

Toward Eliminating Health Disparities in HIV/AIDS: The Importance of the Minority Investigator in Addressing Scientific Gaps in Black and Latino Communities

Lisa K. Fitzpatrick, MD, MPH; Madeline Sutton, MD, MPH; and Alan E. Greenberg, MD, MPH
Atlanta, Georgia

Dialogue in the medical and public health communities has increasingly focused attention in the area of health disparities. We believe that the elimination of health disparities in the United States will require a multipronged approach that includes, at the very least, new approaches in both biomedical and prevention interventions. We also believe that since health disparities primarily affect communities of color, a model which fosters the development of junior scientists, clinicians and researchers of color who serve these communities will yield important progress in this field.

The Minority HIV/AIDS Research Initiative at the Centers for Disease Control and Prevention (CDC) is a program that, through targeted research, aims to address health disparities in HIV/AIDS. Although the program is disease specific, there are a variety of lessons learned from its inception and implementation that can be useful throughout the scientific, medical and public health communities.

Key words: HIV/AIDS ■ minority investigators ■ health disparities

© 2006. From the Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention, Epidemiology Branch, Atlanta, GA. Send correspondence and reprint requests for *J Natl Med Assoc.* 2006;98:1906–1911 to: Dr. Lisa K. Fitzpatrick, 1600 Clifton Road, #E-45, Atlanta, GA 30030; phone: (404) 639-5166; fax: (404) 639-6127; e-mail: lff5@cdc.gov

INTRODUCTION

In the United States, health disparities have received increasing attention in medical and political dialogue and are prevalent in nearly all fields of medicine and public health.¹ Currently, some of the most striking disparities are seen in the epidemiology, prevention and care and treatment of HIV/AIDS for black and Latino persons.² Since 1996, there has been increasing overrepresentation of blacks and Latinos in both newly reported HIV cases and prevalent AIDS cases. In 2004, blacks and Latinos together represented <30%³ of the U.S. population but comprised approximately 70% of all new HIV infections

and reported AIDS cases.⁴ In addition, HIV/AIDS is now among the top-10 causes of death for blacks and Latinos and is the leading cause of death among black men and women ages 35–44.⁵ Surveillance data from 2000–2004 also demonstrate that regional increases in HIV morbidity continue to be most dramatic in the south.⁴ During this period, the estimated number of AIDS cases in the south increased by 25% compared to 13% in the midwest and decreased in the northeast and west by 8% and 6%, respectively. Furthermore, while only 31% of residents in the south are blacks and Latino, the majority of new HIV infections and AIDS cases in the south are reported in blacks and Latinos.

Furthermore, gaps in treatment access and enrollment in HIV clinical trials for these populations are striking.^{6–8} Despite the wide availability of antiretroviral therapy (ART), blacks and Latinos are less likely to be administered these medications and, consequently, are not afforded the quality of life and survival benefits associated with these medications.^{9–12} These disparities in HIV disease burden and treatment access exist despite HIV funding allocations for biomedical, treatment and prevention research. Furthermore, HIV/AIDS prevention and research funding has not shifted in parallel with the changing geography and demographics of the epidemic.¹³ For example, in the early years of the epidemic when the majority of cases occurred in white men who have sex with men (MSM) populations in large, urban cities like New York, Los Angeles and San Francisco, or populations of intravenous drug users (IDUs) in Chicago or Baltimore, much federal and local funding was allocated specifically for research and services for these populations. As described, the epidemic is now expanding in the south and emerging among blacks and Latinos in communities such as Palm Beach, FL¹⁴ and Baton Rouge, LA,¹⁵ where extensive HIV/AIDS epidemiologic and prevention research has not been conducted. In addition, while heterosexual contact is now the second most commonly reported

mode of HIV transmission, particularly among black women, current research funding does not reflect this sobering epidemiologic shift in the epidemic. Given these disparities, until an effective HIV preventive vaccine or microbicide is available and administered to those at risk for infection, strategies to enhance the effectiveness of HIV prevention in black and Latino communities are imperative.

