Distributive Justice in American Healthcare: Institutions, Power, and the Equitable Care of Patients

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The authors argue that the American healthcare system has developed in a fashion that permits and may support ongoing, widespread inequities based on poverty, race, gender, and ethnicity. Institutional structures also contribute to this problem. Analysis is based on (1) discussions of a group of experts convened by the Office of Minority Health, US Department of Health and Human Services at a conference to address healthcare disparities; and (2) review of documentation and scientific literature focused on health, health-related news, language, healthcare financing, and the law. Institutional factors contributing to inequity include the cost and financing of American healthcare, healthcare insurance principles such as mutual aid versus actuarial fairness, and institutional power. Additional causes for inequity are bias in decision making by healthcare practitioners, clinical training environments linked to abuse of patients and coworkers, healthcare provider ethnicity, and politics. Recommendations include establishment of core attributes of trust, relationship and advocacy in health systems; universal healthcare; and insurance systems based on mutual aid. In addition, monitoring of equity in health services and the development of a set of ethical principles to guide systems change and rule setting would provide a foundation for distributive justice in healthcare. Additionally, training centers should model the behaviors they seek to foster and be accountable to the communities they serve.

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Take my state, Colorado. Almost every hospital has an ethics committee, but no one asks ethical questions about the entire system. Over 50% of our hospital beds are empty, we have 21 hospitals doing open-heart surgery, and 3 doing transplants (3 times what is needed). We have (for 3.5 million people) more MRI machines than Canada, and far too many specialists. This, in a state in which 450 000 citizens are uninsured and another 400 000 underinsured. We have large excess capacity in neonatology, yet 21% of our women give birth without adequate prenatal care. Excess capacity sits cheek by jowl with great need.

Richard Lamm, 1994¹

n February 2000, the Office of Minority Health (OMH) of the US Department of Health and Human Services convened a meeting entitled "Conference on Diversity and Communication in Health Care: Addressing Race/Ethnicity, Language, and Social Class in Health Care Disparities." The Office of Minority Health was responding, in part, to public and professional reactions to a paper by Schulman et al.^{2,3} Schulman et al reported evidence of race and gender bias on the part of participants in a study of decision making by physicians trained in internal medicine and

family practice. This article builds on the discussion of a group of experts convened at the conference to explore institutional aspects of the problem.

If provider bias plays a role in healthcare disparities, do healthcare systems independently contribute to inequities in care, and if so, how? By analyzing the performance and organization of selected parts of the healthcare system, we hope to address these questions. This paper's premise is that the institutional structures supporting the American healthcare system have developed in a fashion that permits, and may in fact support, ongoing, widespread inequities based on poverty, race, gender, and ethnicity.

Inequities in Healthcare

Race prejudice is a shadow over all of us, and the shadow is darkest over those who feel it least....

Pearl Buck, 1941⁴

Since the OMH meeting on disparities, racial and ethnic inequities in US healthcare have been documented, notably by William Byrd and Linda Clayton, who published a 2-volume medical history of African Americans in the United States⁵; the Institute of Medicine, which published a major report titled *Unequal Treatment*⁶; and the Urban Indian Health Institute, which reported on health disparities.⁷ These works complement earlier important studies: a 2-volume report by The US Commission on Civil Rights,⁸ the Morehouse Medical Treatment and Effectiveness Center's summary of 180 reports published between 1985 and 1999,⁹ and David Barton Smith's *Healthcare Divided*.¹⁰

Kahn et al, looking at the frequency of services provided to Medicare patients (eg, X-rays, common diagnostic tests, referrals, and intensive-care-unit stays), documented the lower allocation of diagnostic and therapeutic resources to the poor and to African Americans. ¹¹ The work reaffirmed findings of earlier authors. ¹²

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Healthcare delivery disparities are documented for diverse conditions, including asthma, ¹³⁻¹⁵ infant mortality, ¹⁶⁻¹⁸ infectious diseases, ¹⁹ depression, ²⁰ and long-term care. ^{10,21} There are reported differences in total hip and knee replacement, ²² renal transplantation, ²³⁻²⁵ and bone marrow transplantation. ²⁶ African Americans receive lower levels of high-technology testing during cardiac care ²⁷⁻³⁰ and subsequently undergo fewer cardiac bypass or other revascularization procedures. ³¹⁻³³

