|  |
| --- |
| **Disparities, Research, and Action: The Historical Context**  Vanessa Northington Gamble and Deborah Stone  excerpted from: Vanessa Northington Gamble and Deborah Stone, U.S. Policy on Health Inequities: the Interplay of Politics and Research, 31 Journal of Health Politics, Policy and Law 93- 122, 99-108 (February, 2006) (17 Footnotes)   For much of the twentieth century the color line in medicine was so rigidly drawn that hospitals and medical institutions could, and routinely did, exclude African Americans. The racially exclusionary practices of hospitals often had tragic consequences, as the November 1931 death of Juliette Derricotte, Dean of Women at Fisk University, vividly demonstrates (Crisis 1932; Lerner 1972: 384- 396). It also illuminates the limits of individual actions in the context of institutional restrictions. Miss Derricotte died after she was refused hospital care following an automobile accident in Dalton, Georgia. According to witnesses, she received medical treatment from a white physician at the scene and later at his office. According to witnesses, the physician provided good and compassionate care, but because of racial discrimination he could not admit her to the local hospital. Consequently she was moved to the private home of a black woman who had no medical or nursing training. Apparently the residence, which witnesses described as filthy, was where black patients received medical care in the town. Derricotte remained at the private home for several hours and died after she was transferred fifty miles to the black ward of a Chattanooga hospital. The National Association for the Advancement of Colored People (NAACP) publicized the death in black and white newspapers nationwide. By putting a human face on hospital discrimination, the civil rights organization hoped to galvanize support for efforts to desegregate hospitals. African Americans believed that their exclusion from hospitals as patients and health professionals played a major role in their poor health status.  Historically, progress in addressing racial disparities has resulted from the interplay of research and political action. Indeed minority community leaders sometimes deliberately transformed their knowledge about disparities and injustices into scientific research projects to gain recognition for their political claims. As the work of W. E. B. DuBois demonstrates, research became a form of protest, as well as a resource for future protest and political action.  In 1906 DuBois, a sociologist and civil rights activist, published the monograph, The Health and Physique of the Negro American (DuBois 1906), one of a series of research studies published under the auspices of Atlanta University, a historically black institution. DuBois used data such as census reports, vital statistics, and insurance company records to document the poor health status of African Americans in comparison to white Americans. DuBois contended that these disparities stemmed from social conditions and not from inherent racial traits. "With improved sanitary conditions, improved education, and better economic opportunities," he declared, "the mortality of the race may and probably will steadily decrease until it becomes normal" (ibid.: 73). One of the major objectives of The Health and Physique of the Negro American was to refute the theories of Frederick L. Hoffman, a statistician at Prudential Life Insurance. In his influential 1896 treatise Race Traits and Tendencies of the American Negro, Hoffman attributed the poor health status of African Americans to inherent susceptibility and racial inferiority.  The Health and Physique of the Negro American served as the basis for the Eleventh Conference for the Study of Negro Problems. On May 29, 1906, scholars, health professionals, and activists gathered at Atlanta University to review DuBois' findings. At the end of the meeting they adopted several resolutions. They called for the formation of local health leagues to provide information about preventive medicine and urged existing health organizations to institute programs to address the health care needs of African Americans. The latter recommendation might have been developed to remind white Americans that germs have no color line and that self-interest mandated that they not neglect black health needs. Conference attendees also reaffirmed DuBois' stance about the importance of social factors in determining health. They passed a resolution stating that they "did not find any adequate scientific warrant for the assumption that the Negro race is inferior to other races in physical build or vitality. The present differences in mortality seem to be sufficiently explained by conditions of life" (DuBois 1906: 110). In their final resolution they emphasized the connection between research and social reform. It stated, "The Conference above all reiterates its well known attitude toward ... social problems: the way to make conditions better is to study the conditions" (ibid.).  The African American community also attempted to address health inequities by creating its own institutions such as hospitals, medical schools, and professional societies. They also initiated self-help activities such as the National Negro Health Movement. The origins of the movement can be traced to 1915 when the Virginia affiliate of the National Negro Business League established a health week to call attention to the high morbidity and mortality rates of black Virginians and to develop programs to attack them. The league had become interested in health issues because its members believed that the poor health status of African Americans was a "source of economic loss to the race and a hazard to the general welfare of the state" (Moton n.d.). The goal of the health week was to teach African Americans about the principles of public health and hygiene to help them become stronger and more effective citizens. Its activities included lectures in churches and schools and the formation of brigades to clean neighborhoods.   