

Barriers to Improving Diabetes Care for Blacks

In the spring of 1989, the University of Michigan Diabetes Research and Training Center (MDRTC) convened a Task Force on Diabetes and the Black Population. This editorial is based on that task force report, which was issued on 15 January 1990. The mission of the task force was to identify potential barriers to the translation of scientific knowledge into improved health care and health for blacks with diabetes. Although it is known that diabetes affects a disproportionate number of black Americans, there is a paucity of information about the causes and effects of this burden. We hope this editorial contributes to a dialogue within the diabetes community that will lead to an increasingly articulated and tangible commitment to reducing the disproportionate burden that diabetes places on African Americans and other minorities in the United States.

EPIDEMIOLOGY OF DIABETES IN THE BLACK POPULATION

The prevalence of diabetes is substantially higher among blacks than whites. Black men have a rate that is 1.4 times higher than white men, and black women have a rate ~2 times higher than white women (1). During the 1980s, age-standardized mortality for white men and women declined 1.6 and 4.5%, respectively, although among black men and women, mortality increased 11 and 5.5%, respectively. In 1987, the age-adjusted rate of 183 hospitalizations related to diabetes/10,000 black women was 36% higher than for black men (135/10,000), 95% higher than for white women

(94/10,000), and 108% higher than for white men (88/10,000; 1). In 1987, the age-adjusted rate of hospital discharges for diabetic ketoacidosis among black men with diabetes was 24.7/1000. This was nearly threefold higher than the corresponding rate of 8.7/1000 white men with diabetes (1). Similar discrepancies exist between black and white women with diabetes. When end-stage renal disease incidence is calculated with diabetic population denominators, the rates for black men and women are more than twice those for white men and women (1). Finally, the hospital discharge rates for lower-extremity amputation are consistently higher for blacks with diabetes than for whites with diabetes. The relative risks among blacks is ~1.5- to 2-fold higher compared with whites (1). These data confirm that African Americans are at increased risk for both diabetes and its complications. Many of the complications of diabetes are preventable through behavioral changes and preventative health-care services (2).

POTENTIAL BARRIERS

The potential barriers to improved health care and health for blacks with diabetes include racism, lack of knowledge, incorrect beliefs, lack of access to health care, differing cultural values and priorities, and poverty. These potential barriers are interrelated. For example, racism, poverty, and lack of access to health care can be discussed separately but may be inseparable in the real world. Determining the relative impact of these factors requires careful study.

Racism. Individual racism can be defined as the belief that racial differences produce inherent superiority or inferiority in a particular race. Institutional racism is defined as structures that exist to assign power, privilege,

and prestige to one racial group at the expense of another. Racism is discussed first because it has an enormous detrimental impact on the lives of blacks and is related to many of the other potential barriers. Most blacks feel that racism is pervasive, destructive, and affects virtually every aspect of their lives. Because of racism, African Americans living in the U.S. are bound together by a common experience that is different from that of white Americans.

Over the past 25 yr, members of the civil rights movement have worked to diminish and eradicate institutional and individual racism in the U.S. Progress has been made, but racism still exists. The limited progress made in reducing institutional racism has in some ways made life more difficult for individual blacks. Today, they must confront the erroneous belief held by many white Americans that because equality is thought to be a given, the failure of many blacks to succeed is because of their own inferiority, despite the best efforts of institutions and individuals to help them (3). This belief dismisses the reality of racism and its effect on the quality of life for black people. Any organization or program that seeks to overcome or reduce the barriers to improved health care and health for blacks with diabetes must be sensitive to the impact of racism on the population it seeks to serve.

Lack of knowledge. Most daily diabetes care is in the hands of the patient. Yet, the gap between essential information and patients' actual knowledge is large and may be larger for blacks with diabetes than for whites (4). This discrepancy can be attributed in part to the lack of culturally sensitive patient education programs and materials for blacks. Traditionally, education programs have been developed by white professionals for white patients. The same diabetes education program presented by the same health professional may be perceived quite differently by black and nonwhite people (5). Many of the programs and materials created specifically for African Americans have been developed by layering ethnic applications onto preexisting programs. The failure of many white health-care professionals to understand the culture of their black patients may also contribute to this discrepancy.