Because investigators of color may have a clearer understanding of health issues that are specific to minority and underserved communities, increasing the number of black and Latino researchers who are capable of conducting HIV research in their own communities is a strategy that can enhance the effectiveness of HIV prevention in these groups. Given this, in 2003 the Centers for Disease Control and Prevention (CDC) established a \$9 million HIV/AIDS epidemiologic and prevention research career development program executed over three years,

the Minority HIV/AIDS Research Initiative (MARI). This program provides scientific technical assistance to junior researchers who conduct HIV gap research in communities of color. This paper describes this initiative but also suggests justifications for expanding the pool of minority investigators and reviews a few a critical research gaps for black and Hispanic communities that should be addressed by programs like MARI. Although, our focus is HIV specific, the issues addressed and lessons learned from implementing MARI are relevant throughout the medical and public health communities.

Justification and Need for Researchers of Color

Marin et al. described the need to increase the number of black and Latino researchers and outlined a career development program for junior researchers that provides technical assistance for HIV/AIDS researchers

Table 1. First MARI investigators and project titles, October 2003

Investigator	Institution/Affiliation	Project Title
Sonja Arreola	San Francisco Department of Health—San Francisco, CA	Recruiting African Americans and Latinos in HIV Vaccine Trials
Kimberly Coleman	Community Education Group—Washington, DC	Equal Access: Barriers and Facilitators of African-American Participation in Clinical Trials for HIV Vaccines
Chinazo Cunningham	Montefiore Medical Center—Bronx, NY	Determinants of Engagement in HIV Primary Care Services
Muriel Harris ¹ Tiffany Townsend ²	University of South Carolina—Columbia, SC Pennsylvania State University—Philadelphia, PA	HIV Knowledge & HIV Testing Attitudes: Low Income Heterosexual Young Adult African-American Populations
Jeffrey Kibler	Jackson State University—Jackson, MS	Acceptance of HIV Prevention Trials by African Americans
David Malebranche	Emory, University—Atlanta, GA	Resiliency Factors and HIV Risk among Black Men Who Have Sex with Men
Tatiana Perrino/ Christie Vila	University of Miami—Miami, FL	Access to HIV Testing and Treatment in the Nonurban South
Anita Raj	Boston University—Boston, MA	Routine Testing for HIV in Primary Care Settings
Jesus Sanchez	Florida International University—Miami, FL	Prevalence of HIV, Hepatitis and Risk Factors among Hispanic intravenous Drug Users
Emma Simmons	Brown University—Providence, RI	Routine Testing for HIV in Primary Care Settings
John Williams	University of California, Los Angeles—Los Angeles, CA	Gay- and Nongay-Identified Black and Latino MSM Who Meet Male Sexual Partners Over the Internet

who are early in their research careers.¹⁶ In addition, a variety of extramural programs through the National Institutes of Health (NIH) have been established to address the shortage of black and Latino health researchers (NIH LRP).^{17,18} Similar programs are rare yet warranted. However, relative to the available funding for scientific disciplines such as HIV/AIDS, national funding targeting minority junior researchers is scarce and has not been prioritized in parallel with HIV disease demographics, morbidity and mortality.

Although there is little published research data validating anecdotal evidence for our need to expand the pool of minority researchers and scientists, collective action in this area is of paramount importance for several reasons. First, increases in research funding for minority investigators is warranted because this group is uniquely qualified to design relevant and community-specific research because in many instances they possess an innate understanding of social and cultural norms that may impact the AIDS epidemic in their respective communities. Researchers who are indigenous to these communities often are likely to have insights into the relevant research questions and issues that are most important to address in their community.¹⁶ HIV/AIDS-related health disparities, like many health disparities, are often rooted in social phenomena that may not be readily addressed by nonminority researchers. For example, the legacy of slavery and culturally based conspiracy theories may have a profound impact on the health and healthcare-seeking behavior of black Americans. These issues may contribute to the prevalence of mistrust of the medical establishment in a variety of areas, including willingness to access clinical services and enrollment in government-sponsored trials.¹⁹⁻²²

Second, researchers of color often have deeply rooted and personal reasons for answering critical questions about the impact of HIV in black and Latino communities. Many black and Latino researchers have often been born and raised in communities most severely impacted by HIV/AIDS and other health disparities. Consequently, these investigators may be more sensitive to the social condition of black and Latino populations, particularly if they have ongoing personal relationships with people living in these communities. In addition, the relationships and anecdotal experiences derived from these personal and community interactions may ultimately yield conceptualization of relevant study questions that merit scientific attention.

