

The Challenges of Eliminating Racial and Ethnic Health Disparities: Inescapable Realities? Perplexing Science? Ineffective Policy?

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One of the most important new foci of American health policy deliberations since the late 1990s has been widespread concern over racial and ethnic disparities—that is, the disproportionate burden of diseases and other adverse health conditions among specific populations. Serious discussions about inequity in access to care and the epidemiological patterns of illness, disability, and mortality began during the Clinton Administration and through the personal efforts of former Surgeon General Dr. David Satcher. Wide variations in the provision of health and medical care and in health outcomes among racial, ethnic, and other social groups have been viewed as inseparable from issues of social justice and equity in our country.

As health disparities have been examined in the United States or in North Carolina, the predominant emphasis has been on disparities that exist for particular race and ethnic groups (also referred to as persons of color), especially those whose race or ethnicity is identified as African American, Latino/Hispanic, American Indian or Alaskan Native, or Native Hawaiian or other Pacific Islander. These groups collectively represent nearly a third of the nation's and North Carolina's populations and are expected to grow. Latinos now represent our nation's largest minority group (12.5%), with African Americans comprising 12% of the population. North Carolina has experienced one of the most rapid increases in its Latino population among all states, with Latinos now representing 4.7% of the state's population, increasing from 1.04% in 1990.¹ African Americans are now 21% of the state's population and remain as North Carolina's largest minority population group. Recent reports from the

North Carolina State Center for Health Statistics show that African Americans, American Indians, and Latinos are more likely to have poorer health than whites in North Carolina. Given the predicted growth of minority populations—populations experiencing poorer health—our ability to successfully identify and address health disparities will significantly influence the health of our state and nation.

Racial and ethnic health disparities are intricately woven with socio-economic status and the ability to access other educational and social supports. Indeed social and environmental factors, such as having a low income, living in poor housing, having limited education, living with violence in communities, and the limited access to recreational facilities, are important to consider in health disparities research. But, health disparities cannot be fully explained by differences in socio-economic status alone. Health disparities are due to a complex interaction of many factors,

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including: individual behaviors and preferences, cultural beliefs, biological factors, environmental factors, differential health interventions, potential bias among treating providers, public and private health policies, and differential access to healthcare services, in addition to socio-economic factors.²

Latinos, for example are relatively healthy compared to whites or African Americans despite their low incomes and poor working and living conditions. This may be due to their recent immigration to the United States (e.g., the so-called “healthy migrant effect”) and relatively young age. Latina birth outcomes are much better—with lower rates of infant mortality and low-birth weight—than other racial or ethnic groups.³ Yet, Latinas tend to delay or omit prenatal care more often than other groups. Unfortunately, studies from states with more mature Latino communities suggest that, over successive generations, the favorable birth outcomes among Latinos will rapidly disappear.⁴ Culturally and linguistically appropriate interventions need to be developed before these recent immigrants become acculturated to the diet and lifestyle prevalent in the United States. Health literacy issues must also be addressed for this population. Not only do many Latinos have trouble understanding our healthcare system, but many Latinos are faced with a healthcare system that does not understand their culture and providers who cannot assess their health needs and preferences because of language barriers. These problems/differences present a number of health policy dilemmas. To achieve health equity, the priority in all areas of health policy should be to address health differences among population groups.

A nation that boasts as having the world’s best medical care cannot overlook differential healthcare and health status outcomes

where the system’s performance, in some cases, is among the world’s least equitable. The *promise* and *potential* of the American healthcare system is often beyond the reach of persons of color or is culturally inadequate when accessed. The continuance of health disparities lowers our nation’s overall health status and poses social, environmental, and financial risks for everyone. A focus on health and healthcare disparities offers the opportunity to re-examine all that we do (and say) in regard to our highest ideals in American healthcare policy and practice. In addition, it gives us the opportunity to identify programs and policies that need strengthening and to better target resources so that we may attain these important national health goals and objectives.

Measures of Health Disparities

Five principal measures of health disparities are of greatest salience with respect to national and state health policy. First, there are issues related to the epidemiologic distribution and variation among population subgroups in the *incidence/prevalence* of specific health conditions. Second, there are issues related to *accessing* basic healthcare services when the need arises. Third, there are issues related to the *types of treatment* provided when services are obtained. Fourth are issues related to the *quality* of those services that are provided. Finally, there are issues related to the *outcomes* (or the *effectiveness*) of the services for which access has been possible. Though these five dimensions are interrelated, the measurement of health disparities has often given emphasis to one or the other of these dimensions individually, without consideration of their interrelationship.

