Disparities in Population Health — An Overview of Empirical and Ethical Issues

by Erika Blacksher

Natural catastrophes have a way of drawing the public's attention to deep wounds that usually fester unattended.

The devastating tsunami that struck the Indian Ocean region a year ago and the more recent quake in Pakistan laid bare deep, global disparities in wealth and health. Hurricane Katrina exposed deep disparities closer to home.

Erika Blacksher

These disasters do not create the poverty and poor health already suffered by these groups. They only exacerbate an already fragile human existence, one characterized by, among other burdens, poorer health and shorter life spans than that enjoyed by better off groups.

Public health experts have known since the turn of the twentieth century that poor health and poverty go together.

Now, one hundred years later, that understanding is more refined. Thousands of studies have confirmed a "social gradient" in health wherein socially disadvantaged groups – whether measured by race, socioeconomic status (SES), or other indices of hierarchy – shoulder a disproportionate burden of health deficits.[1]

> *"Public health experts have known since the turn of the twentieth century that poor health and poverty go together."*

This gradient in health does not plateau once a certain level of income and wealth is attained. Rather, it extends into the highest reaches of socioeconomic strata and remains after controlling for risk factors.[2] Each rung up or down the ladder yields generally better or worse health, respectively.

Thus, even groups that have accumulated a lifetime of advantages, with access to educational, economic, and cultural opportunities, experience worse health than their more privileged counterparts.

Consensus is lacking on the exact causal pathways between poor health and social disadvantage. Exactly how factors such as education, income, race, ethnicity, and gender operate within human communities and human biology to the advantage or disadvantage of health is unclear.

Does the chronic stress that accompanies living (and surviving) a disadvantaged life trigger biological processes that set illness and disease in motion? Does a disadvantaged life expose one to risks, hazards, and practices that are bad for one's health?

Does higher education and social control translate into better capabilities for health? Does societal inequality per se unravel the social fabric and public infrastructure of a society? The social gradient in health is, in the words of an eminent health researcher, "the major unsolved public health problem of the industrialized world."[3]

From the Contributing Editor

Specialty Healthcare Access — A Response to Disparities and Dilemmas

Ted, a young working father, shows up in the emergency room with symptoms that lead eventually to a diagnosis of lymphoma. His earnings are little more than minimum wage. He has no employee healthcare benefits, and he is determined to be ineligible for Medicaid or other public insurance. Hospital personnel refer Ted for follow-up care to a local free health clinic without oncology services. The medical director there worries that without access to appropriate treatment, Ted will die.

The number of uninsured Americans — more than 45 million — is among the most frequently quoted statistics found in the U.S. Census Bureau survey data. Other census data indicate that, like Ted, most of the uninsured are among the "working poor." As many as 80 percent are "employed households" without medical insurance benefits or total household income sufficient to pay costly premiums. Therefore, many of our neighbors live without healthcare coverage. Lacking adequate access to needed healthcare, too many — perhaps 18,000 persons annually — die as a result. The Institute of Medicine has documented this disparate reality and its tragic consequences (http://www.iom.edu/uninsured).

The uninsured or underinsured who do receive healthcare may be billed into bankruptcy or forced to accept charitable care. Two-thirds of the uninsured who obtain free care do so from the general pool of primary care providers (P. J. Cunningham, *JAMA* 1998; 280:921-927). This service is provided quietly — it is typically unbilled, unreported, and unrecognized. Emergency departments often become the primary care provider for those who cannot get into the system any other way. Others of the uninsured find some access to primary care through the "safety net" of public health departments, public hospitals, and free (or sliding fee scale) nonprofit health clinics.

Tarris Rosell

Some specialty care is also accessible through the safety net. A physicians' review of 158 patient charts from one free clinic in Kansas City indicated that 26.5 percent needed more than primary care. Less than half that number got access to additional care via internal resources or referrals, while the majority simply fell through the systemic cracks.

In 1995, Project Access emerged in Buncombe County, North Carolina, as a partial answer to the un- and underinsured patient's need for specialty care. In the decade since, specialty care referral networks have sprung up in dozens of cities, linking low income uninsured patients with pro bono specialty care providers.

The Center for Practical Bioethics is working collaboratively with medical societies, saftety net providers, and others to foster a similar network in Greater Kansas City. Regional foundations have provided twelve months of strategic planning funds for the Medical Outreach Project. The goal is to expand the currently available referral services incrementally until

African American Health Disparities — To Raise All Boats

by Stacey Daniels-Young

Disparities affecting African Americans have been well documented on many health indicators. For example, amputations due to diabetes occur more often among African Americans than among other racial or ethnic groups; African American women are the largest at-risk group for cardiovascular disease; and asthma, an incurable but manageable disease, disproportionately affects African Americans.

Disparities in treatment also occur. Despite the prevalence of asthma among African Americans, a recent Johns Hopkins study reported that only 38 percent of African-American survey respondents thought they had received enough information on how to avoid asthma triggers, while 54 percent of the Caucasian respondents reported having received this information. More Caucasians than African Americans, 41 percent to 28 percent, also reported being seen by asthma specialists.

Stacey Daniels-Young

Since African Americans have higher mortality rates from several illnesses, they are disproportionately affected by end-of-life issues, such as dying alone, in pain, and attached to machines. Improvements in end-of-life care have been slower to benefit members of the African American community, including unequal access to hospice and a lack of palliative care generally; insufficient stocks of pain medications in nonwhite neighborhood pharmacies; and lack of awareness in the African American community about end-of-life issues.

