centralized authorities of European nations discouraged the involvement of Congress and state legislatures in the regulation of the medical profession. Instead, Americans developed a highly individualistic approach to medicine, modeled on the political philosophy of Adam Smith that promoted a specific, highly individual form of competition, with outcomes being decided by a free-market economy. Success in the American medical marketplace therefore came to depend upon the market forces of a consumer-based public.

Between the end of the Civil War in 1865 and the outbreak of World War I in 1914, improved hygienic measures and technological investments transformed the nature, effectiveness, and cost of medical treatment. American hospitals became permanent fixtures, both in the delivery of health care to the public and in the academic and

clinical training of physicians. But unlike the hospital systems of Europe, which were largely created by religious orders or governments, the American hospital system, influenced more by a British philosophical bent and a disdain for government, developed in a distinct fashion. American physicians, eager to establish hospitals for educational and social purposes but wary of state controls, solicited funds from private donors who in turn became trustees and members of the board. The treatment of patients was then supported with fees charged to patients for individual services.

By the 1920s, American health care was based primarily in a fee-for-service, freemarket system that was buttressed by educational standards and licensure requirements but otherwise few government controls. Ironically, England—whose system had provided the philosophical blueprint for the American approach to medical care—adopted a national health insurance plan in 1911 and, stimulated by the prospect of invasion during World War II, the English concluded that even more state involvement in the health care system was justified, both as a means to ensure care for the needy and to protect and promote public health.

As the 20th century progressed, "scientific medicine" led to extremely rapid advances in clinical care. In particular, after the First World War American medicine gained considerable prestige for its hospital-based medicine and the 1920s witnessed a rapid growth and expansion of hospitals throughout the United States.

In the decades that followed, American hospitals required heavy capital investments for technological developments. Patient fees, which had initially been a primary source of support, were no longer enough to sustain the rapid expansion of hospitals and the technologies they used. As medical care became more effective and expensive, the sense that access to health care was a social obligation requiring a pooling of risks began to take hold. As in Europe, early governmental involvement in providing care revolved around protecting national interests, such as the health of the Merchant Marine and the Armed Forces, and only later addressed care for the elderly, infirm, and poor. Protecting the health of the public was a major goal and, at least for some employers, maintaining a healthy workforce was also important. As effective therapies were developed that individuals could rarely afford to purchase, group hospital insurance plans were developed and the concept of the third-party payer was introduced to fill the void of governmental action.

As these changes took hold and began to shape the demands on the delivery of health care, the AMA's *Code of Medical Ethics* was re-written in the early 1920s and again in the 1940s to reflect the roles and obligations of physicians practicing within these institutional structures. Note how the duty of charity care is shifted to a section in the *Code* that discusses compensation. It reflects the growing insistence that institutions, rather than individual physicians, shoulder some of the burden of caring for the poor:

The poverty of a patient and the mutual obligation of physicians should command the gratuitous services of a physician. But endowed institutions and organizations for mutual benefit, or for accident, sickness and life insurance, or for analogous purposes, have no claim upon physicians for unremunerated services²;

In the ensuing decades of the 20th century, the rising costs of care and the increasing effectiveness of health care have slowly led the relationships of US physicians to be mediated by a host of private, public, and professional bodies-insurance agencies, health care institutions, government bureaus, professional associations, and so forth.

Physicians who have always had civic obligations to the public are now challenged to manage—both organizationally and professionally—the tension of health care as a commodity and health care as a basic social good in the face of patient needs, limited resources, and limited state support. From this tension have come the current Code guidelines on care for the poor³.

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ART OF MEDICINE Migrating Pathogens: Creating Fear of Health Risks Maria V. Ruiz, MD

By assessing the symbols and images that diseases attract we can come to understand the complex phenomenon of illness¹.

During the turn of the 20th century when immigration to the United States was at its peak, immigrants were the target of anxieties over what "face" (racial, class, and cultural characteristics) the nation would have². Immigrants were associated with disease, and public health measures were employed in regulating and disciplining immigrants. One of the important lessons that historians provide is that the association of immigrants with disease has health consequences which result in a cycle of discrimination and disease that *reinforces* the association of immigrants with contamination³. Stigma not only promoted the spread of disease by reinforcing prejudice, but also created fear and mistrust which distanced new immigrants from the medical establishment. In light of currently high rates of "new" (and non-European) immigrants, those concerned with racial and ethnic disparities should take note of these historical lessons. Although health disparities are well documented, the reasons for their existence remain elusive. A recent Kaiser Family Foundation study concludes that racial and ethnic health disparities are "complex" and "difficult to quantify"⁴. As suggested by Brandt, images provide a rich medium by which certain "data" such as attitudes, fears and anxieties, and political context can be qualitatively evaluated⁵.