Typically, most discussions (occurring prior to the late

Table 1.
Age-Adjusted Death Rates (per 100,000 populations) by Race and Ethnicity and Cause of Death, North Carolina Resident Deaths

	White	African American	American Indian	Hispanic/Latino	Asian	Total
All Causes ⁵ 1999-2002	874.2	1,138.9	958.4	410.6	374.4	921.5
Heart Disease ⁵ 1999-2002	240.1	295.9	292.4	87.0	75.0	249.6
Prostate Cancer ⁶ 1997-2000	28.2	79.6	52	7.6	11	
Breast Cancer ⁶ 1997-2000	24.4	35.5	24	10.4	6.7	
Stroke ⁵ 1999-2002	68.3	96.5	75.8	33.2	73.2	42.0
Diabetes Mortality ⁶ 1999-2002	21.5	55.6	52.7	18.1	17.5	27.4
AIDS ⁵ 1999-2002	1.5	21.4	4.0	4.4	0.3	5.7
Motor Vehicle Injuries ⁵ 1999-2002	19.2	20.7	41.6	28.3	12.9	19.6
Chronic Liver Disease & Cirrhosis ⁵	8.9	10.5	8.7	3.8	3.2	9.2
Homicide ⁵	4.6	17.0	18.1	13.3	4.4	7.6

Table 2.
Key Indicators of Health Disparities by Race and Ethnicity in North Carolina

	White	African American	American Indian	Hispanic/Latino	Asian	Total
Infant Mortality ⁶ (per 1,000 live births)	6.3	15.4	11.2	5.8	5.2	8.6
Diabetes Prevalence ⁷	6.7	11.0	11.6	2.4	4.8*	7.4
Arthritis ⁷	28.3	26.0	31.8	11.4	6.0*	27.0
Adolescent Pregnancy Rate ⁵ (Ages 15-19)	62.4	103.0	95.7	168.0	NA	75.1
HIV Rate ⁵	6.5	64.2	14.5	14.7	6.2	19.4
STD Rate ⁵	172.0	1,758.3	580.6	477.9	243.5	515.0
Obese ⁷	20.9	36.0	26.6	19.8	3.5*	23.5
No Healthcare Coverage ⁷	12.8	18.3	26.5	58.9	11.0	15.9

* Percentage is based on less than 20 events in the numerator

Table 3.
Summary Health Indicators for White and Non-White Minority Populations in North Carolina by Gender, 2002⁸

	Years of Healthy Life	Years of Poor Health	Life Expectancy
White Men	62.4	10.6	73
White Women	66.6	13	79.6
Minority Men	53.3	14.7	68
Minority Women	59.3	16.5	75.8

1990s) of health disparities have focused on the differences in the incidence or prevalence of specific health conditions. Key indicators of health disparities among racial and ethnic groups include such rates as infant mortality, life expectancy at birth, cardiovascular disease morbidity and mortality, diabetes incidence and prevalence, and musculoskeletal morbidity (including arthritis and other related conditions). For example, African Americans have higher death rates for stroke, diabetes, septicemia, nephritis, homicide, and AIDS; and lower death rates for chronic lung disease and suicide.⁵ American Indians have high death rates for diabetes, motor vehicle injuries, and homicide. Latinos also have high death rates for motor vehicle injuries and homicide. The incidence and prevalence of different health problems do not affect all racial and ethnic groups equally. For example, Latinos have high death rates for AIDS, but low death rates for chronic diseases. Asians have low death rates for every cause.⁵ The data in Table 1 depict mortality rates attributable to these conditions among racial and ethnic populations in North Carolina. Table 2 provides indicators of the impact of health disparities among racial/ethnic groups in North Carolina. The data in Table 3 summarize more general indices of health status for white and non-white populations, by gender, in North Carolina.

Several gaps in the health of minorities are much wider in North Carolina than they are in the nation as a whole. For

example, African American North Carolinians shoulder a disproportionate burden from prostate cancer than their counterparts in other states.⁹ Although the incidence rate for prostate cancer is lower for North Carolina African Americans than African Americans nationally, the mortality rate for prostate cancer is greater and more than three times that of white North Carolinians. Pockets of extraordinarily wide health

disparities, such as those found in our state among prostate cancer patients, will be particularly challenging for healthcare practitioners and researchers alike. This is an area that needs basic etiologic research to understand the factors that account for the differential incidence of prostate cancer and the poorer health outcomes for some minority populations.

Over the past 50 years in the United States, health status has improved in many areas, such as infant mortality, cardiovascular mortality and morbidity and in reductions in musculoskeletal morbidity through joint replacement. These improvements have occurred among many ethnic groups, yet the gap in health outcomes between black and white, between Latino and non-Latinos, persist even after differences in socio-economic status have been taken into account. Rates of heart disease among adults illustrate the point; black men ages 25 to 64 years have higher death rates from heart disease than those for whites regardless of income. Only at older ages do the rates converge.⁸

Racial and Ethnic Minorities are More Likely to be Uninsured

Racial and ethnic minorities are more likely to be uninsured than whites. In North Carolina, 14% of non-Hispanic whites are uninsured, compared to 19.9% of African Americans, and

55.7% of Latinos.¹⁰ Latinos are least likely to have health insurance coverage because many of the Latinos in North Carolina are recent immigrants, and recent immigrants have a much harder time obtaining public health insurance coverage, regardless of their income,⁹ and many are employed in jobs offering little or no health insurance coverage.