A review of these papers reveals a variety of hypotheses for the disparities they document: from poverty, lack of access, provider bias, biological differences such as HLA typing, donor availability, and community needs, to patient preferences, unspecified cultural differences, lack of trust, levels of education, and so on. With limited exceptions suggesting provider bias on the one hand, 33 and patient preferences on the other, 34 the methodologies used in these studies do not allow the authors to explore provider-patient relations in a fashion that would provide clear answers. If racism is involved, it is unlikely to be overt or even conscious. 35

Researchers have controlled for sex, age, severity of disease, insurance status, access issues, poverty, and comorbidities. Studies done by the Veterans Administration^{30,36} and in Canada³⁷ have been sited in an attempt to minimize the effects of differential access and insurance. Most striking is the consistency with which disparities related to race, access, and poverty have been documented. Care is needed in future research, ³⁸⁻⁴² and studies must better account for "the social, economic, and political forces that constrain the lives of those studied."³⁸

Although the patient's voice generally is missing from work done to date, there are exceptions. Recent studies suggest African American patients were more likely to refuse cardiac surgery, ³⁶ carotid angiography and carotid endarterectomy, ⁴³ and knee replacement. ³⁴ These findings suggest that future research needs to include both provider and patient views and to incorporate a broader range of related issues. Lack of trust and perceived racism may be among the issues playing a role in healthcare inequities. ⁴⁴

Institutional Factors Contributing to Healthcare Inequities

The most basic and irrefutable lesson of the story of healthcare's civil rights struggle is that the problem is much more institutional than individual.

D. B. Smith, 2000¹⁰

Financing and power are core sources of exclusionary institutional practices in healthcare. This section will deal with 4 selected aspects of exclusionary healthcare practices: comparative costs, health insurance, financing/risk reduction, and the relationship between power and rule setting.

THE COST OF AMERICAN HEALTHCARE. WHAT'S THE RETURN? WHO'S PAYING?

Canadians, Australians and Western Europeans spend about half what we do on healthcare, enjoy universal coverage, and are healthier.

S. Woolhandler and D. Himmelstein, 2002⁴⁵

Per capita, the United States has the most expensive healthcare system in the world. In 2000, the US spent \$4631 per capita or 13% of its gross domestic product (GDP) on health. Physicians in the United States are paid higher wages than their counterparts internationally, and the average hospital cost of \$1128 per day ranks highest (by wide margins) among the 29 member nations of the Organization for Economic Cooperation and Development (OECD). Denmark is second at \$632 per day, and Canada ranks third at \$489.46 Researchers estimate that "Americans paid 40 percent more per capita than Germans did but received 15% fewer real healthcare resources."47 Estimates place health expenditures at 15.5% of America's GDP in 2004 and 18.4% in 2013.48 In addition, "much of the energy and capital spent in the development of new healthcare products and services have been targeted at the high end-at sustaining technologies that enable the most skilled practitioners to solve problems that could not be solved before."49

Comparative international rankings place the United States in the lower one half of health outcomes measures. For example, the high US infant mortality rate is 6th from the bottom of the 29 OECD countries with only Turkey, Mexico, Poland, Hungary, and Korea having higher infant mortality rates in 1996. The United States had the highest diabetes mortality, and ranked 12th (second from the bottom) of 13 countries for 16 available health indicators. More than 43 million Americans lack health coverage; and of the 29 OECD countries, only the United States, Mexico, and Turkey lack universal health coverage.