A January 1997 cover of *American Family Physician (AFP)* entitled "Emerging Infectious Diseases: A Challenge to All," illustrates the increasingly interconnected anxieties surrounding disease, borders, and immigration. The *AFP* cover features an unfolded map of a portion of North America. Bacteria, parasites, and other pathogens frame the United States, while bright bursts dot and accentuate its borders. Although the bursts are not explicitly labeled as such, in relation to the topic of emerging infectious disease (EID) they most likely represent disease outbreaks. A mouse straddles the US-Mexico border and points north while a tick hovers above the Canadian border. Looking at this image, how do we read the relationship between borders, disease, and migration? What are the major concerns and priorities communicated in this image? What are the connections between this image and current heated debates about immigration, the US-Mexico border, and immigrants' rights to quality health care? Contrary to the title and the text of the article (described below) which suggest that EIDs are everyone's problem, this image represents EID as a foreign threat which has selectively compromised the integrity of US borders, as well as the health of US residents. One predominant theme is that of migration, as suggested most strongly by the unfolded map, and the animal and insect that have walked upon it and point towards the United States as their final destination. These travels are not innocent, as evidenced by the explosions that occur at strategic points along the borders, but rather are clandestine border crossings that threaten US national security.

This essay concerns images of the US-Mexico border and associations of Latino/a immigrants with disease rather than coverage of EID, per se. However, it is worth noting the discordance between how EID is represented in the cover image and how it is discussed in the text of the article⁶. Although the author, LJ Strausbaugh briefly mentions some of the more "exotic" diseases publicized in the mainstream press (e.g., Ebola virus), for the most part, Strausbaugh focuses on diseases that are either endemic to the US (e.g., ehrlichiosis), are nosocomial infections (e.g., vancomycinresistant enterococci), or are spread by poor food preparation methods (e.g., E. coli 0157:H7). "International travel and commerce" are listed as only one factor among many that are responsible for EID. Others include "changes in human demographics and behavior," "changes in technology and industry," "economic developments and land use," "microbial adaptation and change," and "breakdown of public health measures"⁷. Although the AFP image successfully draws attention to the importance of EID, it does so by drawing on familiar narratives of apocalyptic disease threats that originate from outside the boundaries of the nation; brought on by "Third World" people and pathogens encroaching on the US. The linkage between disease and border crossings does more than compare the problem of the borders to the problem of infectious diseases; the linkage assigns blame for one onto the other.

One of the possible repercussions of the *APF* cover image then is that, intentionally or not, it supports an increasing border patrol mentality in regard to immigrants and medicine, with implications for health interventions. In 1994, Proposition 187 was passed in California. If implemented, it would have mandated that health care workers verify the documents of those "suspected of being illegal," and report the undocumented to the Immigration and Naturalization Service (INS). Proponents of Proposition 187 drew on the stereotype of the dirty and diseased Mexican to support their claim that the US health care system was a magnet that attracted undocumented immigrants to the United States. Though Proposition 187 was held up in courts for many years before it was ruled unconstitutional, its legacy of fear and confusion have had lasting effects for access to health care for those who fit the stereotype of the illegal alien, namely non-European racial and ethnic groups, and the foreign-born. Federal legislation in 1996 made many *legal* immigrants ineligible for publicly funded non-emergency health care⁸.

Furthermore, the *AFP* image has particular implications in the clinical setting, as it is circulated among physicians, nurses, medical students, and hospital

administrators. Most worrisome is that immigrants are seen as disease vectors—like the mouse and the tick—rather than people that themselves suffer from disease. Also, images such as these may affirm nativist sentiments and contribute to the hostility, scorn, and "subtle and not-so subtle discrimination" that immigrants already face in the hospital or clinic⁹.

I believe that border anxiety is shaping health care in the US. But can we imagine the alternatives? If, as Williams and Rucker argue, racial and ethnic heath disparities were a national priority, and if "renewed regulatory vigilance" of discrimination in regards to health care were implemented, then we might be able to read the *AFP* from the point of view of the medically marginalized¹⁰. Each of the blastpoints could represent different factors that have increased the incidence of disease along the US-Mexico border and among immigrants: the widening gap between rich and poor, lack of insurance for the working poor, toxic waste dumping on the border, and an extreme lack of Spanish-speaking health professionals. These factors cause disease along the borders and should also be seen as emerging threats to the health of people living in the United States¹¹.

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PERSONAL NARRATIVE The Haves and Have-Nots Robert Davidson, MD, MPH

To understand the health care system of a country, you must first understand its culture. This is so true in reflecting on the theme issue for this month's Virtual Mentor: disparities in health. It is far too simplistic to merely view the disparities as a problem in access to health care services. No, there is something more profound in the way that countries in East Africa approach basic human services. How these services are allocated is driven not only by how much money one has, but by tribal customs that span national boundaries in Africa and by the continent's history of colonialism. Though I do not claim to be a social scientist, I hope my observations can provide some insight into the complex factors that lead to disparities in health care in Eastern Africa.