Individuals who lack health insurance coverage face financial barriers which make it difficult for them to access health care services. For example, 41% of the uninsured respondents from the 2003 North Carolina Behavioral Risk Factor Surveillance Survey reported that there was a time, in the last 12 months, when they needed to see a doctor, but were unable to obtain such care because of the costs (as compared to only 9.5% of people with insurance coverage).¹¹ This differential insurance coverage, coupled with lower socio-economic status, makes it difficult for some racial and ethnic minorities to access needed services.

Disparities with the Utilization of Lifesaving Treatments

Disparities in healthcare are more easily measured as differences in the *use* of services than as differences in the quality of those services actually used or provided. Differences in insurance coverage do not address all the differences in use of health services. Cardiac catheterization in patients with chest pain, kidney transplants in dialysis patients, thoracic surgery in lung cancer patients, and acute reperfusion therapy for myocardial infarction are illustrations of areas where inequitable utilization (or provision) of life-saving or life-improving therapeutic procedures have been documented, even after controlling for insurance status. Some of these studies are briefly noted here.

One of the most striking health disparity studies used Medicare data to examine surgery rates among 10,984 black and white early-stage lung cancer patients.¹² Bach and his colleagues compared the surgery rates of black and white Medicare patients with stage I or stage II small cell lung cancer (for which surgical resection has been shown to be beneficial). Compared to the white patients, black patients underwent lung cancer surgery less frequently than whites (64.0% vs. 76.7%, $p < 0.001$). Black patients who underwent thoracotomy had mortality rates that were at least equivalent to those of white patients, but overall, blacks had a lower five-year survival rate than whites (26.4% vs. 34.1%, $p < 0.001$). The study attempted to control for socio-economic factors as well as comorbidities that might preclude surgery. Even after controlling for these factors, the authors were unable to determine why black patients

had a lower rate of resection than white patients, whether this difference was due to patient preferences in treatment options, or whether black patients are offered this procedure less frequently.

Investigators at the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill plan to conduct a follow-up study that surveys both physicians and lung cancer patients to determine why some patients eligible for potentially life-saving surgery do not undergo the procedure. In their preliminary analysis of data from patients treated in Chapel Hill and Greensboro, these investigators have found that a surprisingly high proportion of North Carolina lung cancer patients refused to believe their diagnosis or declined surgery and chose to seek non-medical or alternative medical treatments.¹³

Godley et al. used Medicare reimbursement data merged with Surveillance Epidemiology and End Results (SEER) files from the National Cancer Institute to examine racial differences in prostate cancer treatment outcomes among 43,989 patients with clinically localized disease.¹⁴ The investigators found that unlike the lung cancer study, black patients who received the same treatment as whites (whether surgery, radiation or watchful waiting) continued to experience poorer survival, particularly among the surgery patients (median survival after surgery was 1.8 years less for blacks than for whites). Black patients tended to choose surgery less often, watchful waiting more, and radiation at about the same rates as white patients. The challenge that this study posed is not necessarily why treatment is different, but why mortality differs significantly when treatment is similar, and potential confounders are taken into account. In contradistinction to lung cancer, prostate cancer patients tend to live for many years after diagnosis, even without treatment, allowing non-prostate cancer causes of death to account for a substantial proportion of the racial differences in overall mortality.

A study by Bradley et al.¹⁵ of 70,030 patients with ST-segment elevation myocardial infarction or left bundle branch block, used data from the National Registry of Myocardial Infarction to find that non-white patients, as identified by healthcare workers, had significantly longer waiting times before receiving emergency coronary intervention. African Americans waited 41.1 minutes in door-to-drug times (fibrinolytic therapy) and 122.3 minutes in door-to-balloon (percutaneous coronary intervention), Hispanics waited 36.1 and 114.8 minutes, respectively, compared to whites, who waited on average 33.8 and 103.4 minutes. All of the differences were statistically significant. A third of the difference for blacks and 75% of the difference for Hispanics were accounted for by the differences in the hospitals to which the patients were admitted. However, significant

a The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) significantly changed the eligibility of non-citizens for Federal means-tested public benefits, including Medicaid and the State Children's Health Insurance Program (SCHIP). As a general rule, only citizens or legally documented immigrants may be eligible for coverage. Most immigrants cannot be eligible for coverage for five years from the date they enter the country as a legally documented and qualified immigrant. In North Carolina, there are several different groups of individuals who qualify for Medicaid benefits. All have income limits and some have resource limits. To be eligible for Medicaid one must meet the income restrictions and be among one of the following groups: older adults (65 and older), blind, or disabled persons; a person in need of long-term care, a pregnant woman, a child (age 18 or younger), age 65 or older, a caretaker/relative of (living with and caring for) a child under age 19 who receives Medicaid.

differences remained even after adjusting for socio-economic characteristics, insurance status, and clinical and hospital characteristics. The disparity in this case is at least partially due to healthcare access, if not quality of care.