These problems do not exist in isolated localities but afflict and threaten our nation as a whole. Nevertheless, a list of disparities specific to a single region, in this case, Kansas City and the states of Kansas and Missouri, can provide a synoptic view of problems we face nationally:

- African Americans have a higher death rate than other groups for heart disease, cancer, stroke, and diabetes in Missouri as a whole and in Kansas City.

- In Kansas, African Americans have the highest years of potential life lost to coronary heart disease.

- Hypertension is more prevalent among Missouri's African Americans; it develops at an earlier age and is experienced more severely.

- In a set of interviews conducted by the Kansas Health Institute, most African American youth interviewed knew at least one person who had lost vision or a limb to diabetes.

- Missouri blacks are also more than twice as likely to die from diabetes and kidney disease.

- Missouri and Kansas report similar numbers of overweight individuals (both between 20 and 25 percent) although Missouri had a higher rate of obese individuals.

- African Americans have four times the number of emergency room visits for diabetes than do whites in Missouri,
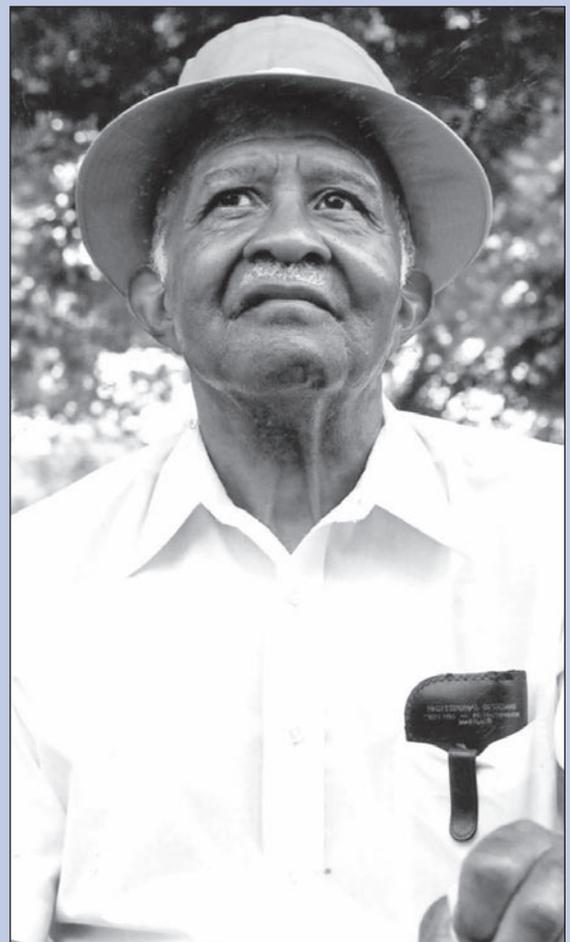
African Americans are disproportionately affected by end-of-life issues, such as dying alone and in pain.

African American Health Disparities

(Continued from page 3)

and three times the number of visits for congestive health failure, illnesses that are exacerbated by being overweight or obese.

- The rate of HIV diagnoses for non-white females has overtaken that of white females in Kansas City and has done so since 1990.

- The rate of hospitalizations due to asthma in Jackson County, Missouri, is four times higher for African Americans than for whites.

- The overall racial disparity observed among Missourians in asthma is even greater among children: 10 percent of African American children are afflicted with asthma compared to only 6 percent of white children.

Tackling the Issues

Of course, health is not the only area of disparities between African Americans and other populations — indeed, whether the discussion pertains to income, housing, education, homicide, or a host of other social indicators, African Americans have noticeably poorer status. To an observer of any of these problems, it may appear that we who are African American are not adequately involved in addressing these issues.

It's not that we're not adequately interested — rather, the dilemma for African Americans is how to decide which issue should be tackled first. Where can we best concentrate our expertise for maximal effect? African American activists have no shortage of issues, any one of which could consume the time and energy of a community. We're not paralyzed or unconcerned — if anything, we're almost overwhelmed.

Even if issues bubble to the top of the cauldron of problems, all too often,

efforts at solution are crisis-based and may be short-lived before attention is turned to the next crisis. Crises and issues become cyclical, in a sort of "movie of the week" approach. Or, once some success is achieved, we as a society declare victory and move to the next crisis.

Reason, resources and compassion

Solving health disparities will require, like solving any problem, sustained, well-reasoned approaches and participation from those affected, those with the resources to make a difference, and those with compassion enough to see that improving the status for some of us improves the possibilities for all of us. We are wasting untold potential with our current approach that accepts leaving

"Addressing health disparities among persons of color… can only add to improving the health status of all persons in underserved communities."

some behind. Who knows what solutions were in the potential of those we leave behind? There is, in fact, an inherent beauty in addressing health disparities among persons of color: it can only add to improving the health status of all persons in underserved populations, thereby improving the whole of human capital.

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Health researchers can agree on this much: societies *structure* their respective populations' health, and it flows upward toward the better off. The impact of social structures and institutions on health is evidenced by the markedly different gradients found across countries, not only between developed and developing countries, but among developed countries. Within countries, health follows similar patterns, flowing incrementally toward the better off.

"Lack of access to timely, quality care can worsen health outcomes and in this way contributes to health disparities."

A fact likely to surprise many in the United States is that healthcare is not foremost among the social determinants of health. Lack of access to timely, quality care can worsen health outcomes and in this way contributes to health disparities. And health disparities can exacerbate disparities in healthcare outcomes because patients enter the system later in the course of illness, sicker, and with fewer resources to devote to recovery. But lack of access to timely, quality care itself cannot explain health disparities.