First, we will start with the obvious. A walk through the campus of the new Aga Kahn Medical Centers in Nairobi and Dar es Salaam gives the impression of "state of the art" medical care. Most of the consultants have impressive post-graduate training, usually in Great Britain, and have the usual string of initials, confusing to Americans, after their names. The laboratory and radiology units with the latest scientific equipment reside in modern air-conditioned buildings. However, as you look around the campus, you see very few people with the typical dark skin of a native African. Most patients are either East Indian or of European ancestry. Almost all services are provided on a cash basis, paid for at the time of the service. Physicians are much more likely to diagnose by history and physical exam without the usual confirmatory lab or X-ray tests since even the "haves" must pay "out of pocket" for these tests and services.

Contrast this with Central Hospital, a government hospital in Lilongwe, Malawi. Here are the old stucco buildings with concrete floors and open windows without screens. The typical adult ward might house 8 patients with no visual barriers between stark cot-like beds. There is 1 toilet without a shower for each 3 or 4 wards. The nursing care is scant; most patients have 2 or more family members who stay with them and sleep on the floor. Family members prepare meals on small charcoal cookers in the room or hallway. There is an open drain down the middle of the hallway that carries a variety of wastes to the drain at the end of the hall. The odor and smoke combine to make the atmosphere as near to Dante's underworld as I care to see. Physicians routinely lament the lack of medications. Various aid groups supply medications in ample quantities, but most of these wind up on the black market and never reach the hospital and those who have little.

Beyond Health Care Services

It is easy to confirm that there is a wide disparity in health care services in Eastern Africa, but I don't believe health care differs in this respect from other aspects of life in this society that also have impact on people's health and quality of life. A fifteen-minute car ride takes one from the worst of the Nairobi slums to palatial mansions with green rolling lawns surrounded by electric security fences and 24-hour guards. The houses in the slums are little more that plyboard or tin sheets held together by whatever is available. There are no toilet facilities, just the occasional water spigot with a line of children carrying "jerry cans" for water.

The public transport system is a combination of old school buses and the notorious Kenyan "matatu." The matatu needs a little explanation for the un-initiated. These are usually Nissan mini-buses decorated with wild colors and slogans. They are meant for 10 passengers. I counted 22 people exiting one at a nearby loading area. There is a driver and a "tout," a combination huckster, money collector, and pusher who crams in as many paying passengers as possible. The drivers are notoriously bad at the job, using horns in lieu of brakes that may or may not work. On the same road will be several Mercedes and other luxury autos with African drivers and Asian or European passengers.

Inequities reign in the utility sector also. When the electricity or telephone goes out in your house, you can expect the requisite 2-week wait for service, or you can ask the dispatcher for special service at an additional cost. Depending on the amount of the "special service" fee, you might get assistance within 15 minutes. Americans often become incensed with the concept of a bribe and rail openly against the system. Their outrage usually causes the waiting period to stretch to 3 weeks. If you have the resources, and are willing to spend them, you can live very well in Eastern Africa. When the drought in Kenya produced staggered electricity blackouts, the generator industry did a land office business. People with money were able to generate power on their own land, although at a major cost to the health of the environment.

The police are not immune to the temptation of providing "extra service" for a fee. I have witnessed a black Kenyan beaten with a police night stick following a minor auto accident while the other driver, a white man, was driven home in the police vehicle. I wonder how much that "special fee" was.

Not Merely a Matter of Money

Even given these glaring examples of the inequities between the haves and havenots, it is nevertheless too simplistic to attribute all such disparity in service and in treatment to money and class. My "boss" is an African American woman born in South Africa. She is a PhD clinical psychologist whose style of dress puts my California casual to shame. Yet, when we travel together, she is routinely stopped and harassed by customs officials, visa clerks, and so on, while my Anglo face gets me waved through with little hassle. I have viewed more blatant racism at times in Africa than I saw, or, at least, remembered, in the US. The curious thing is that much of the racism is by black Africans against other blacks; other factors in Africa's history and tribal culture contribute to this.