The activities in Virginia attracted the attention of Booker T. Washington, one of the most prominent black leaders of the late nineteenth and early twentieth centuries. In 1915, Washington, the principal of Tuskegee Institute and president of the National Negro Business League, moved the program to Tuskegee to give it a national focus. Washington (n.d., quoted in Smith, 1995: 38) saw the effort as critical for the advancement of African Americans because "without health ... it will be impossible for us to have permanent success in business, in property getting, [and] in acquiring education .... Without health and long life all else fails." In 1923 an official of the National Urban League, an organization that promotes economic opportunity and social welfare for African Americans, stated, "the Negro's struggle for health might be considered an effort of the race to survive" (Jones 1923: 72).  Black Americans readily embraced health week. Between 1915 and 1930, African Americans in thirty-two states participated in health week activities. In 1935, 2,200 communities from across the nation sent in reports of their health week activities. In memory of Booker T. Washington, who died shortly after the initiation of the national program, National Negro Health Week was held during the first week of April--his birthday week. Although many health care efforts were concentrated in this week, the organizers of National Negro Health Week saw beyond this annual event and worked to establish the improvement of black health as an ongoing effort. They successfully worked to bring the problem of black health to the attention of the federal government and organizations such as the American Social Hygiene Association, the American Red Cross, and the Rockefeller Foundation. According to historian Susan L. Smith (1995: 34), "Black health activists turned National Negro Health Week into a vehicle for social welfare organizing and political activity in a period when the vast majority of African Americans were without formal political and economic power."  In 1930 the United States Public Health Service (USPHS) assumed operation of National Negro Health Week and it subsequently became a year-round activity. The Tuskegee organizers welcomed this shift because they saw it as a step toward placing black health care on the nation's public health agenda. Two years later, the USPHS established the Office of Negro Health Work under the direction of Dr. Roscoe G. Brown, a black dentist. The creation of this office represented the first time since the end of the Civil War that black health care issues were institutionalized within a federal bureaucracy. The office served as the center of the federal government's black health efforts. Its activities included coordinating health week, developing educational materials, and publishing National Negro Health News, a quarterly journal on black health issues.  The Office of Negro Health Work operated until 1950. Its demise reflected major changes in American race relations--the rise of integrationism as a strategy for black advancement and with it, the rejection of separate programs and facilities for African Americans. Physician-activist W. Montague Cobb contended that "the idea of a special 'Negro Health Week' has become outmoded" because it represented segregationism (Cobb 1950: 8). The federal government decided to close the office because it was "in keeping with the trend toward integration of all programs for the advancement of the people in the fundamentals of health, education, and welfare" (Smith 1995: 78).  After World War II the campaign to desegregate medical facilities and dismantle separate institutions for African Americans gained momentum. Medical civil rights activists accurately maintained that a segregated health care system led to inferior medical care for black Americans. In addition, they charged that the separate-but-never-equal facilities of the black medical ghetto could never adequately meet the health and professional needs of African Americans.  Armed with the precedent set by the 1954 Supreme Court decision Brown v. Topeka Board of Education, which struck down segregation in public education, the medical civil rights activists began a judicial assault on hospital segregation. Simkins v. Moses H. Cone Memorial Hospital proved to be the pivotal case. In February 1962, black physicians, dentists, and patients from Greensboro, North Carolina, brought suit to stop the racially discriminatory practices at two voluntary hospitals that had received close to $3 million under the Hill-Burton Act, a federal hospital construction program. The plaintiffs in Simkins challenged the constitutionality of a "separate-but-equal" clause in the legislation. Although the district court ruled against them, the Court of Appeals found in their favor in November 1963, and its decision stood because the Supreme Court refused to hear the case on appeal (Beardsley 1987: 245-272; Halperin 1988: 59-63; Journal of the National Medical Association 1962; Journal of the National Medical Association 1963; Horty 1964; Hospitals 1964).  The Simkins decision represented a significant victory in the battle against racial discrimination in health care. Its authority, however, was limited to those hospitals that received Hill-Burton funds. A 1964 federal court decision, Eaton v. Grubbs, broadened the prohibitions against racial discrimination to include voluntary hospitals that did not receive such funds (Halperin 1988; Modern Hospital 1964; Hospitals 1964; Journal of the National Medical Association 1957; Journal of the National Medical Association 1961). The 1964 Civil Rights Act supplemented these judicial mandates and prohibited racial discrimination in any programs that received federal assistance. The 1965 passage of the Medicare and Medicaid legislation made most hospitals potential recipients of federal funds and thus obligated them to comply with federal civil rights legislation (Parker 1964; Journal of the National Medical Association 1965).   In March 1966, Reverend Dr. Martin Luther King, Jr., the civil rights leader, went to Chicago to plan direct action against the city's hospitals because of their racially discriminatory practices. He hoped that his efforts would dramatize the health problems of black Americans. "Of all forms of discrimination and inequalities, injustice in health is the most shocking and inhuman," Dr. King declared (Chicago-Sun Times 1966: 12). King's comments vividly illustrate how African Americans throughout the twentieth century saw health care inequities as inextricably linked to the struggle for civil rights. Various segments of the black community--health care professionals, politicians, activists, newspaper reporters--called attention to the community's poor health status and developed multipronged strategies to improve it, including activism, self-help, research, and legal suits.  