Third, racial or ethnic dissimilarity between investigators and the community is sometimes a barrier to the conduct of effective research and to eliciting valid information and responses to sensitive topics. In 1986, Harlan Dalton, professor of law at Yale Law School, related the complexities of conducting HIV research in black communities when he wrote:

Public health officials cannot enter inner cities with expertise in one hand and goodwill in the

*other and expect to slay the disease dragon. They must first discern who this public is and how it sees itself in relation to them.*²³

Similar to the patient-provider relationship, investigators who are from the community may have easier access to their communities and may have fewer barriers to establishment of trust and rapport than nonminority researchers.²⁴⁻²⁶ Furthermore, researchers who are from the community may be able to establish credibility within the community more readily based on racial and ethnic similarities with the target population. Many nonminority researchers have diligently and successfully established strong and viable relationships with communities of color, but this relationship must be constructed in conjunction with key informants and liaisons from the target community and is often developed only after several months or years of interaction with the community.

Literature Gaps and Capacity Building

For HIV prevention to be successful in communities of color, research must specifically target black and Latino communities. The HIV literature is rich with information related to HIV and AIDS prevalence and HIV risk factors. However, there are numerous gaps in the HIV literature for black and Latino populations that warrant attention. For example, the majority of HIV prevention research targeting MSM populations has occurred in major cities in the northeast and the west and, as a result, we know very little about the attitudes, beliefs and risks among MSM living in the southeast.²⁷ Similarly, information is needed pertaining to risks of women of color nationally but more urgently among those residing in the south, where the burden of new HIV reports among black women is greatest.^{28,29} Increasingly, we are unable to discern partner risk for women since the number of women with no reported or identified HIV risk at the time of HIV testing is increasing.³⁰ In addition, given the widespread use of antiretroviral therapy and the wealth of clinical trial opportunities, information is needed to document and address barriers to HIV care and disparities in treatment for blacks and Latinos, particularly for those residing in the south.

Addressing these gaps requires understanding of culture-specific nuances ascribed to black and Hispanic populations. Understanding these nuances leads to appropriate integration of these issues throughout study conceptualization and research design, particularly in the development and administration of instruments, as well as into analysis of outcomes data and implementation of targeted interventions.

Minority HIV/AIDS Research Initiative (MARI)

The solution for addressing these issues, diversifying

the pool of HIV researchers and effectively addressing the scientific gaps for communities of color is multi-pronged. At a minimum, this task requires provision of funding opportunities for investigators of color to engage in the scientific conduct of HIV epidemiologic and prevention research in black and Latino communities. Accordingly, in September 2003, the Division of HIV/AIDS Prevention (DHAP) in the National Center for HIV, STD and TB Prevention (NCHSTP) at CDC established the MARI program to address the issues highlighted in this article. This program primarily addresses the gaps in HIV epidemiologic and prevention research in black and Latino communities as well as the dearth of funded junior investigators of color who have the skills to conduct HIV/AIDS research in black and Latino communities. In short, MARI identifies, funds and partners senior CDC researchers with junior investigators to conduct HIV research in black and Latino communities throughout the United States.

MARI was established beginning with one year of meetings and discussions with both minority and non-minority scientific leaders and public health officials internal and external to CDC. Meetings were held to solicit opinions and ideas from >100 scientists at CDC and 115 external partners and stakeholders across the country, including HIV researchers and other scientists, healthcare providers, university professors, community opinion leaders and other liaisons in the HIV community. The collective input from these dialogues helped to

achieve some national consensus in the public health and HIV research communities about the directions and priorities of MARI.