Many Africans continue to identify with their tribes rather than with their countries. The relatively new and somewhat artificial borders between countries seem strange even to a Western observer. Crossing border checkpoints is laborious, with rampant displays of bureaucratic hurdles to be cleared before one can transit to another country. (Yes, I am sure a special fee would help.) However, not 50 meters away from the checkpoint, is open land with no border fence or even marker. Tribal areas often transcend these country borders, and many view the border as either a colonial invention or a racket to extract visa fees from tourists. In the rural areas, the tribal customs seem to work, and the informal support system of the tribe meets many of the social needs of the group, but not the needs of other "blacks" who are outside the tribe. Perhaps not surprisingly, this tribal identity does not translate well to urban Nairobi, where individual interest, self-gain, and survival dominate the culture. Power and its ability to corrupt rule the political arena; leaders use brutal tactics of oppression to stay in power. The ethics of what people *ought* to do as an alternative to the ethics of "might makes right" is so foreign as to be almost nonexistent

My initial moral outrage at the disparity of health care services in Eastern Africa seems strangely to have lessened as I have begun to be acculturated to Africa. There will always be "haves" and have-nots." Ethics can help to set a floor or basic level of decency in how we interact with the "have-nots." In Eastern Africa, there is little interest or even recognition of what constitutes this floor. "Ethical" seems to be defined as what one can get away with. Perhaps it is not all that different in the US. With more resources, the "floor" and "ceiling" are less far apart in the US, so the disparity seems more tolerable.

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PERSONAL NARRATIVE Through the Patient's Eyes: Health Literacy: What Patients Know When They Leave Your Office or Clinic

Joanne Schwartzberg, MD and Faith Lagay, PhD

Have you ever thought that the patient in front of you, who has listened to a careful explanation of what he or she needs to do, may not understand what you have said? We invite you to listen to some very brave patients who agreed to speak with physician interviewers about this hidden and shame-causing problem.¹

Mrs. Walker:

Can you imagine what it's like being sick, and you know that you have limited skills, okay, and you're talking to an intelligent doctor like yourselves. And these people are using words that you really don't know because they're not speaking in layman's terms, okay?" Most doctors are just presuming that everybody's as intelligent as they are. And that is just not the case. So . . . you come out of that room, that examination room with this intelligent man or woman thinking: God, I hope I don't make a mistake with my medicine, because I did not understand anything he or she said to me.



Mrs. Walker is well-spoken, well-dressed, and clearly competent in many aspects of her life—her work and family life—but she reads at a 3rd–grade level, not well enough to read the front page of the newspaper, find an intersection on a street map, know from the appointment slip when her visit is scheduled, or understand the directions on the prescription.

(Mr. Dallas is reading the label of one of the prescription drugs he takes regularly.)
Mr. Dallas: Take one capsule
Researcher: That's right, one capsule.
Mr. Dallas: One capsule, capsule. I don't know what that says, is that ten?
Researcher: Twice
Mr. Dallas: Twice daily
Researcher: Okay, so how would you take this?
Mr. Dallas: It's not on there how to take it. It says take it twice daily, but it don't say what time to take it.

Mr. Dallas is a respected community leader and church deacon. He also reads at a 3rd-grade level. In addition to his reading problem, Mr. Dallas has pointed out that the simplest medical directions are often incomplete and confusing.

(On the desk in front of Mrs. Irwin and a researcher is a collection of pill bottles that Mrs. Irwin has brought with her, saying that she takes them all.)

Researcher: Tell you what . . . take these two and tell me which one is which and what you take them for. **Mrs. Irwin**: That looks like my medicine that he gives me in the morning. I take that and the little pill that—no this is lithium. Ain't it? Yeah, that's lithium." (The label says Lipitor).

Researcher: Okay, what do you take that medicine for? Mrs. Irwin: Don't ask me. He puts me on that and I just take it. Anything he tells me to take, I'll take it. **Researcher**: Okay. So you trust him? **Mrs. Irwin**: Oh, you better believe it. With my life.



Mrs. Irwin, now retired, had a successful career as a bus driver, though she never went to school and reads at a 2nd-grade level. She identifies her prescriptions by looking at the pills, not at the labels.

(Mrs. Stuart and a researcher sit in front of about 15 over-the-counter preparations.)

Researcher: Your two-year-old has a high fever.

Okay. What would you do?

Mrs. Stuart: Well, I would probably go and get some Tylenol.

Researcher: Okay, so which one of these things would you pick out for a 2 year old?

Mrs. Stuart: Probably this one. (Mrs. Stuart has picked out a pediatric suspension form of Tylenol.) **Researcher**: Okay. Let's take that. Now take a look at it, and tell me how much you'd give your 2 year old of that?

Mrs. Stuart: Probably a teaspoon. (One teaspoon = 8 Adult Extra Strength Tylenol).



Mrs. Stuart reads at a 7th-grade level, and is employed as a nurse's aide in a nursing home; she cannot comprehend dosage instructions.