Another article by Bach et al.¹⁶ also emphasizes the importance of hospital resources in health disparities. The study used data from 150,391 Medicare patient visits linked to 4,355 primary care physicians who completed the 2000-2001 Physician Survey component of the Community Tracking Study. The authors concluded that black Medicare patients received their medical care from a small group of physicians who, when compared to their colleagues practicing in other settings, were less likely to be board-certified (77.4% vs. 86.1%), less likely to be able to provide high-quality care to all of their patients (19.3% vs. 27.8%), and more likely to “not always” be able to access high-quality sub-specialists for their patients (24.0% vs. 17.9%) or not able to arrange non-emergency hospital admissions (48.5% vs. 37.0%). All of the differences were statistically significant. These findings reinforce the observation by Bradley et al. that black patients not only receive care from physicians with different training, but also receive their care in hospitals that have diminished capacity to access needed healthcare resources.

The findings by Bach et al. suggest that disparities in the allocation of healthcare resources may be due to more than a lack of patient education or bias on the part of healthcare providers. The findings project an image of a “shadow healthcare system” that is largely separate and unequal, often offering blacks suboptimal services from less-credentialed physicians who work at relatively resource-poor hospitals and clinics. If this dual system of healthcare is corroborated by subsequent investigations, alternatives to the usual solutions based on interventions with healthcare professionals and patients, will need to be explored.

One possible area to investigate is the efficacy of increased resources for the subset of physicians caring for minority patients. Equalizing access to specialist referrals and expensive procedures for these physicians may help equalize the disparities documented for their patient populations—a kind of “trickle-down” approach to solving the problem of disparities in healthcare. An editorial accompanying the article by Bach et al. suggests that longstanding societal discrimination plays a role in blunting opportunities for patients to obtain high-quality healthcare. Some problems, such as facilitating the granting of admitting privileges to local well-equipped hospitals, may be easy to address, especially in urban areas. Other issues may be more difficult, particularly in more rural areas of the country like North Carolina, where minority patients and their physicians may be geographically isolated from well-equipped medical facilities and sub-specialist physicians. It is also not clear whether the deficit in board certification among the physicians predominantly caring for black patients contributes to health disparities, or if differential access to healthcare resources alone would explain the differences in utilization of medical services.

Are Disparities Caused by Structural Inequalities or Biological Differences?

If available evidence (as just cited) indicates that minority populations (African Americans in particular) are served by *different* healthcare providers (who differ by their training and credentials; their ability [not their desire] to arrange for sub-specialty referrals, diagnostic studies, or non-emergency hospital admissions; and by the quality of the hospitals with which they are affiliated), then are these *structural* facts of American healthcare sufficient to explain the wide variations in the health status outcomes that exist among racial and ethnic groups when they experience similar diseases or health conditions as the majority populations? Are there studies that have been conducted in closed healthcare systems in this country that presumably assure access to the same services for all patients, regardless of racial and ethnic status? It turns out that there *are* such studies conducted within the United States Veterans Health System and in large staff-model managed care systems. These studies have documented that patients served in systems that purport to provide the same services to every eligible patient in fact *do* show patterns of lower quality care for persons of color.^{17,18,19} It should be noted that while a number of Veterans Affairs hospitals have demonstrated disparities, a number of them have not found disparities. Thus, the differences in the structural systems of care provided to racial and ethnic minorities and the interpersonal bias of health professionals and patients contribute to health disparities. It is essential that in our search for policies to address health disparities that we take *both of these explanations* (or factors) into account and develop approaches that will deal with each.

One of the inescapable conclusions from the existing research in this area is that the socio-economic status of patients has much to do with *where* care is received, *what* care they receive, and of what quality, from *which* healthcare providers. The study by Bach et al., mentioned previously, attempted to adjust statistically for the socio-economic status of patients through the use of postal ZIP Codes of both the physician's practice and the patient's residence. Neither adjustment procedure altered the results of their research, although they point out (in a response to letters to the editor of the *New England Journal of Medicine*)²⁰ that “ZIP Code-based estimates (of socio-economic status) are imperfect surrogates for measures at the individual level.” In the final analysis, the significance of the study by Bach et al. is that it clearly indicates the importance of inequality and race as contributing factors to what we now collectively define as “health disparities.”