In countries with universal healthcare, the social gradient holds. Moreover, lack of access to healthcare cannot explain the gradient in disease incidence. Thus:

> While it is plausible that differences in medical care could lead to differences in survival and recovery once someone became ill, it is a good deal less likely that differences in medical care could lead to differences in the rate of new occurrence of disease.[4]

This finding is not a reason to ignore healthcare reform. With some 61 million adults in the United States now uninsured or underinsured,[5] most people recognize that the "crazy quilt" approach to healthcare insurance has failed. That one third of all U.S. citizens

lack reliable access to this important social good is reason enough to justify reform. The lack of trust, skepticism, and fear generated by this broken system contributes to poor population health through mechanisms other than the tangible lack of care. The chronic stress and mistrust associated with trying to navigate the system are themselves potential sources of health harms.[6]

The social gradient in health not only poses an empirical puzzle for health researchers. It also poses profound moral questions for human communities. Questions about the nature of health and responsibility for health are complex and contentious. Health is widely considered a "special good" because some level of health is a basic condition of human agency.[7] Thinking, communicating, and acting all require some level of bodily and mental health, thus making health essential not only to living, but to living well. Yet, despite the significance of health (or perhaps because of it), consensus is lacking on what it is and how best to measure it. Is health a measurement of physiological states, functional states, human preferences, or some mix of all three?
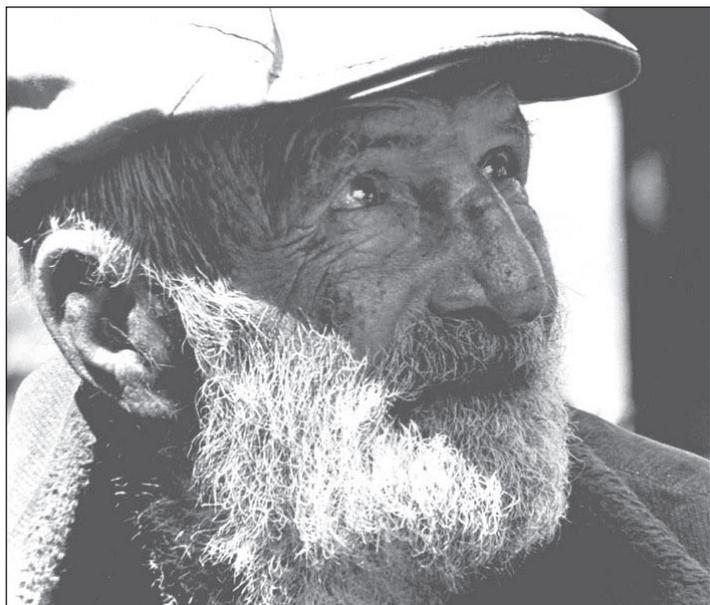
Lack of access to care itself cannot explain health disparities.

> ***"The social gradient in health… poses profound moral questions for human communities."***

The question of responsibility for health is no less contentious. The data show that health is patterned according to advantage both across and within societies, yet health can be harmed or protected by an individual's behavior.

In societies such as the United States, where individualism and personal agency are deeply prized, health is commonly viewed as a function of some interplay among biological, genetic, and personal choices about what to eat and whether to smoke, exercise, or engage in risky behaviors. Here especially the idea that social institutions and policies *distribute* health may be anathema. A stark expression of this view was aired by then president of the Rockefeller Foundation, John Knowles, who wrote, "One man's freedom in health is another man's shackle in taxes and insurance premiums."[8]

Still, it is unclear just how free persons are to be healthy. People clearly are not free to be healthy when they are born with or struck down by a severe genetic disease. Nor do they seem free to pursue health when they are born into absolute poverty, dying of starvation or exposure. However, the case for "unfreedom" is more difficult to make for chronic illnesses and diseases to which lifestyle behaviors significantly contribute.

Still, the case can be made.[9] There are a number of good reasons to think that a focus on personal responsibility for health is misdirected. The origin of illness and disease may be multifactorial, a function of genetic predisposition, exposure to environmental toxins, accidents, or behavioral patterns. Behaviors may be the product of habits learned as a child, of misinformation, or of ignorance. Locating blame for injury, illness, and disease may be as difficult as philosophers' attempts to prove that humans have free will.

> ***"Consensus is lacking on the exact causal pathways between poor health and social disadvantage."***

Even if it were possible to determine with clarity and certainty when health-related decisions are free and informed, it may seem morally unacceptable to hold individuals responsible for poor health outcomes. For example, some free and informed decisions may be laudable yet result in poor health, as when someone decides to support his or her family by taking a high risk job, or when someone devotes herself tirelessly to the care of a chronically ill family member and in the process suffers poor health herself.

For these and other reasons, many think responsibility for health is best understood as a collective problem. As a collective problem, the question arises whether health disparities are a matter of social justice. Indeed, the poorer health and shorter life spans of the disadvantaged have been described as a "double injustice."[10] But whether health disparities constitute an injustice is a complex question. Theories of justice vary significantly in their scope and normative commitments.

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Whether health disparities constitute an injustice is a complex question.

For example, some theories of justice limit claims of justice to harms that accrue from the ongoing effects of unjust social structures and exclude harms caused by nature; others extend claims of justice to harms caused by nature and exclude harms that result from free and informed choice. Yet, as already discussed, it may not be clear whether a disease or illness results from genetic predisposition, social structures, or personal decisions — indeed, the three may be inextricably bound up together.