The potential for serious medical error embedded in the 4 encounters just described cannot be overstated. Especially since research shows that as much as 50 percent of the population has difficulty understanding medical instructions. Mrs. Walker, who has lupus, leaves the office not understanding her doctor's instructions. Mr. Dallas does not know when to take his medicine. Mrs. Irwin would respond to a new doctor's inquiry about her prescription drugs by stating that she was on lithium rather than Lipitor. Mrs. Stuart would give her 2-year-old "probably a teaspoon" of Tylenol suspension, 8 times the adult dosage.

Unfortunately, no one considered the barriers posed by low health literacy in the design of the modern health care delivery system. Patients with low literacy are at greater risk for medical errors and poor outcomes than they were 30 years ago. For example, 30 years ago a patient with an acute myocardial infarction would have been hospitalized for 5 to 6 weeks, surrounded by skilled professionals who took care of every need. With new medical knowledge, drugs, and treatments (as well as cost containment pressures), a similar patient today is out of the hospital in less than a week. Today's patients are quickly on their own, with long lists of instructions, medications, appointments, and very little support from skilled professionals. We expect patients to learn to care for themselves. How much of their "non-compliance" arises from our failure to ensure their understanding and ability to carry out the needed care regimen? How many medical errors occur because we've based our procedures and processes on the false assumption that everyone can read at a very sophisticated level?

Low Health Literacy and Access to Care Mrs. Walker:

When you enter a doctor's office, and you're a first time patient there, they're going to give you a clipboard with a questionnaire, am I right? Sometimes that is very discouraging for a patient who cannot read.

Mr. Dallas:

I would go to the lady, you know, that passed me the thing [clipboard], and say, "Look, I need some help with this, I can't fill it out." I'd ask for help. [She would answer] "I don't have time right now. Can you wait a while, 'cause I don't have time; you're going to be last." You're always last when you don't know.



Handing new patients with low health literacy questionnaires that ask medical and family health history and medical insurance questions is like handing them an entrance test they cannot possibly pass. Some respond like Mr. Dallas, embarrassingly seeking office staff help and treated as an annoying interruption to someone's busy schedule. Some just answer "no," to everything so they can get into the office and talk to a real person about their problems. Others avoid the uncomfortable situation altogether; they avoid routine or even symptom-related office and clinic visits and present at the emergency department only when they are acutely and dangerously ill. At least there someone else holds the clipboard and asks the questions. And still others, like Mrs. Walker, bring their help with them.

Mrs. Walker:

My children knew how important it was to me that people did not know that I had this problem. So any time there was business to be attended to, my daughters surrounded me like a fortress.

Effects on the Patient-Physician Relationship

Fortifying oneself with health-literate family members as Mrs. Walker describes can cause physicians to feel threatened, even suspicious. One physician reported at an ethics case conference on what he saw as a "hostile" family member. The daughter, he recounted, "wrote down everything I said."

Incomplete or inaccurate information on the intake clipboard can also be interpreted as coming from hostile patients. "She checked 'No Prior Surgeries," one physician said, "and when I examined her, I found she had had a C-section. I guess she was testing me."

There's no "right way" for a patient with low health literacy to act. Bringing help along can be misunderstood by doctors and staff. A blank stare of incomprehension seems annoying at best, hostile at worst. Trying to please, agreeing without understanding, leads to misinformation and possible medical error. Avoiding the medical encounter altogether can lead ultimately to an emergency department visit.

Mrs. Walker:

The embarrassment, the shame, I mean, it's just overwhelming, it really is. It paralyzes your every thought completely to think that you may say something or something is put before you to read, and you can't read it. I mean, you live your life like that on a daily basis.

The patient's shame creates yet another barrier between the patient and physician. Shame is ever-present for people with low literacy. One recent study found that 69 percent of people who cannot read have never told their spouses. Nineteen percent have never told anyone. As physicians, we don't want to "corner" low literacy patients; we don't want to force them to admit they cannot read. But we must make it possible for them to get the accurate information they need to care for themselves safely and effectively.

How Can Physicians Help?

Improving health literacy is one of the AMA Foundation's signature programs. The documentary film from which these dialogue excerpts were taken, offers 4 steps physicians can use right now in all their patient encounters that can alleviate some of the problems and establish a much closer patient-physician relationship.

1. Create a Shame-Free Environment

Offer to help, especially with paperwork. Let patients know that many people have difficulty reading and learning new information and that you can help. If you see an incomplete form, just ask the question yourself and fill in the answer, without impatience or annoyance.

- 2. Use Simple and Direct Language and Give Examples Speak slowly and cover only 2 or 3 concepts at a time. Read written material aloud to the patient and emphasize key points.
- 3. Use the "Teach-Back" Technique

Simply asking a patient if he or she understands is not enough. Instead say something like, "Tell me what you will do and show me how you will do it when you are at home."

4. Invite a Family Member or Friend

Ask the patient if he or she would like to have a family member or friend along during the counseling and planning section of the visit.

