

ESTABLISHING A FOUNDATION FOR CARDIOVASCULAR DISEASE RESEARCH IN AN AFRICAN-AMERICAN COMMUNITY—THE JACKSON HEART STUDY

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(*Ethn Dis.* 2003;13:411–413)

Key Words: Jackson Heart Study, Cardiovascular Disease, African American

INTRODUCTION

In this issue of *Ethnicity & Disease*, Wyatt et al report on a pilot project of the Jackson Heart Study (JHS).¹ The JHS Participant Recruitment and Retention Survey (PPRS) was part of the process to design what are usually referred to as “recruitment strategies,” appropriate for a given target population. However, the comprehensive interviewing, surveying, and dialogue described go far beyond the cursory attention researchers often give to “cultural sensitivity.” The important innovation of this effort is the early and concentrated effort to discern the expectations, priorities, and sensitivities of the African-American community about research, and to use the insights as guiding principles in the design and execution of the study. This approach is a significant evolution from the usual “scientist—subject” relationship between researchers and volunteers for research participation, toward a “communitarian” ideal.

THE AFRICAN-AMERICAN COMMUNITY IN CARDIOVASCULAR DISEASE RESEARCH

The integration of community-conceived approaches into multiple aspects of JHS including personnel selection criteria, recruitment protocols, and experimental design are tangible reflections of respect for the intelligence and wisdom of community members. In many ways, the approach is common sense. However, the “sense” to critically analyze the chorus of responses from a community, discern the major themes of concern of that group, and to faithfully apply the insights to the study design, is all but “common” in modern research. To do

so with scientific rigor, as these researchers have done, is especially uncommon. The “community driven” model espoused by the researchers focuses on insuring that investigators and participants are partners in the process of scientific discovery. The analytic methods employed and the conclusions reached by the authors have helped lay the foundation for the still-evolving relationship between JHS and the Jackson-Area African-American population. Further, this work will be of interest not only to investigators focused on ethnicity and health but to those who initiate recruitment for observational investigations.

A COMPELLING RESEARCH AGENDA— CARDIOVASCULAR DISEASE IN AFRICAN AMERICANS

To place the article in perspective, it is useful for the reader to be acquainted with the science-driven rationale for JHS, which is a large and multifaceted epidemiological study. Initial recruitment for JHS, started in the fall of 2000, will continue into early 2004. Similar in design to the renowned Framingham Heart Study, JHS is a population-based epidemiological study of cardiovascular disease among African-American men and women being conducted in Jackson, Mississippi, sponsored jointly by the National Heart, Lung, and Blood Institute (NHLBI) and the National Center for Minority Health and Health Disparities (NCMHD) of the National Institute of Health (NIH).

The primary goal of JHS is to establish a large-scale, single-site epidemiological study of cardiovascular disease (CVD) in African Americans. The major objectives of JHS will subsequently be:

1. To identify the impact of risk factors—traditional and novel (including aspects of the physical and social environment, genetic vulnerabilities) for development and progression of CVD in African Americans.
2. To build unique cross-institutional collaborations to facilitate research and training.
3. To build research capacity at minority institutions and expand minority investigator participation in epidemiological studies of CVD.

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4. To attract minorities to careers in public health epidemiology and biostatistics.

Thus, critical scientific objectives are coupled with the twin goals of capacity building for research in minority health and training of minority students in the sciences of public health. The latter objectives serve the purpose of maximizing productivity of current talent resident at historically Black colleges/universities (HBCUs) and other institutions, while enlarging the cadre of minority scientists for the future. While students and faculty of institutions located in Jackson are the primary beneficiaries of this feature of JHS, scientists and students across the United States will benefit as numerous collaborations and data sharing relationships evolve. The JHS is a national resource.

The results of landmark population-based studies like the Framingham Study have accumulated steadily over the last 5 decades, leading to a better defined understanding of the determinants of cardiovascular diseases than was available a generation ago.² However, cardiovascular disease is still by far the leading cause of death and disability in the United States. Significant differences in survival exist between the White American population and American ethnic minority populations, with a disproportionate share of suffering borne by minority groups. Unexplained regional variations also cloud the otherwise notable progress of the last 30 years; nonmetropolitan and rural areas appear to be uniquely burdened with high rates of mortality and morbidity. For example, African-American men in Mississippi in the 45–54 year-old-age group have a 3.5 greater chance of dying from cardiovascular disease than White men, and African-American women in the same age group have a 4.2 greater chance.