A second complication concerns whether principles of justice apply only to a bounded society or to all persons everywhere. Theories of justice that apply to a particular society or country fail to take account of the many ways in which countries trade, compete, and interact globally to the advantage or disadvantage of population health. Global warming, pollution, and infectious disease show no respect for national borders. Yet, global or cosmo-politan theories of justice may underestimate the degree to which domestic social laws and policies implicate citizens in their fellow compatriots' health deficits more so than those of non-compatriots.

These conceptual, empirical, and moral puzzles demand sustained study, reflection, and discussion. Fortunately, U.S. foundations and universities are increasingly devoting resources to the study of population health disparities. The Robert Wood Johnson Foundation initiated a Health and Society Scholars program several years ago to cultivate leaders in the field; Harvard hosted an inaugural conference on population health ethics to generate interest among bioethicists; courses on global health can be found in bioethics programs to train future bioethicists; and public television is airing a series on global health to raise public awareness — all good news.

> *"Our response may have more to do with our national character than with our national IQ."*

The news may not be all good. Whether or not the United States responds to the challenge of health disparities may, ultimately, have less to do with our ability to find satisfactory answers to these puzzles and more to do with our ability to muster the political will to secure the conditions of health for everyone. In the end, our response may have more to do with our national character than with our national IQ.

Notes

1. For an excellent review of the social determinants of health data, see D. Mechanic, "Rediscovering the social determinants of health." *Health Affairs* 2000, 19:267-276.

2. D. Blane. "Social determinants of health – socioeconomic status, social class, and ethnicity." Editorial. *American Journal of Public Health* 1995, 85:903-904.

3. M. Marmot. "Social determinants of health," Presentation at the inaugural conference, Population-Level Bioethics: Mapping a New Agenda. Harvard University, November 18, 2005.

4. M. Marmot. *The Status Syndrome: How Social Standing Affects Our Health and Longevity.* Henry Holt and Company, Owl Books, 2004, p. 42.

5. http://www.cmwf.org/publications/publications_show.htm?doc_id+280812. Click on Health Insurance.

6. "Social capital" is a term that describes the sense of trust and reciprocity among citizens. Studies suggest that it is associated with better health. See, for example, I. Kawachi, B.P. Kennedy, K. Lochner, and D. Prothrow-Stith. "Social capital, income inequality, and mortality." *American Journal of Public Health* 1997, 87:1491-1498.

7. S. Anand. "Concern for equity in health." In *Public Health, Ethics, and Equity,* edited by S. Anand, F. Peter, and A. Sen. Oxford: Oxford University Press, 2004, pp. 15-20.

8. J.H. Knowles. "The responsibility of the individual." *Daedalus* 1977, 106:59-60.

9. See Dan Wikler's excellent discussion of the debate over responsibility for health in D. Wikler, "Personal and social responsibility for health." In *Public Health, Ethics, and Equity,* pp. 109-134.

10. R. Wilkinson. *Unjust Societies: The Afflictions of Inequality.* London and New York: Routledge, 1996.

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Health and Healthcare Disparities — Do We Care?

by Sharon Lee

Most Americans want to believe that ours is a caring nation guided by altruistic social values. Generally, we believe that our values include actions such as taking care of the sick. Indeed, many people, including other doctors, often remind me that in America, the poor always have access to medical care. They point, for example, to emergency care measures, Medicare, and Medicaid as programs that provide access.

Sharon Lee

The first of these programs is EMTALA (the Emergency Medical Treatment and Active Labor Act, known to many as COBRA because it was part of the Consolidated Omnibus Budget Reconciliation Act in 1986). This program and Medicaid are often cited as proof that in the United States, we provide needed medical care for everyone, regardless of insurance status. But the reality created by our social and political choices is different from this rose-tinted view.

Emergency Care

EMTALA (www.medlaw.com) requires that all patients who present to an emergency department be provided (1) an appropriate medical screening examination to determine whether or not an emergency medical condition exists, and (2) stabilization of the patient's condition. It does not apply to treatment and discharge decisions occurring after a patient's initial screening and stabilizing treatment. No hospital is required to provide post-stabilization services.

Worse yet, EMTALA regulations do not exempt patients from being charged for care regardless of their income status, and emergency care is often charged to the uninsured at even higher rates than insurers are charged for contracted care. Uninsured households often face bankruptcy, lose their homes, or suffer other serious life consequences from charges accrued when a family member requires extensive emergency care.

Medicare

Medicare (www.cms.hhs.gov/home/medicare.asp) is a federal program that provides several levels of medical services, A through D. In general, people qualify for Medicare coverage if they have worked ten years and paid into Social Security. People requiring dialysis or who are disabled for more than twenty-four months may purchase Medicare Part A for up to $375 monthly.

- Medicare Part A covers a portion of in-patient hospitalization, nursing home, home health, and hospice. Patients pay a deductible (amounting, in 2005, to $912) for the first sixty days of in-patient coverage. Co-pays apply to other benefits and are charged to the patient up to $114 daily.

"EMTALA regulations do not exempt patients from being charged for care regardless of their income status."

- Part B is insurance for which the beneficiary must pay a premium. In 2005, the premium was $78.20 per month. Part B helps pay for doctor's services, outpa-

Emergency care is often charged to the uninsured at higher rates than insurers are charged.

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tient hospital services, and some durable equipment. The annual deductible is $100 and co-pays are charged at 20 percent of the costs of services.

- Part C (previously known as Medicare Advantage or Medicare + Choice) is additional insurance that an individual can purchase to cover the added costs (e.g., the 20 percent co-pays). Many plans are offered by private insurers and have variable costs.