The first MARI program announcement, released in June 2003, to publicize the competition for research funding was crafted with attention to the collective feedback from the meetings described above. The announcement invited proposals addressing a variety of gap research topics in HIV/AIDS, including participation in government-sponsored research; voluntary counseling and testing in rural and urban MSM; missed opportunities for prevention of perinatal transmission; and a broad category that addressed behavioral, psychosocial and cultural determinants of HIV risk behavior.

To ensure competition among qualified junior investigators, the eligibility requirements for primary investigators included: 1) having a research or a health professional masters or doctorate-level degree from an accredited school/program, 2) being a first-time primary investigator on an HHS-supported HIV research award and 3) demonstrating previous experience working in and accessing study populations in communities of color.

The response to the program announcement demonstrated an urgent need for programs such as MARI. More than 200 letters of intent were received in response to the program announcement. One-hundred applications were received, which required the coordination of one of the largest review panels in the history of NCHSTP. Applications were received from junior researchers, including cli-

Figure 1. Geographic location of MARI applications received and successfully funded projects, 2003



nicians, behavioral scientists and researchers from universities and AIDS service and community-based organizations nationwide. The geographic distribution of applicants, which largely reflected the burden of HIV disease among minority groups in the United States, is shown in Figure 1. Research populations for the 11 currently funded research projects include six focused in the south. Study populations are enrolled from communities with high HIV morbidity and that reflects trends in the current epidemiology of the U.S. epidemic. Projects address several research gaps in the HIV/AIDS literature and include studies assessing, for example: 1) routine HIV testing in primary care settings, 2) determinants of engagement in HIV care and treatment, 3) attitudes toward HIV testing in young adults, and 4) participation of blacks and Latinos in government-sponsored trials (Table 1). Successfully funded investigators are expected to first-author publish and present the findings of their work locally and at national scientific conferences and will be provided with technical support as well. The current MARI-funded investigators have completed data collection for their research projects and many have published or presented some of their findings for national audiences. According to a poll conducted among the investigators, the research opportunities and experiences gained through MARI were positive and invaluable. Given this, support for MARI will continue through the CDC DHAP. A new MARI program announcement will be released in 2007 inviting applications for research ideas from a new group of junior investigators.

Relevance to Other Health-Related Disciplines

Since MARI is an HIV-specific program, understanding its potential application and relevance to the general medical and public health and scientific communities requires examination of the goals of MARI in a much broader context. Minority investigators and clinicians are scarce in all medical, public health disciplines. The genesis of the problems addressed by MARI and outlined in this article is much more proximal than the current lack of funding programs for minority junior investigators; it is directly correlated with the relative paucity of black and Latino persons entering the graduate school system. As a result, clinical and social science training programs nationwide reflect the relatively small number of successful HIV and other researchers and clinicians of color in the United States. For example, in 2002, according to the American Medical Association, the estimated percentages of black and Latino physicians in the United States were 2.3 and 3.2, respectively, which is considerably less than the proportion these ethnicities represent in the U.S. population.³¹ In addition, according to the Association of American Medical Colleges, the number of black and Latino matriculants in 2003 and 2004 was <7%.³²

Given this, in this age of increasing health disparities in the United States, programs such as MARI can serve as one approach to our response in the elimination of these disparities. Blacks and Latinos bear a disproportionate burden of most nationally reported diseases such as heart disease, diabetes and asthma; therefore, the same need and justifications previously outlined for HIV investigators intuitively apply to other scientific disciplines.

The elimination of health disparities is possible and will require multisectoral commitments and multi-pronged approaches to address these issues. Allied health professionals and researchers throughout the United States can assist in many ways, including: 1) proactively identifying and referring or directing talented students toward health-related careers, 2) personally mentoring or identifying mentors, 3) exposing potential graduate-school candidates to career opportunities in health and research, or 4) creating appropriately directed funding programs such as MARI. We believe that MARI is an important step toward addressing health disparities. It is a programmatic model that can be replicated in medical schools, schools of public health, and academic and clinical research institutions. Furthermore, its premises and goals can be operationalized and tailored to meet the constructs of these entities that are also committed to the elimination of health disparities in the United States.

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