During the 1970s and 1980s it became increasingly clear that, despite the significant impact of the civil rights movement in securing access of minority Americans to the nation's medical institutions, disparities continued to persist between the health of white and minority Americans. In January 1984, Margaret Heckler, President Ronald Reagan's secretary of health and human services (1983-1985), sent Health, United States, 1983 to the U.S. Congress. This annual report card on the health status of Americans documented significant gains. But Heckler (U.S. DHHS 1985: ix) pointed out, it also "signaled a sad and significant fact; there was a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans as compared with our nation's population as a whole" (Heckler's emphasis). She noted that although there had been steady gains in the health status of minority Americans, "the stubborn disparity remained--an affront both to our ideals and to the ongoing genius of American medicine" (ibid.: 185).  In response to this "national paradox," Heckler established the Secretary's Task Force on Black and Minority Health to conduct a comprehensive and coordinated study of these disparities (ibid.: 2). The nineteen-member task force of senior scientists and officials of the Department of Health and Human Services conducted its work over the course of a year. Its activities included analyzing existing morbidity and mortality data, examining the factors underlying these disparities, and consulting with experts in minority health from outside of the federal government.  The task force released its ten-volume report in October 1985. Its most significant accomplishment was its extensive documentation of the extent of the health disparities between the health status of blacks, Native Americans, Hispanics, and Asian/Pacific Islanders compared to those of whites. The task force decided that the statistical technique of excess deaths best defined disparities in mortality. It described excess deaths as the difference between the number of deaths observed in the minority populations and the number that would have been expected if the minority population had the same age- and sex-specific death rates as the nonminority population. The task force used the concept of excess death to graphically illustrate the magnitude of racial and ethnic disparities in America. It found that 60,000 excess deaths occurred each year in minority populations--deaths that probably would not have occurred had the persons been white. The task force identified six causes of death--cancer, cardiovascular disease and stroke, cirrhosis, diabetes, homicide and accidents, and infant mortality--that together accounted for more than 80 percent of the excess deaths observed in minority populations.  The task force recognized that the factors underlying the health disparity between minority and white Americans are "complex and defy simplistic solutions" (ibid.: 7). "Health status," it contended, "is influenced by the interaction of physiological, cultural, psychological, and societal factors that are poorly understood for the general population and even less so for minorities" (ibid.). In its report, the task force did not discuss these factors at great length. Its primary goal was to accurately document the problem of racial and ethnic disparities.  The task force made eight main recommendations to the secretary (ibid.: 8). Strikingly, the recommendations focused entirely on information strategies--improving education, research, data, and communications among agencies--but were silent on the question of politics and political will, as if knowledge deficiencies were the only cause of disparities. Indeed, Dr. Edith Irby Jones, the president of the National Medical Association, a black medical society, criticized the report's emphasis on health education and lifestyle changes. She argued that the Heckler report implied, "If black people would only 'behave' their health problems would be solved .... as black Americans, we know it is not as simple as all that" (Jones 1985: 486).  The release of the Heckler report pushed minority health issues onto the national research and health policy stage. In response to the report, the Department of Health and Human Services swiftly established in 1985 the Office of Minority Health (OMH). In January 1986, Dr. Otis Bowen, Heckler's successor, appointed Dr. Herbert Nickens, a black psychiatrist, as the office's first director. Thirty-five years after the demise of the Office of Negro Health Work, the federal government once again had an office dedicated to improving minority health. Its broadened mandate--minority health, rather than black health--reflected the recognition of disparities in other minority groups and the changing demography of the American population. OMH was given responsibility for implementing the task force recommendations, as well as planning, coordinating, and monitoring activities across the U.S. Department of Health and Human Services that relate to disease prevention, health promotion, service delivery, and research concerning racial and ethnic minorities. In 1990, five years after the establishment of the OMH, the NIH created an Office of Research on Minority Health to coordinate the development of NIH policies, goals, and objectives related to minority research and research training programs. By 2004, thirty-five states and territories had established some kind of office, commission, council, or advisory panel on minority health. The Heckler report can be credited with stimulating the formation of this infrastructure (McDonough et al. 2004: 11).  After the release of the Heckler report, research analyzing racial and ethnic disparities in health status, quality of care, and access proliferated, although the issue did not attract much political attention and, indeed, it remained very much a research issue. In 1990, the American Medical Association--not known as a particularly progressive organization--responded to the growing research on racial and ethnic disparities in treatment. Its Council on Ethical and Judicial Affairs released a report that called these disparities "unjustifiable." It contended that patient characteristics such as income, education, and cultural beliefs played probable roles in these disparities. However, it did not let physicians off the hook. It recognized that "disparities in treatment decisions may reflect subconscious bias .... The health care system like all of society has not eradicated this [racial] prejudice" (Council on Ethical and Judicial Affairs 1990: 2346). Thus, the American Medical Association, however gingerly, applied a civil rights frame to the disparities issue.  