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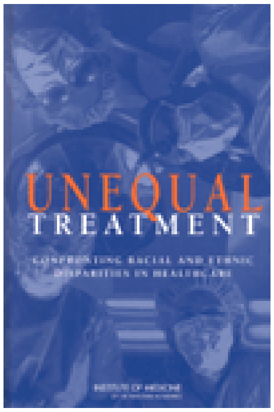

Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care (with CD)

Brian D. Smedley, Adrienne Y. Stith, and Alan R. Nelson, Editors, Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care

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Needed Research

In previous chapters, the committee has reviewed extensive evidence of racial and ethnic disparities in care, and has assessed potential sources of these disparities, as well as promising strategies to eliminate them. In the process, the committee notes that the evidence base to better understand and eliminate disparities in care remains less than clear. In this chapter, several broad areas of research needs are outlined. Some of this research is already underway or planned as a result of leadership and support from the federal Agency for Healthcare Research and Quality (AHRQ) and several private foundations (for a more thorough description of ongoing federal and private research and intervention efforts to address racial and ethnic disparities in care, see *Federal and Private Initiatives to Reduce Healthcare Disparities* in the appendix of this volume). The committee urges greater support from a range of federal and private sources, however, for a more ambitious research agenda aimed at disentangling the many influences on the process, structure, and outcomes of care for minority Americans.

This chapter is divided into several sections. The first three sections highlight research opportunities that should better illuminate the ways in which race and ethnicity influence the delivery of healthcare. To date, far greater research attention has been directed to documenting racial and ethnic disparities in care than in understanding how these disparities emerge in the structure and process of care, as these recommendations illustrate. The latter sections discuss areas where research has been minimal or notably absent. This includes intervention research; research on disparities in care among non-African-American racial and ethnic minority populations, such as Native Americans, Asian Americans, Pacific Islanders, Hispanics, and subgroups of these populations; and research on the role of non-physician healthcare professionals, such as nurses, physician assistants, occupational and rehabilitation therapists, mental heath care providers, and others in eliminating racial and ethnic disparities in care. Finally, the last section offers suggestions for strategies to carry out this research.

UNDERSTANDING CLINICAL DECISION-MAKING AND THE ROLES OF STEREOTYPING, UNCERTAINTY, AND BIAS

Much of the research cited in previous chapters relies on retrospective analyses of administrative claims or hospital discharge data. While these data sets have proven useful in identifying racial and ethnic disparities in a range of hospital and clinic-based services (from relatively routine diagnostic and treatment services through specialized surgical procedures), they pose a number of inherent limitations. Hospital discharge records yield only limited data regarding patients' interactions with the range of healthcare professionals with whom they come into contact and the race or ethnicity of these providers. Further, such data are often limited with regard to clinical decision-making processes and the information that clinicians must consider when recommending a course of treatment. For example, administrative data sets often contain only crude information regarding co-morbid conditions, diagnostic test data, and specific treatments.

Prospective studies are needed to focus on decision-making by patients and providers, to assess care management at different points along the continuum of care, and to assess the impact of patient-provider interactions on diagnosis and treatment. More complete records of patients' co-morbid conditions, as well as results of diagnostic tests, will help in the context of prospective research to assess the appropriateness of treatment. Such data will also assist in determining if physicians experience greater uncertainty in assessing presenting complaints of cultural or linguistic minority patients, or if their treatment decisions for these patients fail to correspond to accepted standards of care.

Beyond prospective studies of healthcare service delivery, additional research is needed on provider decision-making, heuristics employed in diagnostic evaluation, and how patients' race, ethnicity, gender, and social class may influence these decisions. As noted in earlier chapters, some experimental research has been conducted to assess the extent to which physicians' treatment recommendations differ by patient race and gender (e.g., Schulman et al., 1999). This research should be expanded to both replicate these findings and explore how social cognitive processes may operate to influence patients' and providers' conscious and unconscious perceptions of each other and affect the structure, processes, and outcomes of care.

As noted in Chapters 3 and 4, it is likely that clinical uncertainty and discretion with regard to diagnostic and treatment options may play a role in healthcare disparities. When clinicians are uncertain about a patient's presenting symptoms, or when multiple treatment options are available but "best" practices among racial and ethnic minorities are unclear, treatment may be less well matched to patients' needs, because such conditions increase the likelihood that biases and implicit stereotypes may affect clinicians' decisions. Alternatively, when empirically-based practice guidelines offer evidence of the effectiveness of specific interventions among minority patients, uncertainty may be lessened. Future research should therefore assess whether disparities are reduced when clinicians are provided with and make use of evidence of treatment efficacy.