Recent information has surfaced that has raised the question of whether some of the disparities now seen in outcomes (or the effectiveness) of medical therapeutics are a result of the way (or systems within which) those therapies were delivered, or whether an explanation may lie in the biological differences among racial and ethnic groups that may moderate the effects of pharmaceuticals and other therapies. The November 11, 2004 issue of the *New England Journal of Medicine* included a controversial report,²¹ which described a single-race clinical

trial of a fixed-dose combination of two drugs previously approved by the United States Food and Drug Administration (FDA), isosorbide dinitrate^b and hydralazine^c for the treatment of heart failure among blacks (a condition from which mortality for blacks has been argued to be disproportionately higher than for whites, although the evidence for these differences is now questionable, as noted below). The combination pill carries the commercial name “BiDill[®]” and the trial of its use was co-sponsored by the Association of Black Cardiologists. Irrespective of the controversies raised by this publication over granting patents for race-based formulations of therapeutic agents, or the way in which the FDA approval of this new combined regimen may have been assured, there are serious questions about the way racial status is defined (or self-identified by study subjects) and the appropriate interpretation of the results of such trials.

This study, the African American Heart Failure Trial (A-HeFT) study, found that the drug combination being evaluated, when combined with conventional therapy, reduced relative one-year mortality for blacks by 43%, a truly remarkable finding. Bloche,²² in an editorial accompanying the trial’s publication, points out problems relying on single-race studies or self-identified race as a crude proxy for clinically-relevant genetic differences among people. First, studies that focus exclusively on the evaluation of therapeutics in a single race or ethnic group are not able to discern whether there are differential effects of these therapies among groups that are attributable to race alone. Second, when research subjects are asked to self-identify their racial and ethnic status, it is likely that such categorizations are influenced by the social and cultural definitions of race, not an index of the genetic or biologic variables that may determine one’s response to illness or therapies. Racial groups originating from Africa, as well as other racial groups, are genetically heterogeneous. Focusing exclusively on race as a proxy for genetic predispositions may also mask the psychological, economic, cultural, environmental, and social factors that are known to influence human physiology.

The day after the results of the A-HeFT findings were published, the significance of these controversial findings was underscored by an editorial in the *New York Times*,²³ which offered these observations:

“...there are reasons to go slow in moving toward race-based medicine. The chief drawback is that race is too superficial and subjective a concept, mostly based on skin color, to match up well with any underlying genetic or physiological differences that may affect how an individual responds to a disease or a drug treatment. Medical scientists are using race as a crude surrogate for what they assume are genetic differences yet to be identified.

But there is considerable genetic variability within any racial group, so it is likely that the new pill may fail some black patients, while white patients who could benefit may not get it because they don’t fit the racial profile. The ultimate goal, still years or decades away, is

to develop medical treatments based on an individual’s genes and life experiences, not on membership in some poorly defined racial or ethnic category. Race-based prescribing makes sense only as a temporary measure.”

There are substantial questions about the scientific veracity of statements about the variability of response to treatment among groups defined by self-identified sociologic/cultural criteria, which overlook the genetic variability within “racial/ethnicity” categories.

The controversy over the BiDil[®] trial did not start with the publication of the trial’s results. Nearly two years prior to publication of these findings there were numerous papers in the medical, ethics, and social policy journals questioning the inherent logic and rationale for the study. Kahn²⁴ demonstrated the fallacy of arguing a clear disadvantage of blacks in regard to mortality associated with heart failure. The 2:1 mortality ratio advanced by so many to justify the search for a race-based therapy has been shown not to be supported by available epidemiological evidence at the time. The ratio established by the Centers for Disease Control and Prevention (CDC) is approximately 1.1:1, but the 2:1 ratio has been repeated in numerous publications without attribution as a rationale for further clinical trials to address this problem.

The real worry about such efforts to find race-specific therapies is that the investment in these endeavors, and the controversies over the meaning and measurement of “race,” may deflect attention from the basic problem of inequities in American healthcare—allowing those who may deny the existence or extent of these disparities to advocate for further delays in addressing these issues.²⁵

Steps toward the Elimination of Health Disparities

One of the first steps being recommended by the National Research Council of the National Academies (NRC/NAS) is to strengthen the national informational technology infrastructure through which the data pertinent to health disparities may be documented and tracked for future progress. A recent report of the NRC entitled *Eliminating Health Disparities: Measurement and Data Needs*²⁶ has called attention to the need for individual-level data on race, ethnicity, socio-economic position, and acculturation (e.g., language use, place of birth, generational status), which are essential to documenting the nature of disparities in healthcare and to developing strategies for intervention. Not only are individual-level data severely limited, but the data that are available suffer from limited accuracy, completeness, and detail. State governmental data collection in programs like Medicaid, the State Children’s Health Insurance Program (S-CHIP), and various registry systems, are potentially valuable for tracking health disparities, but data from these programs are collected in non-standardized ways. Hence, the NRC report

b Isosorbide dinitrate is used primarily to prevent and treat angina, and in the treatment of acute heart attacks and heart failure.

c Hydralazine is used to treat high blood pressure.