Conclusion

If, as surveys indicate, as much as 50 percent of patients do not understand the doctors' explanations and the instructions on their prescriptions, then low health literacy is a major contributor to disparity in health outcomes. And it cuts across generational, ethnic, and racial lines.

Patients with low literacy face barriers at every step in their attempts to receive health care. Physicians can ease those problems or make them worse. If we are unaware of the problem, we may interpret the patient's self-protective behavior and coping mechanisms as inappropriate or hostile and label the patient "difficult." Our instinctive withdrawal will only add to the patient's problem. To the degree that we can aid patient's understanding and compliance, we work toward better health outcomes and fewer medical errors, and we reinforce health maintenance behavior.

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PERSONAL NARRATIVE Through the Physician's Eyes: The Despair of Health Disparities William McDade, MD, PhD

The disparity between health outcomes of minority groups and the majority white population in the United States has attracted a great deal of interest lately. Over 600 papers have been published in the last 10 years attempting to measure inequity in outcomes in dozens of diseases and conditions. There is now a Center at the National Institutes of Health dedicated to the study of health disparities. Today, it is very clear that your race or ethnicity can be an important variable in determining your predisposition to certain medical conditions. The problem that remains is how to use these data to adjust practices so as to eliminate the disparities. There are multiple impediments to accomplishing this, and, as physicians, we should commit ourselves to removing barriers that allow health disparities to exist.

The simplest barrier to overcome—absence of data on race and ethnicity—seems like a reasonable place to start, but that course is mired in racism, fear, history, greed, and inertia. Without data on race and ethnicity, no valid measures of disparity in outcomes can be made. Collecting data regarding race of patients seems easy enough to do; and those unfamiliar with the issue may assume that this information is already available. However, it is rarely available for study and review. Thus, whatever changes in practice studies may advocate, we cannot measure the extent to which the solutions implemented are efficacious without identifying the race of the patients. There are distracting arguments about what constitutes race and differences between groups. There is also distracting argument over who makes the classification, the patient by self-identification or the physician. Fear of discrimination prevents some individuals from giving this information, and fear of being sued for discrimination prevents some physicians, hospitals, and health systems from collecting it. In few instances is there a legal barrier to the collection of these data, yet many are under the impression that there are laws against it. Irrespective of the method used to classify patients, a system of consistent data collection must be implemented immediately. We need a stratification system based on race that everyone agrees to use and that is not subject to political whim or current fad. This system need not impose anything more on the individual than a way of counting that leads to consistent analysis of interventions used to correct health disparity.

An interesting question arises when an individual in the majority group fails to respond to questions regarding race in the health care setting. The fear of discrimination felt by minority people, predicated on historical social discrimination

in other arenas, does not apply here, so why would majority patients refuse to cooperate? There could be a self-serving reason. If one considers health care a zerosum game, and disparities in health care are to be corrected to advantage minority patients, then this would imply to some self-interested majority patients that cooperation in collecting race data would disadvantage them. Greed concerning scarce resources should not be justification for not cooperating with the collection of race data. Likewise, fear of discrimination should not be a reason for withholding this information. In the latter case, safeguards should be implemented to prevent possible misuse of data. In the former case, assurances should be made that the elimination of disparities will not come at the expense of increasing the exposure of medical risk to the majority.

The human genome project has given us the insight that there may be greater biological similarities between humans of anthropologically different racial groups than between two given individuals within the same group. The Office of Management and Budget's Directive #15 states that race and ethnic categories have been socially and politically determined and were never intended to be used scientifically or biologically. The anthropathology of race and disease has been used to "prove" the superiority of whites and should be abandoned as racist and morally corrupt. However, health patterns may be identified within groups that can point to solutions to reduce disease disparity. Explanations for disease disparity that are couched in arguments of biological determinism based on race and ethnicity should be abandoned. Rather, rational, strategic approaches should be devised that seek to eliminate the effect of poverty and culture on disease; that work to improve access to health care for all so that early identification of disease is enhanced; that are designed to improve social and environmental discrimination that leads to illhealth among minority groups; and that eliminate health illiteracy.

We as physicians, have a special role in reducing disparities. Physicians must acknowledge the role segregation plays in enabling cultural ignorance to be perpetuated in this country. We are all inadequately trained in understanding cultural nuances of those different from ourselves and how these elements impact our delivery of health care to patients. Morally responsible individuals do not like to think of themselves as racist, yet all must look within to determine whether the documented unequal outcomes experienced by minority patients is the result of unconscious thoughts or cultural arrogance. The concept of cultural competence has helped define standards in the training of medical students and physicians. Fear of additional standards, imposed mandates to provide services without compensation, and difficulties in measuring competence for certification purposes are barriers which prevent wide acceptance of the concept. However distasteful changing our practice or admitting cultural ignorance may be, health disparity results in preventable excess mortality, and thus we must bear the responsibility for our arrogance. A recently described replacement for cultural competence is the admission of cultural humility. It is the first step in recognizing our own weaknesses and thus provides the impetus to incorporate culture into our clinical

decision making and to recognize the ultimate impact of cultural competence on the health care of our patients.