UNDERSTANDING PATIENT-LEVEL INFLUENCES ON CARE

As noted earlier, patient mistrust of providers may affect decisions to seek care, and may negatively influence the quality of the patient-provider relationship. Investigators should assess patients' attitudes and preferences toward healthcare providers and services, and examine the extent of these influences on the quality of care and treatment decisions. Research should also evaluate appropriate means of addressing and modifying negative cultural beliefs about care-seeking and mistrust of healthcare systems. Further, strategies to increase minority patients' ability to participate in treatment decisions and empower them as self-advocates within healthcare systems should be evaluated. It is important that these research efforts be conducted in active collaboration with racial and ethnic minority communities, both to avoid the perception that patients are to blame for unequal or poor treatment in healthcare settings, as well as to tap into cultural knowledge and traditions that may serve as sources of strength in the effort to "activate" patients.

UNDERSTANDING THE INFLUENCE OF HEALTHCARE SYSTEMS AND SETTINGS ON CARE FOR MINORITY PATIENTS

Studies Within Healthcare Plans

There is considerable variation across healthcare plans in the type and extent of coverage that beneficiaries receive. Even among those insured by public programs such as Medicare, some beneficiaries may hold a variety of types of supplemental insurance that enhances coverage for specific services, thereby increasing their access to care. Many studies of racial and ethnic differences in healthcare, however, fail to account for these differences, often collapsing the privately-insured or publicly-insured into broad categories that mask differences in coverage. Future research should better account for these differences by assessing racial and ethnic disparities in care among similarly-insured patients within the same plan.

Studies of DoD and VA Systems

The committee's analysis revealed that for some healthcare services and under some conditions, racial and ethnic disparities in care are less pronounced. These findings are somewhat more consistent in studies of healthcare provided to active-duty personnel and their families through the U.S. Department of Defense healthcare system, which provides universal access to care, and are inconsistent among studies of the "equal-access" Veterans Administration healthcare system. Future research should seek to illuminate the conditions of health systems, including factors such as co-payment and accessibility that may be associated with racial and ethnic disparities in care.

Type of Hospital or Clinic and Racial and Ethnic Disparities in Care

Several studies find differences as to where racial and ethnic minorities receive care, even when holding insurance status constant. Lillie-Blanton, Martinez, and Salganicoff (2001) found that independent of sociodemographic factors, health status, and insurance status, African-American and Latino patients are more likely than white patients to have a hospital-based provider and are less likely to have an office-based provider as a usual source of care. Lillie-Blanton et al. (2001) note that these differences could reflect geographic or sociocultural barriers to care, patient preferences, or some combination of these factors. Structural, institutional, and organizational aspects of healthcare settings can affect the cost, content, and quality of care, as well as patient satisfaction. The contribution of these factors to healthcare disparities must be more thoroughly assessed. In addition, research should determine whether structural, institutional and organizational factors of healthcare settings affect the content of care or quality of communication for racial and ethnic minority patients.

Similarly, little is known about the healthcare providers that tend to serve racial and ethnic minority patients. Research indicates that racial and ethnic minority physicians, particularly those who are African American and Hispanic, disproportionately serve poor, underserved and minority patients (Komaromy et al., 1996). However, these providers remain a small fraction of the overall healthcare workforce. More must be understood about the racial and ethnic composition of providers who tend to serve minority patients, and the impact of racial concordance/discordance on care. In particular, little is known about the impact of international medical graduates working in minority communities. As noted earlier in this report, these providers disproportionately serve racial and ethnic minority patients, yet little is known about the quality of their interactions with minority patients, despite the apparent greater likelihood of cultural and linguistic misunderstanding. To better understand sources of racial and ethnic disparities in care, future research should analyze the experience, qualifications, specialties, and other attributes of providers who disproportionately serve racial and ethnic minority patients and to assess whether these factors may in part explain racial and ethnic disparities in care.