In 1999, the New England Journal of Medicine addressed the issue of physician bias head-on with an article from a team of researchers led by Dr. Kevin A. Schulman (Schulman et al. 1999). For this study, the researchers developed a standardized computer program to survey primary care physicians' recommendations about chest pain. The computer program included videotaped interviews with patients (white males, white females, African American males, and African American females) about the nature of their chest pain. Unbeknownst to the physicians taking part in the study, the patients were actually identically dressed actors reading from identical scripts. The researchers had also standardized most aspects of the patients' medical and social histories-- age, cardiac risk factors, health insurance, and job. The only variables were the race and gender of the "patients." The study found that African Americans and women with chest pain had relative odds of referral for cardiac catheterization that were 60 percent of the odds for whites and men. African American women faced the greatest disparity--relative odds that were 40 percent of those for white men. The researchers attributed the disparate care to "subconscious perceptions rather than deliberate actions or thoughts" on the part of physicians (ibid.: 624).  Schulman's research design incorporated a variation of a traditional civil rights strategy--the use of testers. Civil rights activists have long used this strategy to determine whether the treatment afforded to white and black people in the same situation varies. For example, black and white testers with identical credit histories and perhaps résumés are sent to rent an apartment, apply for a mortgage, or purchase insurance. If blacks with the same characteristics as whites are turned down while whites are accepted, it is likely that race was the decisive factor. The tester strategy is a powerful civil rights enforcement technique because it figuratively catches people in the act of discriminating. The Schulman study combined elements of political action and scientific research and essentially brought a testing program to medicine.  The Schulman study received widespread media attention. Most major newspapers covered it (Goldstein 1999; Wall Street Journal 1999; Rubin 1999; New York Times 1999), and it was a feature story on Nightline, a highly regarded television news program (ABC News Nightline 1999). The study provoked strong responses because it told a powerful story of discrimination at the hands of physicians. Perhaps because of its wide media exposure, this study became a lightning rod for discussions about racial discrimination and racial and ethnic disparities in health care. Six months after the publication of the Schulman study, an article in the New England Journal of Medicine harshly criticized the study's methodology and called its findings "overstated" (Schwartz, Woloshin, and Welch 1999: 279). But as Thomas Perez, the former director of the Office of Civil Rights in the Department of Health and Human Services, has noted, attempts to dismiss the Schulman study "miss the mark, and ignore the wide body of research, both before and after the Schulman study, suggesting that race continues to matter in health care, and racial bias may contribute to racial and ethnic disparities in health status" (Perez 2003: 633).  The Schulman study was released a year after Dr. David Satcher assumed the positions of U.S. surgeon general and assistant secretary of health. Satcher, an African American physician who had dedicated his career to improving the health of minority and underserved patients, praised the study on ABC's Good Morning America (1999) as "the best that we have documenting subconscious prejudice." During his tenure as the nation's top public health and health policy adviser, Satcher once again pushed the issue of health disparities onto the nation's health policy and research agenda. His efforts led to the development of the Initiative to Eliminate Racial and Ethnic Disparities in Health and the inclusion of the elimination of health disparities as one of the two major objectives of Healthy People 2010 (U.S. Department of Health and Human Services 1998).  In November 2000, President Bill Clinton signed the Minority Health and Health Disparities Research and Education Act of 2000 (Public Law 106-525). One of its major provisions was the elevation of the NIH Office of Minority Health to the Center for Minority Health and Health Disparities. This move was not without controversy (Healy and Brainard 1999; Brainard 1999). Dr. Harold Varmus, then NIH director, opposed the elevation because he believed that the creation of the center would confine research on minority health to one center. However, African American political and medical leaders believed that the change in status would give the office more clout because, as a center, it could award its own grants. They passionately supported the change and gathered bipartisan support, including that of Senator Bill Frist of Tennessee, to push the legislation. Frist, currently Senate majority leader, is a cardiothoracic surgeon who wields great influence on health policy issues. Frist agreed to support the legislation after provisions were included that would also cover poor white Americans. Thus the act was not just a minority health bill, but one that also recognized health disparities in white, economically disadvantaged Americans. Another provision of the act directed the Agency for Health Care Research and Quality, the agency in the federal government primarily responsible for health quality and health services research, to conduct and support research on health disparities. In the years since the Heckler report, the federal government has expanded its support of research to eliminate racial and ethnic disparities in health, and the pace of research is accelerating. Although disparities research has gained momentum in the United States, questions still remain as to how to create political will to sustain the issue and how to translate research into action. |
|  | |