For years, Americans have equated healthcare coverage with employee benefits. Estimates of health insurance coverage have not distinguished between coverage provided by federal and state agencies and that provided by the private sector. Broad references to "private" coverage thus masked a large portion of publicly funded healthcare. Current estimates of healthcare financing are that tax dollars support 59.8% of American healthcare. This figure includes persons who rely on tax-funded government insurance such as Medicare, Medicaid, former or current military coverage, Indian Health Service, and tax-funded coverage for government employees such as FBI workers. ⁴⁵ In a second recent

study, private-sector workers whose employers arranged their insurance accounted for only 43% of the total.⁵³

HEALTHCARE INSURANCE AND POLITICS

There are some questions that historians return to so often that they become classics in the field. . . . No inquiry better qualifies for this designation than the question of why the United States has never enacted a national health insurance program.

D. J. Rothman, 1993⁵⁴

The primary source of rationing and inequities in American healthcare is the political system. To date, Congress has resisted enactment of universal healthcare coverage and has instead relied on a patchwork of "safety nets," many of which are imperiled. Since being established in 1967, Community and Migrant Health Centers have served as a primary care safety net for medically vulnerable populations. 55 A more recent safety net program is the State Children's Health Insurance Program (SCHIP) established by the 1997 Balanced Budget Act. Cited for successful enrollment of previously uninsured minority children, 56 studies of SCHIP document the need to "initiate programmatic efforts to ensure that the disparities children experience before enrollment are not perpetuated." 57

Writing in 1996, Krieger commented that "Congress is awash with legislation intended to cut back, if not end, many programs that have improved public health and reduced social disparities in health, such as Aid to Families and Dependent Children (AFDC), Head Start, Medicaid and Medicare, unemployment benefits, regulatory powers of the Environmental Protection Agency and the Occupational Safety and Health Administration. Much of the rhetoric around these political changes is couched in racially coded language that suggests the working poor and unemployed are solely responsible for their plight." True to Krieger's observations, new economic downturns and state budgetary changes have led to threats to both Medicaid and SCHIP coverage for children.

A 1999 study showed that "the proportion of Americans without insurance increased from 14.2% in 1995... to 16.1% in 1997 [when] 43.4 million (16.1%) were uninsured." In addition, "71.5 million [26.6%] lacked insurance for at least part of the year... 24% of those with incomes less than \$25 000 had no coverage [and] despite Medicaid 11.2 million persons with incomes below the poverty line or 31.6% of the poor had no health insurance in 1997. Today the vast majority of uninsured persons are employed." In 10 jurisdictions, more than 33% of children went without insurance for some period "between 1995 through 1996, led by Texas (46%), New Mexico and Louisiana (43%), Arkansas

(42%) and Mississippi (41%)."⁶¹ More than one third of the population, or 84.8 million, were uninsured for at least 1 month between 1996 and 1999.⁶²

"Medical care has always been rationed, primarily through ability to pay and by doctors working within fixed budgets." One hope and promise of managed care was that if insurers exercised the necessary controls on medical expenditures for the insured, funds would be freed up to insure more of the uninsured; unfortunately, this hope was not realized. In managed care, rules and incentives for physicians often limit patients' choice without these restrictions being apparent.

HEALTHCARE FINANCING: MUTUAL AID VERSUS ACTUARIAL FAIRNESS

In the current system, the most profitable plans are those that avoid caring for sick patients. Those that care for many sick patients and do a good job are penalized. Managed care plans are adept at . . . enrolling a disproportionate number of healthy persons and . . . reducing the contingent of sick patients.

J. Kassirer and M. Angell, 1999⁶⁶

The concepts of mutual aid and actuarial fairness have shaped the development of health insurance. Distributive justice in mutual aid assumes shared responsibility for risk across a broad community of participants. The logic of mutual aid supports governmental social insurance programs as well as insurance programs offered to large collectives of employees in which the insurer agrees to cover a community of workers. Historically, between 1934 and 1945 the Blue Cross plans used community ratings and "charged the same premiums to all employee groups in a geographic area or industry, thus pooling the risks of illness broadly in a region."

Actuarial fairness now dominates private health insurance systems in the United States. Broadly shared or communal risk has been shifted to the public sector. "The entry of commercial insurers into the healthcare business in the 1960's and 1970's produced a shift away from community rating [mutual aid or assistance]" and toward pricing based on actuarial or experience-based rating in which insurance companies work to lower costs (termed losses) by selectively insuring lower-risk populations.

