

Let's Get Serious About Racial and Ethnic Disparities

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ABSTRACT

Racial and ethnic disparities in health and health care have been documented for over two decades in kidney disease, in a variety of other conditions, across settings, and for different medical and surgical interventions. We now have government reports that track progress on reducing racial disparities, but the pace of progress has been disheartening. The reasons for some of these disparities are known and include biologic, socioeconomic, cultural, and environmental factors as well as system, patient, and provider factors that affect access and quality of medical services. For other disparities, they remain an enigma. Solutions have been slow incoming in large part because we have not held ourselves, and others, accountable for better results. It is time to get serious about equitable health care for all of us.

J Am Soc Nephrol 19: 1271–1275, 2008. doi: 10.1681/ASN.2008040358

I just received two government reports addressing the state of health and health care for minorities in the United States: Health United States 2007 and the 2007 National Health Care Disparities Report (NHDR). I always wait with great anticipation to open the covers. Health United States 2007, produced by the Centers for Disease Control and Prevention and its National Center for Health Statistics, is an annual snapshot of our progress on the nation's health.¹ It states that life expectancy in the United States at birth is 6.2 yr shorter for black males and 3.5 yr for black females *versus* their white counterparts (75.7 yr for white males, 69.5 yr for black males, 80.8 yr for white females, and 76.3 yr for black females). In a special feature on access to healthcare, Health United States 2007 says that black patients with end-stage renal disease (ESRD) make up 33% of all patients on the kidney transplants waitlist compared with the proportion of 13% they make up in the general population. White patients in 2004 were more

likely to receive a transplant within 2 yr (30%) than black, Asian, or Hispanic patients (~20%). Less prominently displayed in this chapter on kidney transplants is the well-known fact to the kidney disease community that black persons with chronic kidney disease (CKD) accelerate faster to ESRD than similar white persons, black persons are significantly more likely to develop ESRD, and black persons do so at an earlier age, even if we take into account their higher diabetes and hypertension prevalence rates. The U.S. Renal Data System has been documenting this information in its annual data reports for years.²

The 2007 NHDR, produced by the Agency for Healthcare Research and Quality, now in its 5th year in collaboration with agencies across the Department of Health and Human Services, describes the quality and access to care for multiple subgroups of the population across the United States and tracks their progress over time.³ In a chapter on ESRD, I am delighted to see in 2005 (the most recent data available), black

adults who have the misfortune of needing chronic hemodialysis are almost equally as likely as whites (87% and 88%, respectively), and Hispanics more likely than whites (91% and 87%, respectively), to receive adequate dialysis as reflected by a urea reduction ratio of 65% or greater. However, the data on the proportion of black dialysis patients who are registered on the waitlist for transplantation remained the same over 5 yr (10.5% in 2003) and lower than that for whites (16.1% in 2003).

These disparities are not peculiar to CKD. The 2007 NHDR indicates that across all of its core measures, and for all priority groups, the number of measures of quality and access where disparities exist grew larger over 5 yr (Figure 1, A and B). The measures of healthcare quality are structured along four dimensions: effectiveness, patient safety, timeliness, and patient centeredness. They address four stages of care: staying healthy, getting better, living with illness or disability, and coping with the end of life. The measures of healthcare access address how easily patients are able to get needed health care and their actual use of services. The indicators are structured along two dimensions: facilitators and barriers to care and healthcare utilization. For

Published online ahead of print. Publication date available at www.jasn.org.