- Part D, the prescription drug benefit, is the newest addition to the Medicare program. It is offered by numerous private insurers. The plan has a $250 deductible for 2006 and requires co-pays. The plan pays 75 percent of the next $2,000, nothing for the following $2,850 and 95 percent for drug bills over $5,100. Under these plans, many beneficiaries will pay out-of-pocket expenses greater than $3,550, which is more in 2006 than they paid in 2005. Early difficulties in implementing Part D have been widely reported.

Kansas Medicaid guidelines (http://www. healthinsuranceinfo.net/ks05.html) can be used to illustrate these constraints. Kansas Medicaid eligibility is restricted to those with specific characteristics who meet certain income guidelines:

- Persons who are disabled according to Social Security rules and live at or below 74 percent of the federal poverty level (FPL).

- Persons who are nineteen years-old or younger and who live below 100 to 200 percent (depending on age) of the FPL.

- Persons who are age sixty-five or older and who live below the FPL.

- Women who are pregnant and who live at or below 150 percent of the FPL.

- Working parents of children who live below 39 percent of the FPL (i.e., who qualify for Temporary Assistance for Needy Families [TANF])

- Women who have been diagnosed with breast or cervical cancer and who have incomes below 250 percent of the FPL.

Medicaid guidelines require that a person be disabled, pregnant or have a specific diagnosis (e.g., breast or cervical cancer) and be living on income approximating the poverty levels. Or, if the person is working, the income level allowed is a mere 39 percent of poverty. Medicaid works for those who qualify, but it is so restrictive that it leaves many needy individuals without any coverage, especially if they are working. How is this so?

Understanding Federal Poverty Levels

Federal poverty thresholds are used by the U.S. Department of Health and Human Services to determine annually updated Federal Poverty Guidelines. The Guidelines list income levels for households by the number of persons living in the household and

"Medicare is perhaps the most successful of all efforts to help insure large numbers of people."

Although Medicare is a complex system, it covers most of the disabled and most of those over age sixty-five. The majority of doctors and hospitals accept Medicare payments, and it is perhaps the most successful of all efforts to help insure large numbers of Americans.

Medicaid

Medicaid (www.cms.hhs.gov/medicaidGen-Info) is a state and federally funded insurance for those who qualify. Medicaid regulations vary by state and have many constraints. The

Medicare covers most of the disabled and most of those over age 65.

represent the income level at which a family is presumed to be no longer sustainable. This level is referred to as the federal poverty level.

> *"People who work for the federal minimum wage of $5.15 per hour would require a work week of sixty hours to reach the poverty threshold."*

The federal poverty thresholds were first proposed by a government analyst named Mollie Orshansky in the early 1960s. Orshansky based her calculations on a 1955 U.S. Department of Agriculture (USDA) survey which indicated that most households were spending about one-third of their income on food. Then, using data from USDA dieticians which included the nutritional values of four food plans, Orshansky proposed using the third low-cost or adequate food plan estimate as a guide and multiplying that by three to determine poverty thresholds. Her concept was that although it is not possible to determine how much is enough to sustain a family, it is possible to calculate how much is too little.

The Johnson administration adopted Orshansky's proposed levels in the 1965 war on poverty, although they used the fourth or "economy" food plan costs as a basis for the levels. This plan, which the USDA had determined was the cheapest of the four plans, was described as being "designed for temporary or emergency use when funds are low." It was not considered nutritionally adequate for long-term use. Finally, the income levels are based on before-tax income rather than usable income. Using Orshansky's base calculations, the current Federal Poverty Thresholds are adjusted annually by the consumer price index (for the 2006 guidelines, see http://aspe.hhs.gov/poverty/06poverty.shtml).

When parents balance family needs, they sometimes gamble and frequently lose.

> *"What happens to a pregnant woman who makes 151 percent of poverty? What of the disabled person who makes 75 percent of poverty, or the working parent who makes 40 percent of poverty?"*

The application of these guidelines to Medicaid recipients leaves many individuals without the help they need. What happens to a pregnant woman who makes 151 percent of poverty? What happens to a person with disabilities who makes 75 percent of poverty, or the working parent who makes 40 percent of poverty? For a family of three, the 2005 poverty level is $16,090 which is about $7.75 per hour for full-time work. People who work for the federal minimum wage of $5.15 per hour would require a work week of sixty hours to reach the poverty threshold.

For a single parent with two children, the 2005 guidelines in Kansas allow Medicaid coverage for the children if the annual household income is 200 percent of poverty ($32,184). The parent would not be covered by Medicaid, unless the family income is below the TANF guidelines, which is 39 percent of poverty ($6,275 per year).

Despite efforts by many safety net providers to help fill the gaps in care, we are failing to provide even basic or emergency

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coverage for an increasing proportion of our population. Alarmingly high numbers are not getting vital medical care. Currently the uninsured number more than 45 million and those who are chronically underinsured represent another 16 million. For people with few or no benefits, a simple medical condition can represent a significant financial decision, and a serious or chronic medical condition can literally bankrupt a family.

> *"Parents make budget decisions that pit their children's medical care against shoes, a coat, or even supper."*

When parents or other individuals weigh costs of care in the balance with the rest of the family's needs, they sometimes gamble and, frequently, they lose. They can't afford to do anything else. Their losses accumulate with increasingly bad health and even death. The poor in Kansas City, Kansas, die at more than twice the rates of those with higher incomes. Lack of health insurance and the access that insurance provides to medical services is the greatest disparity. "Of all the forms of inequality, injustice in health care is the most shocking and inhumane," is a statement widely attributed to Martin Luther King, Jr.