Consider a 1989 health insurance ad picturing a young man and woman playing basketball one-on-one. The caption ran: "Why should men and women pay different rates for their health and life insurance?" Following a brief explanation of actuarial fairness, the ad continues: "That's why insurers have to group people with similar risks when they calculate premiums. If they didn't, people with low risks would end up subsidizing people with high risks. And that wouldn't be fair [emphasis added]."

Advertisement campaigns such as that one are designed to persuade Americans that they should not be responsible for the poor and the unfortunate⁵⁴ and to "feel morally comfortable about refusing to help others."67 The ads reflect the power and interests of the health insurance industry. Among the stakeholders in the system's evolution are the unions, which at one time "preferred to obtain healthcare benefits . . . through contract negotiation . . . even if that meant that nonunion members would go without benefits."54 The divisive nature of the system that has evolved is clear. For example, on February 17, 1993, a state insurance commissioner argued for the use of HIV testing as a prerequisite to health insurance before the Advisory Panel to the Office of Technology Assessment: "We encourage insurers to test where appropriate because we don't want insurance companies to issue policies to people who are sick, likely to be sick or die."67 The ethical principles of community-based mutual assistance and shared risk are anathema to a powerful, bottomline-oriented healthcare insurance industry.

INSTITUTIONAL POWER AND RULE SETTING

Should the child of a poor American family have the same chance of avoiding preventable illness or being cured from a given illness as does the child of a rich American family?

U. E. Reinhardt, 1997⁶⁹

Cross helps us define the relationship between power and oppression. The makes a clear distinction: crossing the line from class-based or ethnically based bias, prejudice, and ethnocentrism to institutional oppression or racism requires the presence of power. Cross's work provides a useful reminder about potential risks and outcomes of the day-to-day work of rule setting in institutional process. Examined in this light, the rule-setting underpinnings of insurance systems appear to be based on fundamentally exclusionary principles: "The underwriting criteria that insurers have found so necessary to preserve their fiscal soundness and actuarial fairness dovetail precisely with those identities that have formed our major social cleavages: race, ethnicity, class, and more recently sexual orientation and disability." 100 or 100

Relationships between HMOs, ethnic bias, clinic and hospital relocations, and minority physicians are discussed at length in the September 1999 report of the US Commission on Civil Rights. S(vol I) Facility relocation to the suburbs is an example of institutional choice. This strategy can place health plans in a position where they can avoid dealing with the poor as well as with providers that traditionally have served minority populations. These strategies are often supported by the rhetoric of sound business practice and marketing. Evidence for

exclusionary practices led to an editorial conclusion in *The New England Journal of Medicine* that "managed competition and capitated payment systems may increase discriminatory [outcomes]." ³⁵

Bias in Decision Making by Healthcare Practitioners

We may recognize that the judgments we make are based on a person's race, sexual preference, age, disability, or other characteristic, but we do not acknowledge the invalidity of these prejudgements. We treat our biases as truth.

Calman, 2000⁷²

Bias in clinical decision making is well described.^{2,73-75} Gentilello et al described nurses and physicians in trauma centers making biased clinical decisions based on sex, age, income, appearance, and insurance status: "Patients suspected of alcohol intoxication [who, in fact, had negative blood tests] . . . were either young, male, perceived as disheveled, uninsured or had low income." Additionally, ethnic bias has played a role in case presentations by residents and interns at academic training centers. ^{77,78}

The work of Todd et al⁷³⁻⁷⁵ documenting biased decision making parallels similar findings of undermedication of minority patients who have cancer⁷⁹ or depression⁸⁰ and most recently, of evidence that pharmacies in minority neighborhoods do not stock medications necessary to treat patients with cancer-related pain.81 Although Schulman's work² attracted national attention, being reported on "Nightline" and in multiple newspapers,3 little or no media attention has been paid to evidence of disparities in nursing home care, 10,21 infant mortality, 82-84 and avoidable hospitalizations, 85 as well as a long list of other important disparities in healthcare. Documented disparities in physician recommendations for cardiac surgery in 1999 left the causes for disparate decision making unexplained. One study that examined whether physician recommendations (1997-1999) for cardiac revascularization varied according to patient race found that African Americans were less likely to be recommended for revascularization in a public hospital.⁸⁶