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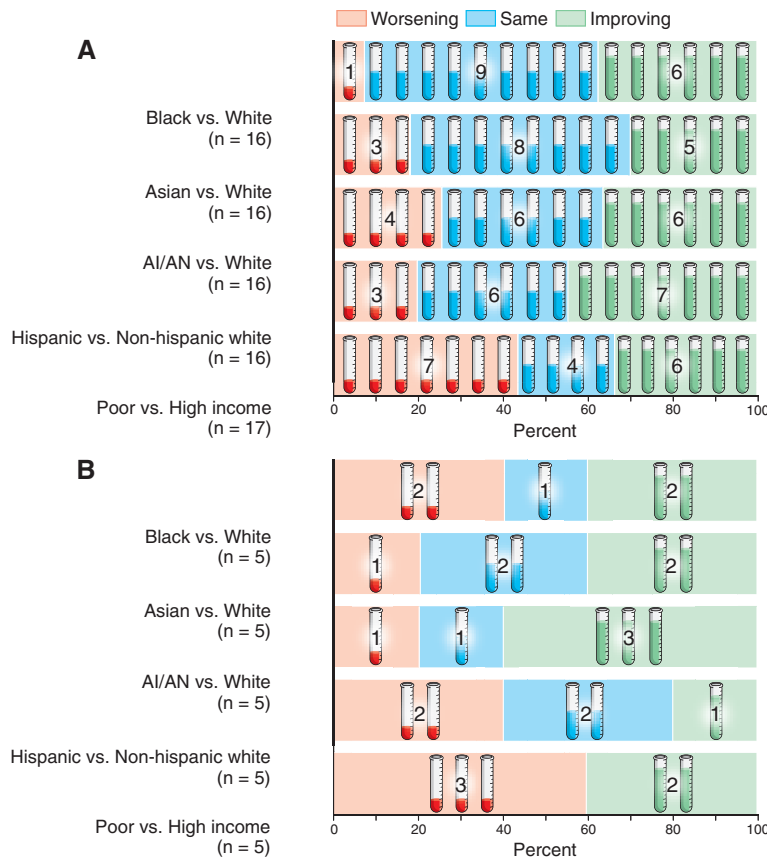


Figure 1. Change over time in core quality and access measures for members of selected groups compared with reference group from 2000 to 2001 to 2004 to 2005. The number of measures of quality and access where disparities exist grew larger between 2000 to 2001 and 2004 to 2005. From the Agency for Healthcare Research and Quality: 2007 National Healthcare Disparities Report. (A) Change over time in core quality measures. (B) Change over time in core access measures. Improving, population-reference group difference becoming smaller at rate greater than 1% per year; Same, population-reference group difference changing at less than 1% per year; Worsening, population-reference group difference becoming larger at rate greater than 1% per year; AI/AN, American Indian or Alaska Native. “Asian” includes Asian or Pacific Islander when information is not collected separately for each group. Data presented are the most recent data available.

blacks versus whites, 60% of disparities in quality of care are not getting better. For Hispanics, 56% of disparities in quality of care are not getting smaller. For the poor, more than 60% of disparities in quality of care are not getting smaller.

I appreciate that our nation now tracks these important statistics very carefully. Arguably, this is an incomplete picture of kidney disease disparities, but I am grateful that kidney disease gets some attention in these national reports and statistics. My first quantitative glimpse of race and ethnic disparities was 23 yr ago when the Report of the Secretary’s Task Force on Black and Minority Health

(also known as the Heckler Report) was released, a 1985 landmark, 10-volume set that attempted to document the extent of health disparities by race.⁴ Since that time, we have witnessed a plethora of research studies and reports illuminating how racial and ethnic disparities are almost omnipresent in different conditions, among the young and the old, in hospitals and physician offices, and across preventive, diagnostic, and therapeutic services. Specific disparities have been extensively and repeatedly documented in CKD (Table 1). I am surprised, but thankful, when rare reports say no race or ethnic disparities exist.

In the last two decades, we have come a long way in learning that possibly biologic, socioeconomic, psychosocial, cultural, and environmental factors, and access and quality of health care are responsible for differences in health along race and ethnic lines. System, patient, and provider factors are barriers to good access and quality of health care (Figure 2). Studies have suggested that a broken healthcare system that concentrates the care of minorities in certain types of facilities and physician practices with limited access to medical technologies and other resources may play a role in disparities.^{5–7} Primary care providers seem to lack knowledge about the epidemiology of kidney disease, particularly that black race and family history are risk factors for CKD.⁸ In other settings, healthcare providers have been shown to associate race with patient intelligence, education, feelings of affiliation, and beliefs about risk behavior. Providers’ communication and the nature of their interactions with patients (such as the extent to which they involve patients in decisions) also seem to vary with the race of their patients.⁹ Finally, a myriad of factors—patient knowledge, attitudes, cultural beliefs, health behaviors (smoking, exercise, diet, care seeking), adherence, language, health literacy, social support, religious beliefs, fear, self-efficacy, preferences, psychosocial factors, and trust in providers (physicians and hospitals)—have been demonstrated to vary by race and ethnic group.^{10,11} The racial disparities in kidney transplantation documented in the government reports on my desk illustrate the myriad of factors that could be responsible. Racial disparities in kidney donation and transplantation can arise from genetic incompatibility, waitlist registration practices, the procedures by which organizations request and consent families for kidneys, donor kidney acceptance practices, patient interest in a transplant, provider inferences about the adherence to or ability to pay for immunosuppressive therapy, attitudes and beliefs about organ donation, and differences in risk factors for kidney disease progression post-transplantation.