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VIEWPOINT Dying Poor in an Urban Hospital Gregory P. Gramelspacher, MD

End-of-life care for the dying poor challenges me, empties me and yet fills me with great satisfaction for the privilege of being a doctor to these patients. In 1995-96, the Open Society Institute's Project on Death in America awarded a grant to Wishard Health Services that allowed us to study the problems the urban poor face at the end of life. One major hypothesis: it is difficult to be poor and it is difficult to be dying, so it must be doubly difficult to be poor and dying. This study provided a thick description of the problems and desperation of the dying urban poor. Recommendations following this study led Wishard to begin a Palliative Care Program.

One noteworthy finding from our study was that many of the poor patients who come to our inner-city hospital accept the bad news of their fatal diagnosis and approaching death with a dignity and grace that is remarkable. "Well, doctor, that is the fifth bad thing that has happened to me this week." Given such bad news, how many of us could honestly make a statement like that? Raymond Carver's poem "What the Doctor Said" offers a glimpse into one such mind and heart. Carver recounts receiving the bad news about his metastatic lung cancer: "he said something else/ I didn't catch and not knowing what else to do/ and not wanting him to have to repeat it / and me to have to fully digest it / I just looked at him. . . may even have thanked him habit being so strong"¹.

Despite the resignation we encounter, I know that dying and death could be better for poor and vulnerable patients. Hospice programs have shown us that it is possible to die peacefully at home surrounded by family and friends rather than in the hospital surrounded by strangers and medical technology. However, the road to the good death is rather narrow compared to the six-lane superhighway that leads to our hospitals and ICUs. Everything about our current health care system directs the dying patient to our hospitals rather than to hospice care. That is why almost 80 percent of Americans (rich and poor) still die in our hospitals (60 percent) and nursing homes (20 percent). Many private foundations have recognized that "the nation needs the moral equivalent of a Manhattan project on care of persons with serious and eventually fatal illness"².

Disparities in Care for the Urban Poor

More often than not, the urban poor seeking health care find themselves in the crowded and hectic environment of the hospital emergency room. It is tragically

unfortunate when they come there at the end of their lives. While the door to the ER remains the only open door for poor people who are dying, in almost every circumstance it is the wrong place to be if you know you are dying. Yet, that is where the dying poor find themselves, diagnosed too late at too young an age, lacking health insurance or even life insurance that they might use for a funeral. About 50 patients die each month in our hospital, 20 in the ER and another 30 after admission. Many of these latter 30 patients die in the ICU after a decision is made to stop treatments that should have never been started.

The list of reasons why terminally ill patients die in our hospitals and ICUs is lengthy and might be debated by health policy experts. The simple and most direct reason that I see is that there are not enough people who care to be involved in the lives of these patients as they approach their final days. But there are many other reasons: problems with health care financing, strained city budgets, over-burdened community health centers, public expectations about EMS and 911, lack of coordination between specialists and primary care physicians, dependence on medical students and residents to staff our city hospitals, and a failure to teach our medical students and residents how to do things differently.

A different scenario would unfold *if* each of those impoverished patients had a physician whom he or she could call and trust, one who could prognosticate and provide advance care planning, deliver bad news, conduct a family conference, provide adequate pain and symptom relief at home, and understand what patients or family mean when they say "do everything—for nothing is impossible for God"; if they had a physician who could call on nurses, chaplains, and social workers for assistance; a physician who could pray with patients and their families, make home visits, attend funerals, send sympathy cards, and not forget the courage and grace that we all hope we have when it is time to go—and could do all these things with compassion and understanding.

Wishard Health Services Palliative Care Program

Our hospital-based palliative care program builds a bridge from the complex and chaotic hospital system to local nursing homes and home hospice programs (involving local churches and volunteers in this hard work). The program redirects efforts in a way that presents real choices for dying patients, allowing providers to create an individual plan of care centered on the needs of each patient and his or her family. We have found that a small interdisciplinary team can sometimes slow down the locomotive that is pulling dying patients to the ICU. First, we try to get involved with patients as soon as possible, even at the time when they are told about terminal diagnoses. Early involvement and consistent support lead to a degree of trust essential to help patients and their families cope at this time. Second, we listen to patients in order to determine what is important to them. Seldom is the decision of whether or not to be resuscitated important. In fact, we often don't ask whether or not they want CPR. Instead, we engender trust by showing up, calling, and checking on them. We commit to non-abandonment by making home visits and by providing them with cards that include our pager numbers so that they can contact

us at anytime they have a question or problem. Not many patients leave city-county hospitals with a physician's card that includes a pager number for emergencies. In fact, most patients who show up in the Emergency Room do not know their doctors' names. Our patients are shocked but overjoyed to learn that we will make home visits to see them so that they don't have to return to long waits in the clinics or ER.