Parents make budget decisions that pit their children's medical care against shoes, a coat, or even supper. The elderly are forced to choose between food and medicine, unable to adequately cover the cost of both. For those who don't qualify for state Medicaid and cannot afford health insurance, it's a "no go." That is "no go" to the doctor, "no go" to the pharmacy, "no go" to the hospital (except in truly dire emergencies for which they will be billed later). The results of the choices that people make are seen in the statistics: the poorest and lowest insured areas of the country have higher death rates at all ages and for almost all causes.

Disease kills faster with delayed diagnosis and treatment. A small skin cancer on the neck may be treated readily at an early stage, but once it erodes into a large vessel, or other vital structure, even aggressive emergency treatment is likely to fail. Congestive heart failure is often a result of long-term untreated high blood pressure. Treatment can prevent the development of high blood pressure related problems. Uncontrolled diabetes leads to blindness, loss of kidney function, and loss of limbs. Treatment can stave off these effects. HIV kills in months without medication. Treatment can increase life expectancy to unknown limits. Even aggressive diseases that can sometimes lead to death in months may be blunted or even cured with early treatments.

It is ironic that the United States has the largest Gross Domestic Product in the world and is the global leader in proportion of Gross National Product applied to healthcare (14.6 percent, compared to Europe and Canada with an average of less than 10 percent) according to the World Health Organization. Yet, we accept being the only industrialized or developed country without a universal health coverage plan.

We are failing to provide health services and care for many of our sick and vulnerable. The situation for the poor without insurance in our country today is neither caring nor kind.

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The situation for the poor in our country today is neither caring nor kind.

Before the Revolution — What We Can Do to Control Healthcare Costs

by Steve Roling

In 1966, Martin Luther King, Jr., called the nation's attention to the fact that "of all the forms of inequity, injustice in health care is the most shocking and inhumane."

Steve Roling

Many U.S. population groups, including racial and ethnic minorities, and some geographic and socio-economic groups (low income and rural), experience a disproportionately high burden of disease and mortality. Unfortunately, this disparity begins early in life and many are never able to overcome this injustice.

According to former U.S. Surgeon General Dr. David Satcher, some progress has been made, but there is much work to be done. Satcher states,

In many ways, Americans of all ages and in every race and ethnic group have better health today than a decade ago yet considerable disparities remain. We should commit our nation to eliminate disparities in the next decade, for through prevention we can improve health for all Americans.

In fact, the United States spends more money on healthcare than any other nation in the world but twenty-four other countries have a higher life expectancy. Dr. Satcher suggests that one reason for this discrepancy may be that our nation spends 90 to 95 percent of its healthcare dollars on the treatment of illnesses and only 5 percent on the prevention of illnesses.

Given these facts, what are the implications for community-based initiatives and national policy?

Perhaps communities need to focus more effort on prevention to avoid chronic illnesses, for example, by becoming more educated on health and nutrition issues, exercising more, and avoiding tobacco use.

According to the Missouri Department of Health, Missourians pay approximately $1.6 billion per year in healthcare costs to treat diseases related to obesity (e.g., heart disease, high blood pressure, Type II diabetes, asthma, arthritis, liver disease, breast cancer). Missourians also pay approximately $1.7 billion in medical costs to control problems caused by smoking (e.g., emphysema, lung cancer, heart disease) — despite the fact that 75 percent of Missourians don't smoke.

We could revolutionize the healthcare system, save billions of dollars and simultaneously improve the overall health of our citizens simply by investing more in prevention.

> *"We could revolutionize the healthcare system and save billions of dollars while simultaneously improving the overall health of our citizens by simply investing more in prevention."*

However, focusing on habits and lifestyle issues and prevention alone will not solve all healthcare disparities. We also need good policymaking at all levels of government to address the social forces that directly influence one's ability to access and receive quality healthcare. These forces include poverty, safe living environments, jobs that pay a living wage, affordable housing, and high quality schools.

> *"Health care premiums… for family coverage reached $10,880 this year… eclipsing the total gross earnings for a full-time minimum wage worker ($10,712)."*

According to Kaiser Family Foundation research, employee health care premiums have gone up 73 percent since 2000, and average annual premiums for family coverage reached $10,880 this year. This figure eclipses the total gross earnings for a full-time minimum wage worker ($10,712).

We also know that in 2000, 69 percent of U.S. businesses offered healthcare insurance coverage for their employees; in 2005, only 60 percent of U.S. businesses offered insurance coverage for their employees. National and state polls show that this number will continue to decrease as healthcare prices increase.

Most people who receive Medicaid and the overwhelming majority of those without health insurance, are from working families. How then are low wage earners going to provide quality healthcare for their families (in addition to food, clothing and shelter) if their employers do not cover a substantial amount of their premiums? It's not going to happen!

Before the Revolution

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Despite recent severe cuts in the Medicaid program at the state and national level, state and federal governments still spend billions of dollars on healthcare for the poor. In addition, insurance companies and some businesses are beginning to offer helpful innovative programs to provide cost-effective insurance for the poor and uninsured.

In some cities, doctors are working together to make sure that everyone has access to quality healthcare — in some, each doctor volunteers to see a certain amount of uninsured and Medicaid patients. When every doctor participates, no doctor has to bear more than a fair share of the financial burden; yet every person in the community, whether insured or not, has access to quality healthcare.

Although addressing the social forces that directly prevent some people from receiving quality healthcare may be difficult for individuals in the short term, all Americans can fully participate in this revolution of our healthcare system — starting today, we must engender change and reduce health disparities at the same time.

I believe that access to quality healthcare should be a right for all people rather than a privilege for some Americans. Each of us can, however, take responsibility for his or her own behavior: we can engage in healthier lifestyles, stop smoking, exercise, and eat properly. Such changes will greatly impact the current financial crisis in healthcare costs, extend our life expectancy, and begin to revolutionize the current healthcare system. Such a beginning will not end all healthcare disparities; it will, however, contribute to healthier and longer lives for many of us.