UNDERSTANDING THE ROLES OF NON-PHYSICIAN HEALTH PROFESSIONALS

The vast majority of research that documents racial and ethnic disparities in care and patient-provider communication in racially concordant and discordant dyads has focused on the role of the physician. This research has been important in illuminating key processes and decision points that may contribute to healthcare disparities. The disproportionate focus of research on physicians, however, unfairly places the locus of attention regarding disparities primarily on physicians. This fails to reflect the reality that much of healthcare is provided by non-physician professionals, including nurses, physician assistants, occupational and rehabilitation therapists, mental health professionals (including psychologists, social workers, and marital and family therapists), pharmacists, and allied health professionals. Further, with a few exceptions, research on racial and ethnic disparities in care has failed to consider the roles of other hospital and clinic staff—such as receptionists, admitting clerks, translators, and others—in contributing to the “climate” in which care is delivered. These individuals play at least as significant a role as physicians (if not more so) in conveying messages of respect and dignity to patients and in influencing how patients feel about the healthcare setting. Research is critically needed to assess how these individuals communicate with racial and ethnic minority patients, and in turn, how patients respond to them. Further, research should assess how educational programs can best improve these staffs’ attitudes, behaviors, and communication with racial and ethnic minority patients. In this regard, the committee notes that many corporations and organizations (and indeed, some health plans) have developed extensive training programs to assist their workforce in better serving and addressing needs of culturally and linguistically diverse customers; these training programs offer potentially valuable models for healthcare institutions wishing to become more "customer-friendly" and improve service.

ASSESSING HEALTHCARE DISPARITIES AMONG NON-AFRICAN AMERICAN MINORITY GROUPS

A central concern throughout the committee's review of the literature on racial and ethnic disparities in healthcare has been the relative paucity of research on non-African-American racial and ethnic minority groups. While a number of important studies have sought to assess the extent of disparities among diverse racial and ethnic populations (e.g., Carlisle et al., 1995), the extent of disparities in care faced by Asian-American, Pacific Islander, Native American, and Hispanic populations remains unclear. Furthermore, barriers to care experienced by various subgroups of these populations must be better assessed. As noted earlier, focus group data and other information gathered by the committee suggest that linguistic and cultural mismatches pose greater challenges for recent immigrant minorities than for African Americans. There is tremendous cultural, linguistic, and socioeconomic variation within the "racial" populations noted above, and their historic and contemporary experiences in the United States—as noted by Byrd and Clayton (see appendix)—vary considerably, all of which significantly influence the context by which care is delivered to these populations.

ASSESSING THE EFFECTIVENESS OF INTERVENTION STRATEGIES

The committee's analysis suggests several promising avenues for interventions to eliminate racial and ethnic disparities in healthcare. To date, however, relatively less research attention has been devoted to assessing intervention efforts than to understanding the extent and sources of disparities in care. Several promising strategies have been identified that should continue to be the focus of research efforts, such as comprehensive cross-cultural education and communication training for healthcare providers. Research should assess not only the effectiveness of these interventions in reducing racial and ethnic gaps in appropriate care, but also their cost-effectiveness and the extent to which these interventions result in organizational and institution-level changes to improve care for minority patients. Research should also assess the benefits of other intervention strategies described earlier in this report, including language translation and interpretation services, lay health navigators, patient education and "activation" strategies, and efforts to make healthcare services more culturally and linguistically accessible.

DEVELOPING METHODS FOR MONITORING HEALTHCARE DISPARITIES

As discussed in the chapter on data collection and monitoring, the collection and reporting of healthcare information by patient race and ethnicity is an important step in monitoring the nation's progress in eliminating racial and ethnic disparities in healthcare. Such efforts will assist consumers and purchasers in making better-informed choices about health plans, will help plans and providers to identify effective intervention strategies, and will identify practice settings where disparities occur and assist efforts to monitor compliance with civil rights laws. Data collection and monitoring efforts, however, will face several significant challenges to implementation, as noted earlier. Among these challenges are the need to ensure the privacy of medical records, problems posed in analyzing data from small population groups, the inconsistent use of and understanding of the federally-defined "race" and "ethnicity" categories, and the effect of differences in enrollee case-mix among plans on plan performance. Future research must address these challenges and identify efficient means for such data to be collected that do not pose undue bureaucratic burdens on healthcare providers, consumers, and plans.