This work is not for the faint-hearted, and team members need compassion and humor as much as they need scientific knowledge. Our patients' spirited strength ennobles them and also carries us through this tough time. We all need to become forceful advocates for change in the care of the dying, especially for marginalized populations with limited access to the care that you or I want when we are at the end of life.

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VIEWPOINT Disparity in Health: Is Geography Destiny? Audiey Kao, MD, PhD

- Small area analysis, a methodology for assessing health care utilization rates across geographic areas, was pioneered by Dr. John Wennberg, the Peggy Y. Thomson Professor of the Evaluative Clinical Sciences at Dartmouth Medical School. Nationally and internationally recognized in medical epidemiology, Dr. Wennberg's work has catalyzed a whole new field of inquiry in the examination of geographic variations¹ in the utilization of medical services such as cardiac catheterization/angioplasty^{2, 3, 4}, diabetic amputation⁵, and orthopedic surgical procedures⁶.
- According to the <u>Dartmouth Atlas of Health Care 1999</u>, initially created by Dr. Wennberg to chronicle geographic variation in health care utilization, the rate of cardiac bypass graft surgery (CABG) was 5.4 per 1,000 Medicare enrollees living in Gainesville, Florida, while it was 9.4 per 1,000 Medicare enrollees living in Hudson, Florida, approximately 120 miles from Gainesville.
- This variation in CABG rates between two Florida communities relatively close to each other persists even after potential explanatory factors including the health profile and status of patients are adjusted for. This variation in care may be secondary to a variety of factors, including patient preferences, local practice norms, and economic and market incentives. Some of these factors may not be valid reasons for the decision to perform or not perform a CABG, and thus may indicate either an overuse or underuse of such medical services.
- Given that, on average, a Medicare patient in Gainesville is more likely to get a CABG than a Medicare patient in Hudson, it is critical that efforts be made to assess the outcome implications of such geographic variations in care. In other words, what is the "right" rate for coronary artery bypass surgery? Without this information, we cannot adequately address these variations in care, and, in terms of disparities in health, geography may well end up being destiny.

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VIEWPOINT David Satcher, MD, PhD, US Surgeon General Karen Geraghty

Satcher was one of 9 children born to poor, self-educated farmers who supported their family on less than \$10,000 a year. At the age of 2 he nearly died of whooping cough because the vaccine to combat the illness was not available in rural Alabama. He survived to become one of only 3 students in his high school to go to college and was the first African American to earn a combined MD-PhD from Case Western Reserve University in Cleveland in 1970. He began his medical career in Los Angeles, where he directed a sickle-cell program and opened a free clinic in a Watts church basement. He was the chairman of Morehouse School of Medicine's community medicine department before serving as president of Meharry Medical College in Nashville for more than a decade. At various times throughout his practice he treated the sick and injured in the underserved areas of Cleveland and in the immigrant communities of New York.

Since becoming the nation's leading spokesman on public health matters, Dr. Satcher's agenda can be summarized by his rallying cry, "to make public health work like it's never worked before." In addition to his priorities of establishing a balanced community health system and maintaining a global approach to public health, one of Dr. Satcher's top goals is to address and eliminate disparities in health.

According to Dr. Satcher, "Compelling evidence that race and ethnicity correlate with persistent, and often increasing, health disparities among US populations demands national attention. Indeed, despite notable progress in the overall health of the Nation, there are continuing disparities in the burden of illness and death experienced by blacks, Hispanics, American Indians and Alaska Natives, and Pacific Islanders, compared to the US population as a whole. The demographic changes that are anticipated over the next decade magnify the importance of addressing disparities in health status . . . therefore, the future health of America as a whole will be influenced substantially by our success in improving the health of these racial and ethnic minorities."

Citing the Initiative on Race and Health unveiled by President Clinton in February 1998, Dr. Satcher has set the goal of eliminating racial disparities in health by the year 2010. Despite advances in medicine, significant disparities are apparent between racial groups in this country. Under Dr. Satcher's watch, the Office of the Surgeon General has made a priority of eliminating—not just reducing—disparities

for minority populations in the areas of infant mortality, child and adult immunizations, HIV/AIDS, cardiovascular disease, cancer screening and management, and diabetes.

For his commitment to the health of all Americans and his willingness to take a stand as a physician in the political arena to shape health policy, we are proud to name Dr. David Satcher a role model in medicine.

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