Steve Roling, *a former director of the Missouri Department of Social Services, is president and chief executive officer of the Health Care Foundation of Greater Kansas City.*

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Idealism, Impotence, and Justice

by Jack Coulehan

Applicants to Stony Brook School of Medicine complete a supplementary questionnaire that includes three short essays. In one, they respond to the question, "In your opinion, what contemporary medical issue in the United States most needs to be addressed?" The vast majority of these bright young men and women choose to write about a single issue — the gross inequity of our American healthcare system.

Jack Coulehan

These essays sound genuine and often passionate. Some applicants focus on numbers (e.g., 47 million persons without insurance), others on concepts (e.g., justice, rights, and allocation), and still others tell of personal experience in their own families, or that of patients they've encountered in hospitals or clinics. Many applicants strongly advocate that we adopt some form of national healthcare system.

I've interviewed scores of these young people over the years, and I'm convinced that most of them sincerely believe the sentiments expressed in their essays. Nonetheless, when these same individuals graduate from medical school several years later, they tend to have changed dramatically their beliefs and attitudes regarding justice in healthcare.

In one sense this is quite natural. Medical education is an intense process that results in both medical sophistication and professional character formation. Trainees internalize values and attitudes characteristic of the profession. This incorporation ought to be a good thing, but unfortunately, contemporary clinical education provides dramatically mixed messages. On the one hand, we teach students altruism, compassion, respect, courage, justice, and self-effacement. These concepts belong to the explicit (what we say) curriculum. However, as they work long hours in hospitals and clinics, students are exposed to a stronger implicit (what we do) education that is frequently inconsistent with virtue. This conflict drives a wedge between values and behavior; a wedge that ought to be apparent to young physicians, but often isn't. Why not?

> *"Doctors do a lot of highly complex thinking, but most devote little effort to understanding themselves and others."*

As Tom Inui has eloquently described, an enormous gap occurs between ethical values we espouse in the medical profession and the way we behave in everyday practice.[1] Of course, we're only human, and humans are notoriously bad at living up to their ideals. But contemporary medicine is remarkable in the extent to which we pride ourselves in high professional values, while at the same time acting in quite contrary ways. We say patient welfare, but act in self-interest. We say respect, but treat the patient as an object, rather than a person. We say that Americans have a right to healthcare, but remain complicit in the status quo.

Most physicians are not aware of these inconsistencies. Because they work exceptionally hard, usually under stressful conditions, physicians genuinely believe that they're doing the best they can. When they encounter situations that call this belief into question (e.g., dissatisfied patients, poor relationships, lack of health insurance, mistakes, and negligence suits), they tend to blame others (e.g., managed care, bureaucracy, unrealistic expectations, or our American culture of avarice).

Peter Williams and I call this pattern of belief "non-reflective professionalism," because it is based on a deficiency in self-awareness.[2] Doctors do a lot of highly complex thinking, but most devote little effort to understanding themselves and others. When it comes to professional virtue, these doctors talk the talk, but they don't walk the walk.

We start out with starry-eyed young laypersons who want to become doctors and save the world.

Idealism, Impotence, and Justice

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A major outcome of medical education is the cult of expertise. Students internalize the concept that experts provide the "best" care for patients who fall into their area of expertise; the expert holds a kind of moral authority in his or her field. This is one reason why a career in primary care is unattractive to many students. While they understand the many positive features of primary medicine, they also believe that expertise in a specific organ system inevitably trumps generalist care. In a specifically medical sense, the generalist is second rate, or at least is susceptible to feeling second rate, or to being considered so by others. This cult of expertise also contributes to doctors abandoning whatever personal commitment to social justice they might have had.

Why? First of all, students rarely encounter activist role models during their clinical education. They encounter specialists and scientists and perhaps a few generalists, but virtually every one of these role models works in the context of one-to-one medical care, even if sometimes in publicly funded clinics. However, they have little exposure to public health physicians in governmental or nongovernmental positions, or to experts on healthcare policy and administration. Nor do they get to know practicing physicians who donate a part of their time to free clinics or medical service in third world countries.

> *"Fortunately, of course, most physicians don't lose their initial passion for justice."*

Second, as noted above, they become so attached to the ethic of expertise that they feel impotent when it comes to health policy and administration. Over the years they learn a great deal of misinformation about the social and legal context of healthcare; the strongest of these messages is, "You're only one person. There is nothing you can do about it." If you're not an expert in health policy, and if the political cards are stacked against you, you might as well just accept the way things are.

Thus, we start out with starry-eyed young laypersons who want to become doctors and save the world, and after many years we turn out rigidly realistic doctors who can save individual patients, but feel totally at sea with regard to social injustice. Fortunately, of course, many physicians don't lose their initial passion for justice; some of them engage in significant work toward healthcare reform and national health insurance. But such physicians have managed to nurture their sense of social responsibility in spite of, rather than as a result of, their professional training.

In medicine we often talk about the "real" world as a hostile place that excludes idealism. Wouldn't it be wonderful if somehow we could avoid dampening our students' idealism, and instead allow it to continue and flourish in their lives as physicians?

Notes

1. Thomas S. Inui. *A Flag in the Wind: Educating for Professionalism in Medicine.* (Washington, DC: Association of American Medical Colleges, 2003).