The University of North Carolina at Chapel Hill Launches ECHO Program to Address Health Disparities in North Carolina

The Program on Ethnicity, Culture, and Health Outcomes (ECHO) has been created at the University of North Carolina at Chapel Hill (UNC-CH) to support and strengthen existing health disparity research, training, and education activities and to develop additional initiatives within the university. Recognizing the importance of an interdisciplinary focus, the deans of the UNC Schools of Public Health and Medicine, as well as the deans of the UNC Schools of Dentistry, Nursing, and Pharmacy and the College of Arts and Sciences, provide the executive oversight for the program.

Directed by Paul A. Godley, MD, PhD, Timothy S. Carey, MD, MPH, and Anissa I. Vines, MS, PhD, the program has employed multiple approaches to address health disparities in North Carolina. The program has helped to sponsor research by UNC-CH faculty on an intervention study of obesity prevention among Latino children, the effects of massage therapy on diabetes control among African Americans, laboratory-based experiments of genetic polymorphisms related to prostate cancer; pilot awards, designed to fund innovative health disparity research and to enhance the careers of young health disparity investigators who are faculty members at North Carolina's historically black educational institutions; a 10-credit hour Inter-disciplinary Certificate Program in Health Disparities open to all UNC-CH graduate, professional, and continuing education students.

One of ECHO's primary goals is to help communities identify and solve community health problems through facilitation of increased student and faculty involvement in community-oriented research. One of the most innovative ECHO initiatives has been to establish Centers for Community Research to facilitate constructive communication between community groups and researchers, and to provide an enduring UNC presence in communities across the state. ECHO's mission is to work with communities to identify and develop resources in the community to meet healthcare challenges and to build strong relationships with community groups. The Centers are based at two of the 13 Area Health Education Centers (AHECs), covering 13 North Carolina counties, and provide continuing education and related services to health professionals in all 100 North Carolina counties. Locating the Centers within the AHECs allows the ECHO program to establish relationships with local healthcare providers as well as faith-based organizations and not-for-profit agencies within the AHEC's catchment area. These relationships will be critical to the success of the Program's community research efforts.

ECHO also provided the administrative and organizational structure for the, "Carolina-Shaw Partnership for the Elimination of Health Disparities," a National Institutes of Health, National Center for Minority Health and Health Disparities (Project EXPORT) center grant. This Center provides \$6 million to UNC-CH and Shaw University over a period of five years to address health disparities in North Carolina using novel faith-based interventions. The most innovative Carolina-Shaw Project EXPORT center components include: a recruitment core tasked with building a database of minority candidates who have expressed an interest in participating in clinical trials; a community outreach core that will connect to the internet 25 African American churches in five regions in eastern and central North Carolina to form a network of congregations interested in participating in health promotion research, and a new survey research unit created at Shaw University that will have specific expertise in surveying minority populations.

The ECHO program is an initial step to develop concentrated research efforts that will build on decades of minority research at UNC-CH. The challenge of eliminating health disparities lies with all of us—health professionals, policy makers, researchers, and citizens. We must move from merely reconfirming the documented disparities to documenting the social inequities that perpetuate these differences. This is necessary in order to disentangle issues of racism, access to care, and mistrust.

makes a number of suggestions for how these informational resources could be made more useful for documenting the extent of current disparities as well as for monitoring the success of efforts to reduce or eliminate disparities.

Administrative data such as those collected through the operations of health service delivery programs often are limited in scope to records of service use, costs incurred, and expenses covered. They rarely give any information about the processes of care (including the range of healthcare professionals with

whom a patient may interact, the clinical decision-making processes involved in rendering care, and the types and results of diagnostic studies carried out in making such decisions). If race, or the more obvious race and ethnic characteristics of patients, is but a shorthand index or "place marker"²² for a much more complex social and cultural set of phenomena, there is a need to know far more about how these shorthand indices lead healthcare providers to presume certain characteristics of patients and then factor these categorical notions into their

recommended treatment strategies. There is a need for a much better understanding of the roles of stereotyping, uncertainty, and bias in clinical decision-making by all types of healthcare providers, as well as evaluated demonstration efforts designed to offset the potential influence of these factors in the care of patients.

Because so much of biomedical research in this nation has, until recently, been conducted exclusively among majority populations, the National Institutes of Health mandated, in 1993, following passage of the NIH Revitalization Act, that research funded by any of the National Institutes of Health should include adequate numbers of both women and minorities, or provide substantial justification for their lack of inclusion. This has been an important development in the American health science community. Yet, there remain substantial problems in encouraging minority participation as subjects in health research, for reasons explained by Dr. Giselle Corbie-Smith elsewhere in this special issue of the *North Carolina Medical Journal*.²⁷ Until there is evidence to clarify the presence/absence of differential effects of clinical interventions among minority populations, we are unable to ascertain the extent to which biological disparities exist, or, if they do, to what extent they matter.