Table 1. Racial and ethnic disparities

Observed Racial and Ethnic Disparities in Chronic Kidney Disease
<ul style="list-style-type: none"> • Minorities with early-stage CKD appear to progress faster to ESRD • Minorities with early stages of CKD are less likely to see a nephrologist • Minorities with early-stage CKD are less likely to receive cardiovascular procedures • Minorities are less likely to receive peritoneal dialysis than hemodialysis • Minorities are more likely to receive inadequate dialysis doses (improving) • Minorities are less likely to be placed on the waitlist for a transplant • Minorities are less likely to receive a transplant (deceased, living related, or preemptive) • Minorities have worse transplant outcomes • Minorities in the general population are less willing to be a deceased kidney donor
No Observed (or Reverse) Race or Ethnic Disparity in Chronic Kidney Disease
<ul style="list-style-type: none"> • Minorities get dialysis as often as whites • Minorities have better or equal survival on dialysis • Minorities on dialysis are equally likely to receive cardiovascular procedures

I am quite incensed by the lack of more rapid progress and outraged that we can't cure these disparities. In 2006, 14.7% of the U.S. population declared themselves as Hispanic, 12.3% black, 0.8% American Indian or Alaskan Native, 4.3% Asian, 0.1% Native Hawaiian or Pacific Islander, 1.4% of mixed race, and 66.5% white. Projections suggest that 50% of the U.S. population will be comprised of minority groups by the year 2050. The state of California has already reached this mark. Therefore, the price of suboptimal health, including kidney disease, to our society and its human and economic losses in the future will be large. We have talked and collected statistics about health disparities for decades. Why are disparities still with us? I believe this is because no one has been held accountable. Isn't it time we got serious about accountability for curing racial disparities and restoring health to persons from racial and ethnic minority groups?

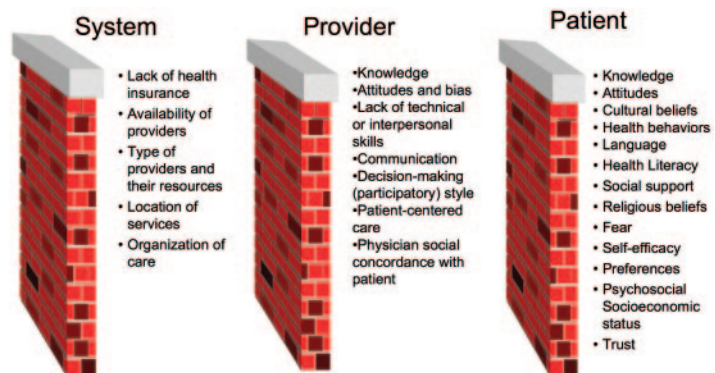
There are several ways we can get serious. First, let's get serious about research and the creative solutions it may bring. We need to accelerate investment into understanding the "pathophysiology" (all of the mechanisms and their inter-relationships) for disparities in kidney disease and translate that understanding into testing effective interventions to address them. For example, we still do not understand why blacks and Hispanics are more likely to progress to

ESRD, whether it is biologic (genetic), nonbiologic (lack of optimal care or poverty), or most likely a combination of pathways to a complex disease. The long-term cohort study sprung from the recent African American Study of Kidney Disease suggests that the cumulative incidence of combined serum creatinine doubling, ESRD, and death events still continues to rise to 54% over 10 yr among the black persons followed in the study, despite some reduction by treatment with a renin-angiotensin system blocking agent.¹² Quality improvement programs have also been disappointingly ineffective.^{13,14}