2. Jack Coulehan, and Peter C. Williams. "Vanquishing Virtue: The Impact of Medical Education." *Academic Medicine* 76 (2001): 598-605; and Jack Coulehan. "Today's Professionalism: Engaging the Mind, but Not the Heart." *Academic Medicine* 80 (2005): 892-898.

Jack Coulehan, *is the director of the Institute for Medicine in Contemporary Society, and professor of Medicine and Preventive Medicine at the State University of New York at Stony Brook. Among his interests are medical education, clinical ethics, and literature in medicine. He is the author of four books of poetry and editor of* Chekhov's Doctors *(Kent State University 2004).*

Wouldn't it be wonderful if somehow we could avoid dampening our students' idealism and instead allow it to continue and flourish?

"It's Too Much — First My Daughter, and Now This"

Case Study by Sharon Lee
Discussion Questions by Rosemary Flanigan

Fiona's twenty-two-year old daughter was killed in a car wreck. Fiona took custody of her two grandchildren and worked as a housekeeper in a private home while the children were in school. Fiona had no health insurance. She earns too little to buy an individual plan and too much to qualify for Medicaid. When she started bleeding, she just kept buying napkins to absorb the blood.

She continued to work until she collapsed on the job and was taken to an emergency room. Once there she was diagnosed with uterine fibroids, a treatable condition. But in the ER her bleeding stopped. She received a transfusion and was released.

Three months later Fiona was back in the ER, again with uncontrolled bleeding. This time, while she was being stabilized, the bleeding became a mere trickle; again, she was transfused, given the name of an OB/GYN physician to see, and released. Fiona tried as much as possible to do what the ER providers suggested. She did not, however, make an appointment with the physician because she feared medical debt. The bill from her first ER visit, including the ambulance ride, exceeded two months' salary.

Twice more Fiona visited the ER, but her medical problem was not treated either time, though she was encouraged to get help. On the fifth ER visit, Fiona was admitted to the hospital and even though she was not insured, the hospital consented to allow her to undergo an "elective" hysterectomy. Fiona has been billed for the surgery, and is attempting to pay. She is depressed, however, because she knows she can never finish paying this bill, given her current employment.

Sharon Lee, MD, is founder and medical director of Southwest Boulevard Family Health Care Center in Kansas City, Kansas.

Rosemary Flanigan, PhD, is professor emeritus of Rockhurst University and a program associate at the Center for Practical Bioethics.

Case Studies are a regular feature of **Practical Bioethics.** *For more cases, visit www.practicalbioethics.org or ask about our online discussion group. Email your requests to join the discussion group to bioethic@practicalbioethics.org.*

We are failing to provide care to our sick and vulnerable.

Questions for Discussion

1. Step into Fiona's shoes. What else would you do besides go to the ER five times?

2. Many physicians and nurses in ERs work three 12-hour shifts a week. It could easily be the case that Fiona was seen by different staff members each time she came. But her medical record has the history of each visit. Role play the procedure that your ER would have used when Fiona comes for her third visit.

3. According to EMTALA regulations, no hospital is required to provide post-stabilization procedures. But does a moral obligation increase with each of her visits?

4. Is Fiona's hysterectomy an elective procedure? Why? Why not? What difference does it make?

5. Are the procedures for debt collection at your hospital regularly reviewed by your ethics committee? Why? Why not?

6. At your hospital, who would advocate for Fiona? Who would help her contest the bill, especially if it represented the full amount that her hospitalization cost the institution?

Email your questions or comments about this case to bioethics@practicalbioethics.org.

Specialty Healthcare Access

pro bono specialty care is available to all in need. The network will help ensure that provider services are shared equitably and efficiently — a reasonable, achievable, and ethical goal, but one that is also marked by dilemma.

Besides the practical dilemmas spawned by disparities grounded in socioeconomic difference, we note the dilemma of conflicting rights and responsibilities. Is access to healthcare, whether it be primary or specialty care, a basic human right? Much of the world outside this nation seems to think so. But there is arguably a right also to fair and reasonable compensation for services rendered. Expectations of pro bono specialty care affirm the first right while somewhat negating the other.

The difficulty may be mitigated by reference to professional responsibilities. We reasonably expect a degree of charity from those most able to respond to the needs of others, some of whom are made vulnerable by the very socioeconomic conditions that have made possible physicians' *response-ability.* The physician's covenant is one of beneficent intent toward patients; and relevant oaths, Hippocratic or others, do not premise the provision of care on a patient's ability to pay.

Responsibility rests with patients, too, of course. Each of us surely bears some responsibility to care for our own bodies, to engage in self-care and in behaviors conducive to health main-tenance. We might reasonably be expected to make adequate provision for anticipated health problems, including accidental injury. The tragic reality is that some of society's members do not, and many cannot, do these things. Some of us are likely irresponsible with our health or the health of our dependents; many others simply are not *response-able.*

The dilemmas of healthcare access are complex and complicated by systemic factors larger than any individual patient or provider. Solutions to the problems of the uninsured are elusive, and establishing specialty care referral networks like Project Access, or the Medical Outreach Project, are short-term solutions at best. As an interim response, however, these are worthy efforts to reduce disparities by increasing access. They promote charitable response with more equitable sharing of both the burdens and joys of pro bono healthcare for society's most vul-nerable members and, in that way, the patient benefits, society benefits, and so do providers. "When you truly help someone," says Dr. Milton Grin, an ophthalmologist profiled in UMKC's *Panorama* (Muder 2003), "it helps your day, your month, your year go better. You made that difference, and if you didn't take care of it, who would?"
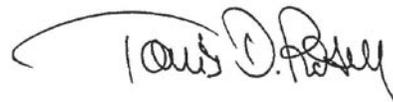
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