

Improving the Health of Minority Women: The Role of Research

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The Office of Research on Women's Health (ORWH) at the National Institutes of Health (NIH) is the catalyst and focal point for research related to women's health issues supported and conducted by the institutes and centers of the NIH. Because health status is the result of the complex interplay of genetic inheritance and lifestyle and environmental factors, the ORWH—through a coherent agenda on research—encourages biomedical and behavioral studies that seek to elucidate and mitigate the ways in which age, ethnicity, economic status, and lifestyle influence the health of women of all ethnic backgrounds and socioeconomic circumstances.

In 1985, a report issued by the Department of Health and Human Services' Secretary's Task Force on Black and Minority Health documented disparate disease prevalence, progression, and health outcomes for many diseases, such as cancer, diabetes, and cardiovascular disease, and excessive mortality for members of minority groups. Although questions remain as to why these disparities exist, access to diagnostic, preventive, and curative health services is certainly an important factor in understanding these differences. For example, a study done by the American Cancer Society Demonstration Projects to Reach the Underserved has shown that, at one site, women had to wait seven to eight months to get a mammogram for a suspicious clinical finding, and then required three to four additional visits for diagnostic work-up. Unfortunately, many minority women have reduced access to diagnostic and preventive procedures, such as mammography screening, because of socioeconomic constraints and a lack of adequate health insurance coverage.

While access to health care is an important contributor to health status, it is not the only factor that influences minority women's differential health status and outcomes. It is essential that we expand the science base that underpins medicine by increasing the medical community's understanding of sex and gender differences and the interplay of race and culture in illness, so that physicians will be able to provide reliable diagnoses and effective treatment and prevention strategies for all their women patients, regardless of the patients' racial, ethnic, or socioeconomic backgrounds. Research is essential to providing the scientific foundation for changes and improvements in health practices and health care policies.

If the disparities in health status and health outcomes for minority women are to be eradicated, then the knowledge about why these disparities exist is essential. To obtain that knowledge and have it affect health care delivery and public policy, study populations must include women and minorities so that such contributing factors can be identified and studied. Guidelines on the inclusion of women in clinical studies have been in place at NIH since 1986. In 1987, minority and other scientists at the NIH recognized the need to address the inclusion of minority populations, and in 1987 a policy encouraging the inclusion of minorities in clinical studies was first published. In 1990, the U.S. General Account-

ing Office conducted an investigation into the implementation of the guidelines for the inclusion of women by NIH. The resulting report indicated that the implementation of the policy was lacking, slow, not well communicated, that gender analysis was not implemented, and that the impact of this policy could not be determined. The GAO study also indicated that there were differences in the implementation of the policy recommending the inclusion of minorities, and that not all institutes factored adherence to these policies into the scientific merit review.

Following the publication of the GAO report and the establishment, in September 1990, of the ORWH—which has a legislative mandate to ensure that women and minorities are included in NIH-supported clinical research—the NIH strengthened and revitalized its inclusion guidelines. The ORWH is now responsible for overseeing implementation of the revised inclusion guidelines and monitors the adequate inclusion of women and minorities in clinical trials to ensure their adequate representation in such NIH-supported studies.

Unfortunately, historical events—such as the Tuskegee Syphilis Study in which African American men were denied treatment so that researchers could study the natural progression of disease, and the health consequences associated with the use of DES and Thalidomide by pregnant women—have created biases and cultural barriers against medical research in many communities. To understand and overcome such barriers, the ORWH and the NIH have undertaken a wide variety of efforts, ranging from a 1993 workshop on recruitment and retention of women in clinical studies and an outreach publication that provides guidance to clinical investigators on programs that foster the participation and advancement of women and minorities in biomedical research careers.

The ORWH and the NIH recognize that the barriers to including women of all races and cultures in research can only be overcome through cultural sensitivity on the part of researchers; the participation of clinicians within communities and community groups in the planning and implementation of such research; and having researchers who are themselves from the communities they seek to include in studies. We also recognize that if we are to succeed in recruiting and retaining minority women in clinical trials, we need the help of community-based individuals and organizations and health professionals who are on the front lines of health care delivery. The NIH is relying on members of minority communities to be our partners in encouraging women, especially minority women, to help the medical community better understand the health of *all* women by serving as volunteers in both prevention and treatment studies. Only by ensuring the inclusion of women of all backgrounds and circumstances in clinical studies can we develop appropriate preventive and treatment interventions to improve the health and longevity of all women in the United States. ❖