Clinical Training Environments Linked to Bias and Abuse of Patients and Coworkers

I was annoyed beyond my capacity to remain civil. I was waiting at 6:30 PM for the on-call intern to show up and relieve me and I had plans for the evening . . . when he finally arrived he wanted the most excruciatingly detailed sign-out conceivable. Finally, I nearly shouted at him, "Look you're just here for the night! I'm not telling you anything more about these patients' 'social problems."

Resident in training, quoted by D. A. Christakis and C. Feudtner, 1997⁸⁷

Silver first suggested that students might be abused during training in 1982.88 The 1984 report by Silver and Rosenberg included a survey of medical school deans, who almost uniformly denied that a problem existed and attributed the problem to "stress:"89 "There has never been any evidence of abuse [at our school] . . . you have my sympathy if the situation at Colorado is otherwise."89 Since 1984, more than 30 articles about student mistreatment and abuse have been published. By the mid-1990s, the articles began to deal with solutions. 90-93 The report by Kassebaum and Cutler94 for the Association of American Medical Colleges (AAMC) Liaison Committee on Medical Education was a long step away from the initial denial reported by Silver. Evidence that the abuse is passed on to patients has been documented. A Canadian study found that "a significant relation was shown between male students who reported experiencing abuse during medical training and mistreating patients."95

The report for the AAMC documented that Native American/Alaska Native and African American women have the highest reported incidences of public belittlement and humiliation and that African American women report the highest incidence of perceived racial harassment. Hese findings provide a clear underpinning for earlier reports about medical students' experience of racist attitudes, remarks, and behaviors during training, he sa well as a medical school faculty member who describes experiencing racial and gender prejudice in faculty interactions. He had a sa medical school faculty member who describes experiencing racial and gender prejudice in faculty interactions.

Of 164 nurses participating in a California study, 64% reported experiencing some form of verbal abuse by physicians at least once every 2 or 3 months. Thirty percent of female nurses in the study reported sexual harassment by physicians at least once every 2 to 3 months (sexual propositions [20%], sexual insults [16%], or suggestive touching [13%]). Similar findings are reported in healthcare training institutions. These studies illustrate the dysfunctional use of power at the level of institutional, professional, and cross-gender relationships.

Examining the slang used by the subculture of medicine, George and Dundes published "The Gomer" in 1978. 101 The title arose from their observation that student and house officer teams in a Veterans hospital had developed a "gomer" score sheet (gomer is an acronym for get out of my emergency room). Coombs et al later concluded: "medical slang eases the way for young men and women who are trying to meet the demanding expectations of a formal training system designed to change them from laymen to physicians . . . slang is shared by a beleaguered circle of insiders who are confronted daily with overwhelming evidence of their own limitations and inadequacies." Slang expressions about patients who have low social status, few economic resources, or low

intelligence, or who are otherwise viewed as undesirable offer an insight into the functions of power and stress as well as the links between biased, elitist, and racist attitudes. The common theme is disrespect for individuals.

Is some bias acquired during training? Does exposure to healthcare process magnify preexisting forms of bias and prejudice? The answer to these questions may be emerging. Referencing earlier "studies¹⁰³ [that] have documented race- and sex-based differences, including race-discordant perceptions of patients," Rathore et al have produced evidence suggesting that bias is present in the earliest years of clinical training. 104 They studied the response of first- and second-year medical students to videos in which professional actors played out the role of an African American woman and a white man with symptoms of angina. The students rated the quality of life of these patients quite differently, although the differences were less when white female students did the analysis. 104 Programs in medical education have begun to address these issues, 105-109 even framing a patient-centered approach in the context of cultural humility as opposed to cultural competence. 110

Provider Ethnicity, the Safety Net, and the Imperiled Preparation Pipeline

In 1970 . . . the AAMC designated blacks, Mexican Americans, Mainland Puerto Ricans and American Indians as underrepresented in medicine . . . regrettably this problem persists.