These disparities in CVD morbidity and mortality related to race, ethnicity, gender, and geography remain incompletely explained. Hypotheses abound; documented chains of causality are few. Many investigators cite the critical need for better access to health care to diminish the disparities. While improvements in access to care for clinical conditions will likely reduce disparities to a degree,^{3,4} it is clear that much of the health inequality derives from problems that develop beyond the view of the clinical encounter, and will not yield to broader access alone.⁵ Informed intervention—preventive and therapeutic—is critical. The best approaches will continue to rely on good epidemiological (and subsequent clinical trial) research to inform our interventions.

These facts, combined with the fact that few population-based studies have been conducted in this high risk group, constitute sufficient reason for JHS, a study that will offer other important approaches to understanding the CVD epidemic. Few studies have focused on the role of many of the “novel” nontraditional cardiovascular risk factors and biomarkers among Blacks, especially non-hospitalized populations of the size of JHS. The study of genetics of CVD in the Black pop-

ulation—including gene by environment and gene by gene interactions—is only in its infancy. These areas will be the target of focused investigation in JHS. Also, a central thrust of the investigation will be to better characterize the impact of socio-cultural and psychosocial factors on CVD genesis, progress, and prevention. Social and psychological environment are believed by many to be the key determinant in ethnic disparities. An important feature of JHS is its focus on the roles of psychological, social, and cultural factors, racism and discrimination, religious practices, and other “non-biological” variables (which may have important biological impact) on CVD health and disease. A focused examination of risk in this uniquely vulnerable population may offer many new insights into the disease process—insights that could benefit many, regardless of race.

THE RESEARCH ENVIRONMENT AND INFRASTRUCTURE FOR THE JACKSON HEART STUDY

The Jackson Heart Study is being conducted in 3 contiguous counties in the Jackson, Mississippi area. The triple goals of scientific investigation, capacity building for research in minority health, and expanding the ranks of minority researchers in public health make this site ideal. Jackson is the capital of Mississippi, the state with the largest percentage (36%) of African Americans in the country. It is also the state with the nations' highest rates of CVD death; research into the determinants of the epidemic here may be particularly informative and helpful in addressing the epidemic nationwide. The variety of environments—urban, suburban, and rural—that comprise the tri-county metropolitan area will allow important evaluations of the impact of urbanization on CVD health.⁶ The Jackson population is not prone to out migration, a characteristic that facilitates a longitudinal study where periodic follow up of study participants is a critical factor.

The academic infrastructure also offers significant opportunities for collaboration, capacity building, and training. Jackson, Mississippi is the location of 2 historically black colleges/universities (HBCUs) with established histories of service to Jackson's African-American community: Jackson State University and Tougaloo College. Also, the state's only medical school and university hospital—the University of Mississippi Medical Center (UMMC)—exists in the same community. It boasts a long-standing research emphasis on hypertension and CVD epidemiology. In the 1980s and 1990s, UMMC developed one of the 4 sites of the landmark Atherosclerosis Risk in Communities (ARIC) study.⁷ The Jackson ARIC site was the only all African-American site in that study. The group of already engaged ARIC participants provide a part of the sample population for JHS. In this environment, the goals of broadening

minority researcher participation in important epidemiological studies can be optimally addressed.

Finally, the physical headquarters of JHS is the Jackson Medical Mall located in the heart of the African-American community. The Jackson Medical Mall (JMM) was formerly a shopping mall that flourished then floundered. It was remodeled and converted to a variety of health-related enterprises. All operational units of JHS are located in a designated area of the JMM inclusive of the offices and staff of the primary investigators, as well as the Coordinating Center, Examination Center, Undergraduate Training Center in Public Health and Epidemiology recruitment unit, and NHLBI support staff.

SUMMARY

The JHS is the largest single-site prospective, epidemiological study of CVD among African Americans undertaken to date. It is focused on African-American health, yet comprehensive in its scientific scope. Its design will allow future refinements in scientific direction, the development of ancillary projects, and the formation of synergistic collaborations to develop and test novel hypotheses as our understanding of the CVD

epidemic continues to evolve. This effort represents an important part of a broad-based, multi-pronged assault on ethnic disparities in the United States. Its novel capacity-building, minority training, and community participation components make it an exemplary model for American research. Meaningful community participation in the development of JHS owes much to the approaches described by Wyatt et al¹ in this issue.

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