Health behavior is strongly influenced by cultural patterns. When health professionals and patients are from different ethnic and cultural backgrounds, they may have different beliefs and expectations about health behaviors. Conflict and educational and communication failures may result from these differences. For example, most white health-care professionals do not understand or appreciate differences in the use of the English language by many blacks. Some words are pronounced differently while others have a completely different meaning for blacks. Also, there can be subtle differences in the use of body language between blacks and whites. Black people tend to move in close while talking and look away while listening, which can lead to awkwardness in communication between blacks and whites and can decrease the potential for learning (6). Also, the

black culture has an active folk medicine system comprised of European folklore, classic medicine, and current medicine. Folk remedies may be tried first or in conjunction with orthodox treatment (6). Health professionals may not recognize some of the patient's self-care activities because they do not fit with the traditional medical model, yet they may be an important part of the patient's folk model of care (7).

Incorrect beliefs about diabetes. Often there is a strong "sense of the present" within the African-American community. Orientation toward the future, the advantages of planning, and the necessity of preventive health measures are not consistent within this cultural pattern (6). This problem is compounded by the fact that non-insulin-dependent diabetes mellitus is often a silent disease until complications appear. Therefore, it may be difficult to convince some black patients to care for their diabetes today to prevent future complications.

Health beliefs are also affected by how people perceive their ability to control their lives or fates. Members of minority groups, particularly older people, have been found to exhibit characteristics of an external locus of control or a fatalistic helpless attitude (8–10). Peoples' belief that there is little that they can do to influence their health can have an impact on their decisions to seek treatment or to adhere to care regimens. In one study of black low-income clinic patients, 69% reported having family members with diabetes. However, few reported that these family members took care of themselves. Most recalled relatives who did not follow their self-care programs, had complications, and eventually died of diabetes or related factors (4).

Lack of access to care. About 12% of the diabetic population <65 yr of age lacked medical insurance in 1977. Those with diabetes who were uninsured tended to be blacks, Hispanics, poorer, and younger than the rest of the diabetic population. Those diabetic patients who were female, black, or Hispanic and in reported poor health were more likely to be covered only by Medicaid than the rest of the diabetic population (10). Being poor and in poor health is a form of double jeopardy that affects many unemployed, underemployed, and black people lacking medical insurance who may use the health-care system only when faced with a crisis. One study indicated that physicians with predominantly black or Hispanic patient populations were significantly less likely to recommend preventive practices and screening tests compared with physicians with predominantly white patient populations (11).

Cultural values and poverty. Exploring the values and attitudes of the poor and of blacks is controversial because it is reminiscent of previous debates concerning the "culture of poverty" (12,13). Implicit in the culture of poverty argument is the notion that the problems of low-income minorities are created by minorities themselves. It is argued that these deficiencies are the results of deep-seated cultural values and could not be easily modified. It is unclear whether the impact of poverty on diabetes care is the same for people of all races or

whether there are race-specific barriers that affect black people regardless of their socioeconomic standing. Although it is known that many blacks are poor, it is a mistake to equate blackness with poverty.

A central question is the relationship among knowledge, attitudes, beliefs, and socioeconomic status and use of services within the black population. Addressing health problems in the black community requires explicit recognition of the fact that the black population is probably quite diverse in its behavioral responses to diabetes. There may be forces, e.g., such as racial discrimination or black-white differences in value preferences and health attitudes, that limit access to care for blacks regardless of their socioeconomic status. If health-care utilization among blacks and whites in the same socioeconomic groups is similar, this would suggest that financial problems are most important. However, if studies show that there are differences in utilization between blacks and whites when financial factors have been accounted for, this would suggest that interventions are needed to influence the help-seeking behavior of blacks.

PRINCIPLES THAT SHOULD GOVERN DIABETES CARE AND RESEARCH PROGRAMS DIRECTED AT BLACKS

Involve target audience. Blacks should be involved in each stage of the planning and implementation of health care and education programs intended to be used primarily by black people. African Americans in the target community should have input into programs designed to overcome the barriers to the translation of scientific knowledge if such programs are to be relevant and credible. Individuals and organizations in the community that are seen as leaders and sources of credible information should be identified by organizations planning to develop community-based programs. The concept of a community leader in black communities should be viewed in the widest possible sense. It should include people that are traditionally thought of as community leaders such as teachers, preachers, nurses, social workers, and leaders of civic organizations. Members of organizations of minority business people who possess marketing and communication skills who are adept at the use of technology and in the transfer of knowledge and who have access to equipment and other resources should also be included. Black business and professional people who are seeking a meaningful social mission to return something to their community can be a valuable resource.