H. W. Nickens, T. P. Ready, and R. G. Petersdorf, 1994¹¹¹

Access for vulnerable populations is problematic and has been positively impacted by the presence of minority practitioners. Minority and women physicians are much more likely to serve poor, minority, or Medicaid patients. At the same time, "communities with high proportions of black and Hispanic residents were 4 times as likely as others to have a shortage of physicians, regardless of community income." Minority physicians are most likely to practice in communities with high proportions of minority patients: "Black physicians practice in areas where the percentage of black residents was nearly 5 times as high, on average, as in areas where other physicians practiced." 114

In the late 1960s, AAMC initiated a successful effort to increase the participation of minorities and women in healthcare. In 1964 "93% of medical students were men and 97% were non-Hispanic whites. [By 1994] 40% were women and 31% belonged to racial or minority ethnic groups." However, this effort plateaued in the 1980s. In 1993, the Council of Graduate Medical Education, authorized by Congress in 1986 to provide

ongoing assessments of the physician supply, supported AAMC by recommending that the "number of entering minority medical students should be doubled from 1500 to 3000 by the year 2000." The council's perspective on the mission of medical schools and residency training institutions focused on "graduating generalists and minorities and the number who choose to practice in underserved communities."

The focus and direction of efforts to produce more minority practitioners now are threatened by dismantling affirmative action. Early anti-affirmative-action efforts were undertaken in California, Texas, Louisiana, and Mississippi. In 1998, Carlisle et al estimated that the United States needs "roughly twice as many Hispanic and African American and 3 times as many Native American physicians as it now has."116 Nonetheless, affirmative action has been under assault, as exemplified by actions in Florida¹¹⁷ and Washington State. 118 Many believe that dismantling affirmative action will result in serious problems with access to care over the ensuing years. 119-121 In the face of the Supreme Court upholding affirmative action in the University of Michigan's admissions policies, 122 there is concern about the lack of subsequent federal action. 123

Minority physicians' lack of access to participation as health plan providers impedes the delivery of care to minority communities. In 1995, an extensive note in the Harvard Law Review predicted that "if a relatively unregulated change [in HMO development] occurs, many minority physicians and physicians who serve the poor and minority communities may be squeezed out."124 Listing economic credentialing and practice profiling among the tactics that allow plans to limit "risk," the note in the Harvard Law Review pointed to "the perverse incentives of many HMOs to exclude providers with less healthy patients."124 In 2000, members of the National Medical Association charged that managed care plans systematically excluded black physicians from physician panels nationwide. 125 These unsubstantiated charges warrant further inquiry.

Data, Research, and Monitoring Equity in Health Services

We have the language to name and methods to measure how inequality and social justice affect health . . . to generate knowledge that public health and medical practitioners, policy makers, activists, and others need to guide fruitful action to improve the public's health.

N. Krieger, 1996^{58}

Smith pointed out that "eliminating the collection of data by race would, for all practical purposes, negate all affirmative action programs, the Civil Rights Act, the Voting Rights Act, the Fair Housing Act, and other related legislation." ¹⁰ In Madison v. Shalala (1996), ¹²⁶ health-care advocacy groups argued that "HHS regulations require that HHS collect patient- and provider-specific data from recipients as part of its title VI enforcement efforts. At issue was the Healthcare Financing Administration (HCFA) billing form, HCFA-1450, used to collect information on each transaction between a Medicare or Medicaid patient and a healthcare provider." ^{8(vol II)} Form HCFA-1450 lacked race or ethnicity data.

The National Hospital Discharge Survey has found that hospitals in their sample not reporting race were overwhelmingly white. 10 Similar problems exist in the collection of data regarding language needs of patients with limited English proficiency (LEP). In 1996, only 1 of 8 healthcare institutions surveyed in the Seattle area had a centralized system to flag language needs. 127 Lack of data figured prominently in a major report on linguistic access to healthcare by the National Health Law Program. This program recommended improved data collection "on the language and health needs of LEP patients" as well as changes in Health Employer Data and Information Set 3.0 data regarding language accessibility. The report includes "Nine Principles of Contracting with [Managed Care Organizations],"128 which help state and local agencies review arrangements with insurers who have underwritten healthcare of LEP populations.