UNDERSTANDING THE CONTRIBUTION OF HEALTHCARE TO HEALTH OUTCOMES AND THE HEALTH GAP BETWEEN MINORITY AND NON-MINORITY AMERICANS

As noted earlier in this report, health status disparities observed between many minority and non-minority populations in the United States likely reflect a complex interplay of social, economic, biologic, and environmental factors. While some evidence suggests that preventive and primary care services can have a greater impact on improving health status for low-income than middle- and higher-income individuals, the contribution of healthcare disparities to health status differences between minority and non-minority populations remains unknown. Future research must assess this contribution, and identify how and why healthcare disparities play a role in poorer health outcomes for minorities relative to non-minorities. In addition, future research is needed to determine whether new medical services and technologies are implemented among minority patient populations at the same rates as the general patient population. New medical breakthroughs are occurring at staggering rates, and promise to improve the quality of life and mitigate disease in ways never previously imagined. To the extent that these new technologies are made available and are within economic reach, research must assure that racial and ethnic minorities who have the ability to pay for such care are not disadvantaged in their efforts to receive it.

MECHANISMS TO IMPROVE RESEARCH ON HEALTHCARE DISPARITIES

Research on racial and ethnic disparities in healthcare has grown significantly over the past two decades, and continues to offer new insights into the causes of and possible solutions to care disparities. To strengthen this research, however, and stimulate new insights and perspectives that may lead to innovative intervention strategies, the research enterprise may be strengthened in a number of ways. Much of the research reviewed earlier in this report has been conducted in specific departments of academic or research institutions, and has not taken full advantage of opportunities for interdisciplinary collaboration. Such collaboration will be necessary to address the complexities and multiple causal dimensions of healthcare disparities, as discussed earlier. Therefore, rather than dispersing research throughout the various departments of academic hospitals or other research institutions, researchers may seek to establish multidisciplinary units that encourage collaboration between departments as well as institutions (e.g., law, public health, sociology). In addition, federal and private research sponsors should encourage the conduct of research in a variety of settings (inner city; other urban; community health centers; etc.), and should encourage the participation of researchers from ethnic and racial minority groups.

Recommendation 8-1: Conduct further research to identify sources of racial and ethnic disparities and assess promising intervention strategies.

Research is needed to illuminate how and why racial and ethnic disparities in care occur and to test intervention strategies to eliminate them. Specifically, research is needed to:

- **Better understand the relative contribution of patient, provider, and institutional characteristics to healthcare disparities;**
- **Further illuminate provider decision-making, heuristics employed in diagnostic evaluation, and how patients' race, ethnicity, gender, and social class may influence these decisions;**
- **Assess the relative contributions of provider biases, stereotyping, prejudice, and uncertainty in producing racial and ethnic disparities in diagnosis, treatment, and outcomes of care;**

- **Understand the role of non-physician healthcare professionals, including nurses, physician assistants, occupational and rehabilitation therapists, mental health professionals (including psychologists, social workers, and marital and family therapists), pharmacists, allied health professionals, as well as non-professional staff in contributing to healthcare disparities;**
- **Assess healthcare disparities among non-African-American minority groups and subgroups;**
- **Assess the impact of international medical graduates (IMGs) on healthcare service delivery in racial and ethnic minority communities;**
- **Develop and test the utility for healthcare improvement of patient-based measures of (1) trust in providers and systems and (2) exposure to discriminatory practices by providers or systems;**
- **Develop methods for monitoring progress toward eliminating racial and ethnic disparities in healthcare; and**
- **Understand the relationship between healthcare disparities and the health gap between minority and non-minority Americans.**

Finally, it is apparent that efforts to eliminate healthcare disparities will benefit from efforts to better address barriers to research and intervention. As noted earlier, these include ethical issues and data-related concerns, such as the need to protect patient privacy. At minimum, research and intervention efforts must conform to the Health Insurance Portability and Accountability Act of 1996 (HIPAA) regulations regarding the protection of patients' medical records and other confidential data. The Agency for Healthcare Research and Quality (AHRQ), the Centers for Disease Control and Prevention (CDC), and the National Institutes of Health (NIH) have already begun to address some of these concerns through ongoing research and data management, and should be encouraged to continue addressing barriers to data collection and research.

Recommendation 8-2: Conduct research on ethical issues and other barriers to eliminating disparities.
AHRQ, CDC, and NIH should conduct research on barriers to eliminating racial and ethnic disparities in care, including data-related concerns (especially those related to HIPAA privacy regulations) and ethical issues.