Low Health Literacy Levels Contribute to the Health Disparity Problem

As previously mentioned, there is growing awareness of the problem of patient “health literacy” in this country that deserves serious attention in any attempt to address issues of disparities in either health status or healthcare access and outcomes. Though language-related problems for non-English speaking population subgroups are significant, issues of health literacy go beyond language facility. There is now substantial evidence to suggest that large segments of the United States population (regardless of native language) simply cannot comprehend, and thereby comply with, disease-related information and other instructions offered by healthcare providers. Even for native English language speakers, there are substantial numbers of United States adults who lack the basic skills to read and understand the information contained on a conventional prescription bottle or in a drug package insert.²⁸ This is a huge problem that will require broad-sweeping efforts on the part of public education *and* healthcare systems. Efforts currently underway at the University of North Carolina School of Medicine dealing with the health literacy of patients with diagnoses such as diabetes have shown remarkable levels of success in achieving critical clinical outcomes.²⁹

Cultural Differences

Some racial and ethnic groups, especially those who are more recent immigrants to the United States, will require intensive and more focused efforts that offer healthcare services in a manner consistent with cultural patterns to which these populations have been accustomed in their native countries. For example, it appears that Latinos do not experience (and

therefore do not interpret) the symptoms of ill health in ways similar to the majority white or African American populations. The matter of Latino culture and belief systems would not be major concerns if we were dealing with the health and medical care needs of this population in their native countries. There, both the patients and their healthcare providers would share the same culture and spoken language. But this lack of a common understanding of the etiology of health—exacerbated by language barriers—may lessen the potential effectiveness of healthcare services and interventions offered by healthcare professionals to the growing Latino population. Language and cultural differences, along with lower education levels, make it difficult for Latinos to access and use the United States healthcare system and may lead them to seek care in inappropriate places (tiendas, emergency departments, etc). These healthcare challenges faced by the Latino population are ripe for more intensive investigation by health disparity investigators. Moreover, the lessons to be learned from these studies may lead to interventions applicable to other racial and ethnic groups in the United States who are not recent immigrants, and for whom teasing apart the cultural, lifestyle, and dietary contributors to health disparities from issues of racism, healthcare access, and mistrust of the medical system may be more difficult.

The Role of Institutional Racism

Racism also has links to disparities in health due to race and ethnicity.³⁰ Racism leads to many stress-related reactions such as changes in eating patterns, a lack of sleep, high blood pressure, and an increased reliance on alcohol and other substances.³¹ Institutionalized racism is another factor that impedes the narrowing of the health gap between whites and non-whites. Despite legislation to end segregation and other blatantly racist practices, many structures and policies that shape the health of this nation are racially and culturally biased. In a recent study by Vines et al., 23% of African American women in metropolitan Washington, DC perceived experiences of racism in the medical care setting.³² The persistence of racism and its manifestation in the built environment are contributors to both physical and mental health problems as well as the persistent racial profiling in medical care.

Summary

Despite the accomplishments of American medical science and the impressive array of healthcare facilities and service delivery models available in this country, the existence of significant health disparities is a matter of urgent national and state health policy priority. Policies to address these issues should address fundamental problems having to do with access to care (such as health insurance coverage and the availability and the geographic and culturally-appropriate accessibility of personal health services), the educational preparation of healthcare professionals for the challenge of caring for the increasing diversity of patients in a truly “patient-centered” healthcare system of the future, efforts to deal with widespread problems

of health literacy that reduce the likely impact and effectiveness of healthcare, and a more aggressive effort to assure that future medical science continues to include minorities and women (and they continue to participate) as subjects in clinical trials of innovative therapeutic interventions.

The policy agenda to address these issues is both broad and demanding, as would be expected of any set of problems which is so widespread and complex. But, America is no stranger to challenges, and few are more worthy of the effort than this. **NCMJ**