An Institute of Medicine committee examined the "Unfinished Business" of the National Institutes of Health for its Health Disparities Research Plan.¹⁵ The committee called for refinement and development of conceptual, definitional,

and methodologic issues in health disparities research to further understand the cause of disparities. It also called for updating of a strategic plan to address the multifactorial nature of health disparities, including the role of nonbiologic (in addition to biologic) factors, population research and causes, and importantly the setting of targets for accountability. The National Institute of Diabetes and Digestive and Kidney Diseases has admirably increased the percentage of its total appropriation for health disparities from 8.64% in 1999 to 10.85% in 2004, just above the average (9.29%) for all Institutes and Centers. It was 9th in health disparity funding rank among the 25 National Institutes of Health institutes and centers in 2004. It was 15th in the ranking of percentage (~5%) of Research Career Awards awarded to budding, underrepresented minority scientists with a rank of 4 in total number (n = 25) of Research Career Awards. Minority scientists are more likely to be interested in minority health issues and delivery of care to minority patients. While National Institute of Diabetes and Digestive and Kidney Diseases progress is better than the National Institutes of Health average, there is clearly room for improvement and accountability.

Second, let's get serious about and accountable for the health care we provide. Physicians, other providers, and health-care delivery organizations should view disparities in care as a quality of care problem in need of improvement. Disparities should be a metric in performance measurement and quality im-

**Figure 2.** Barriers in access and quality of health care leading to disparities.

provement initiatives. Our healthcare institutions should measure how they are performing with regard to providing equitable care across both race and other dimensions of diversity. The disparities in both the early and late stages of CKD are challenging because they involve physicians other than nephrologists; primary care physicians are involved early on, transplant surgeons later, and other specialists, including endocrinologists, cardiologists, and vascular surgeons throughout the course of the patient's life. When many minorities develop kidney disease, often no physicians are involved in their care. Screening programs that appropriately target high-risk minorities unlikely to have access to health care for CKD are important. Indeed, minorities who develop ESRD are less likely to have seen a specialist early on in their course of kidney disease.¹⁶ Research shows racial disparities in the use of cardiovascular procedures diminish when patients develop ESRD, obtain Medicare coverage, and come under the care of nephrologists.¹⁷

Research has also shown that concordance of patient and physician characteristics leads to greater shared decision-making and patient satisfaction.¹⁸ Although we cannot alter immutable characteristics, we can become more competent in how we communicate with patients who do not share our background. We should also embrace our responsibility to become aware of situations where disparities exist and be attentive to our biases in interacting with patients or providing the services they need.¹⁹ Providing equitable care, according to the Institute of Medicine, is to provide "care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location or socioeconomic status."²⁰

Finally, some of the lesions leading to the persistence of disparities may lie in policy decisions for health care nationally or locally. The kidney disease community should strongly advocate for solutions that address broader issues, such as lack of awareness of kidney disease and its prevention, inadequate health insur-

ance, and forces leading to the concentration (if not segregation) of care of racial and ethnic minorities to certain institutions, providers, and community services. We should hold elected officials accountable for equitable policies. We should not use flawed health policy such as lack of health insurance as an excuse for inertia, as it has been shown that disparities in care exist even among those with public health insurance coverage through Medicare. We all need to join the patient advocacy and public health campaign for prevention and optimal treatment of CKD.

As physicians, scientists, and educators, we have a collective responsibility to make sure that substantial progress will be made and demonstrated in the government reports that will land on my desk in future years. There is a professional, economic, and ethical imperative to eliminate health disparities. We have the means to find and implement solutions by holding ourselves, and others, accountable. So, along with me, please get serious about eliminating disparities.

ACKNOWLEDGMENTS

Dr. Powe is supported by Grant No. K240502643 from the National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, Maryland.

DISCLOSURES

None.

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See related editorial, "Is the Ethnic Disparity in CKD a Symptom of Dysfunctional Primary Care in the US?" on pages 1249–1251.