What becomes clear in a review of the extraordinarily extensive documentation of disparities in healthcare is that much of the material has been biomedically focused. In contrast, the work of Lurie et al illustrates the use of traditional health services research methods to study the serious impact of changes in public policy, political, and economic decision making on health outcomes. 129,130 Additionally, the recent study by Silverman et al demonstrated increased Medicare spending and costs in for-profit hospitals in the areas of hospital services, physicians' services, home healthcare, and services at other facilities. 131 The work of these authors exemplifies the numerous investigations done to date that have studied public policy, healthcare systems, and their implications for American healthcare. More interdisciplinary efforts and community-health services research partnerships are needed.

More than 2 years of work have resulted in the development of standards for culturally appropriate healthcare; this work involved policy analysis and an extensive effort to obtain stakeholder and community input. ¹³² This OMH report, together with policy statements crafted by the National Center for Cultural Competence, ^{133,134} outlines fundamental issues associated with culturally competent healthcare. These approaches parallel the work of researchers who studied the struggles, successes, and

failures of community clinics and organizations, in order to test the reality of doing the work against well-constructed theory and principles.¹³⁵

Best Practices—Trust, Relationship, and Advocacy

Fundamental "caring" aspects of medicine depend on the sort of personal bonding that is only possible with those one trusts."

D. Mechanic and M. Schlesinger, 1996¹³⁶

Trust and relationship lie at the core of effective healthcare. Although trust "affects almost every aspect of doctor-patient interactions, from personal disclosure to treatment, . . . trust is at best only a secondary consideration in [setting] health policy."137 Physician advocacy also is key because "it is essential for patients to believe that their physicians are their agents and will represent their interests effectively."138 These roles that "rest substantially on the perception of physicians as dedicated patient advocates"65 have been sorely tested. "Health plans and hospitals employ economic leverage to an unprecedented degree to influence clinical decisions,"138 and use physician gatekeepers to regulate patients' access to expensive medical services. Clear ethical conflicts are created in which "physicians have an incentive to reduce services even when it is in the patient's interest to receive them."65 Should disclosure of fiscal incentives be required, and how would this disclosure impact physician-patient trust and relationship?

There is clear evidence that building trust and relationship lowers costs and improves quality even in the face of aging and diminished well-being. Weiss and Blustein¹³⁹ referenced a broad literature identifying numerous benefits of sustained relationships, including greater satisfaction among patients, 140-143,146,148 greater satisfaction among physicians and other staff, 144 fewer and/or shorter hospitalizations, 145 fewer broken appointments, 146 decreased use of laboratory tests, 147 and decreased use of the emergency room, 148 increased patient disclosure of personal problems, 144 and better compliance with physician instruction. 149 Furthermore, Daumit et al demonstrated that once economic barriers are removed and long-term, regular patient-provider interactions occur in cases of end-stage renal disease, racial inequities in the care delivered are eliminated. 150 Patients who have been in relationship with their physicians for "10 years or more incurred \$316.78 less in Part B Medicare costs per annum."¹³⁹

CONCLUSION

The evidence presented bears out the initial premise that institutional structures in American healthcare permit and even support ongoing, widespread inequities and injustice. Training systems need to model the behaviors they seek to foster in their trainees, and to be accountable to the communities that they serve and through whom they teach, learn, and study. Investing in data systems for healthcare, research, funding, recruitment, and training is a necessity; and these systems must include information about race and ethnicity. Best practices will demand a focus on trust, relationship, advocacy, and partnership with patients and communities.

We concur with Governor Lamm¹ that it is time to ask ethical questions of the entire system of healthcare. Such questions will need to focus on establishing healthcare for all in the United States and on developing written ethical principles for American healthcare. These principles would provide a foundation for distributive justice in the healthcare system, and for systems change and ethical rule setting.

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