REFERENCES

- 1 NC Latino Health, 2003. Durham, NC: North Carolina Institute of Medicine, February 2003.
- 2 US Department of Health and Human Services. Healthy People 2010. 2nd ed. With Understanding and Improving Health and Objectives for Improving Health. 2 vols. Washington, DC: US Government Printing Office, November 2000.
- 3 McGlade MS, Saha S, Dahlstrom ME. The Latina paradox: an opportunity for restructuring prenatal care delivery. *Am J Public Health* 2004;94(12):2062-65.
- 4 Buescher PA. A review of available data on the health of the Latino population in North Carolina. *NC Med J*. 2003 May-Jun;64(3):97-105.
- 5 Racial and Ethnic Differences in Health in North Carolina: 2004 Update: A Special Report from the State Center for Health Statistics and Office of Minority Health and Health Disparities. NC State Center for Health Statistics. May 2004. Available at <http://www.schs.state.nc.us/SCHS/pdf/RaceEthnicRpt.pdf>.
- 6 Ngui, E. 2002. From disparity to parity in health: Eliminating health disparities-Call to action. NC Department of Health and Human Services, Office of Minority Health and Health Disparities, Raleigh, NC. Available at http://www.omhhd.dhhs.state.nc.us/omhhd/OMH_Documents/Implementation%20Plan/Complete%20NC%20DHHS%20Implementation%20Plan.pdf.
- 7 NC State Center for Health Statistics. 2001-2003 BRFSS Survey Results: North Carolina.
- 8 Buescher, PA, and Gizlice, Z. Healthy life expectancy in North Carolina, 1996-2000. NC Department of Health and Human Services, Division of Public Health. A Special Report Series by the State Center for Health Statistics. January 2002. Available at <http://www.schs.state.nc.us/SCHS/pdf/SCHS-129.pdf>
- 9 Racial and Ethnic Health Disparities in North Carolina: Report Card 2003. Office of Minority Health and Health Disparities and the State Center for Health Statistics. NC Department of Health and Human Services, January 2003.
- 10 Holmes M. Overview of the uninsured in North Carolina: 2004 data update. Presentation to NC Institute of Medicine Safety Net Task Force. Cary, NC. September 23, 2004.
- 11 NC State Center for Health Statistics. 2003 BRFSS Survey Results: North Carolina.
- 12 Bach PB, Cramer LD, Warren JL, Begg CB. Racial differences in the treatment of early-stage lung cancer. *N Engl J Med*. 1999 Oct 14;341(16):1198-205.
- 13 Cykert S, Carcy T. Surgical decisions for early non-small cell lung cancer: a prospective pilot study [abstract]. *J Gen Intern Med* 2003;18:281.
- 14 Godley PA, Schenck AP, Amamoo MA, Schoenbach VJ, Peacock S, Manning M, Symons M, Talcott JA. Racial differences in mortality among Medicare recipients after treatment for localized prostate cancer. *J Natl Cancer Inst*. 2003 Nov 19;95(22):1702-10.
- 15 Bradley EH, Herrin J, Wang Y, McNamara RL, Webster TR, Magid DJ, Blaney M, Peterson ED, Canto JG, Pollack CV Jr, Krumholz HM. Racial and ethnic differences in time to acute reperfusion therapy for patients hospitalized with myocardial infarction. *JAMA* 2004 Oct 6;292(13):1563-72.
- 16 Bach PB, Pham HH, Schrag D, Tate RC, Hargraves JL. Primary care physicians who treat blacks and whites. *N Engl J Med*. 2004 Aug 5;351(6):575-84.
- 17 Wheeler MB. Letter to the Editor. *N Engl J Med*. 2004 Nov 11;351(20):2126-2127.
- 18 Petersen LA, Wright SM, Peterson ED, Daley J. Impact of race on cardiac care and outcomes in veterans with acute myocardial infarction. *Med Care* 2002;40:Suppl:I-86-I-96.
- 19 Schneider EC, Cleary PD, Zaslavsky AM, Epstein AM. Racial disparity in influenza vaccination: does managed care narrow the gap between African Americans and whites? *JAMA* 2001;286:1455-60.
- 20 Bach PB, Schrag D. Letter to the Editor: the authors reply. *N Engl J Med*. 2004 Nov 11;351(20):2127.
- 21 Taylor AL, Ziesche S, Yancy C, et al. Combination of isosorbide dinitrate and hydralazine in blacks with heart failure. *N Engl J Med*. 2004 Nov. 11;351(20):2049-2057.
- 22 Bloche MG. Race-based therapeutics. *N Engl J Med*. 2004 Nov 11;351(20):2035-2037.
- 23 New York Times. Editorial: Toward the first racial medicine. November 13, 2004.
- 24 Kahn J. Getting the numbers right: statistical mischief and racial profiling in heart failure research. *Perspectives in Biology and Medicine* 2003 46;4:473-83.
- 25 Kahn J. How a drug becomes "ethnic:" law, commerce, and the production of racial categories in medicine. *Yale J Hlth Pol, Law & Ethics* 2004 4;1:1-46.
- 26 VerPloeg M, Perrin E. Eliminating Health Disparities: Measurement and data needs. National Research Council/National Academies Press, 2004.
- 27 Corbie-Smith G. Minority participation in clinical research: are there consequences to the lack of research on the health of minority populations? *NC Med J* 2004 Nov-Dec;65(6):385-387.
- 28 Tuckson RV. Keynote address. Proceedings of conference on health literacy: advancing public policy. 2000 January 18-19. Washington, DC: Pfizer.
- 29 Rothman RL, DeWalt DA, et al. Influence of patient literacy on the effectiveness of a primary care-based diabetes disease management program. *JAMA* 2004 Oct 13;292(14):1711-1716.
- 30 Jones CP. Invited Commentary: Race, racism and the practice of epidemiology. *Am J Epidemiol*. 2001;154(4):299-304.
- 31 Sanders-Thompson VL. Racism: Perceptions of distress among African-Americans. 2002;38(2):111-8.
- 32 Vines AI, Baird DD, Hertz-Picciotto I. Perceptions of and responses to racism among black women: the results of the Telephone-Administered Perceived Racism Scale. *Annals of Epidemiology* 2002;12(7):503.