The black church has been identified as a means of promoting health issues and intervention programs. One study described the implementation and evaluation of a colorectal cancer prevention and screening program in community black churches (14). The involvement of black church leaders was an important component in attracting community members and establishing rapport and credibility for the program with the community

members. Black opinion leaders will lend credibility and visibility to health education efforts. To the extent that they are indigenous to the community, they will have access to information about other community members and should be able to help health-care professionals take a culturally sensitive approach to the implementation and diffusion of essential diabetes care information.

Provide a service. Research institutions should avoid studying minority patient populations without providing an appropriate and adequate service to the same community. Diabetes intervention programs developed for African-American communities must offer and be seen to offer service to blacks with diabetes as opposed to merely "studying" them. It is unrealistic to expect any group of people to participate actively in a program whose only goal is to generate new knowledge for the sponsoring institution. Science must be combined with service. The value of providing a service has benefits for both the providers and the community. The service component provides the sponsoring institution with hands-on learning regarding the care of minority populations.

Empower people. Programs directed at improving the quality of life may focus on helping individuals change their behaviors and/or on influencing institutions to change their practices and policies toward a particular group. Although it is beyond the scope of this article to argue the merits of either approach in detail, both approaches may involve empowerment. Empowerment can be defined as the process of increasing the personal, interpersonal, and political control of individuals so they can take action to improve their life situations. Thus, empowerment operates at multiple levels. Personal empowerment is present when people in problematic situations enhance and use their personal abilities to change their own behavior and to influence the behavior of individuals and organizations that affect their quality of life. Equitable and accessible diabetes care and culturally sensitive diabetes education can foster empowerment by enabling blacks with diabetes to take care of their health through the recognition and promotion of individual strengths and personal goals. Political and institutional empowerment is also necessary to improve the health and health care of black people. Governmental organizations and health-care institutions that serve black people must find ways to include them at all levels, from the formation of policy to the delivery of services.

The issue of empowerment poses a dilemma. On one hand, the very act of "helping" a minority group may reinforce the disparity between the power of the "helper" and that of the minority clients. On the other hand, adopting the position that "we are ready to provide a service whenever you can demonstrate the ability to seek and utilize that service" could serve as a justification for abandoning a major segment of our population who have not had access to the resources necessary to change the quality of their lives. This di-

lemma will have to be addressed on a case-by-case basis through negotiation between health-care and research institutions and black community leaders and organizations.

Respect cultural diversity among blacks. Black people, although bound together by the experiences and effects of racism are still culturally diverse. Factors such as history, region, and community all play a role in this diversity. Educational and social programs must embrace and incorporate the cultural diversity of black people. They must seek to optimize the quality of life for African Americans while respecting their cultural beliefs, traditions, and life-styles. Appropriate models for influencing health behavior that detail how to plan diffusion strategies to disseminate multiple risk factor information to people of color at the community level are available (15). These models and others yet to be developed can lead to the development, implementation, and evaluation of more culturally sensitive health-care providers, programs, and materials. Furthermore, programs designed to serve blacks can educate mainstream health-care providers, policy makers, and institutions as to the cultural and individual diversity of blacks. At the same time, diabetes-related interventions and research studies can contribute to our understanding of the impact of racism on the socioeconomic status, health, and quality of life of the black population.

POSSIBLE RESEARCH AND INTERVENTION AREAS

The deliberations of the task force identified some broad areas that would be appropriate for diabetes-related research and intervention programs.

The first potential program area is the development and evaluation of culturally appropriate and linguistically sensitive education materials for blacks with diabetes. Educational programs and materials for blacks with diabetes should reflect the particular regional and socioeconomic culture of the people they are intended to serve. The development of appropriate educational materials and programs requires collaboration between diabetes experts and representatives of the population for whom the programs and materials are intended.

A lasting improvement in the health care and health of black people must include a commitment to educate more black health professionals. The mainstream medical and other schools for preparing health-care professionals in the U.S. should make and maintain a commitment to the training of more black and other minority health-care professionals. Because the emphasis in health care in the U.S. continues to shift toward health promotion, disease prevention, and the treatment of chronic disease, the ability of health-care professionals and patients to communicate and understand each other will become increasingly important.

There is also a need for continuing education programs for the practicing health-care professionals who provide care to black and other minority patients. Insti-

tutions offering diabetes continuing education programs should consider tuition waivers and scholarships for health-care professionals treating minority and underserved populations. Often these health-care professionals work at health-care facilities with little or no funds available for continuing education, e.g., clinics for migrant farm workers or inner-city poor people.

There is a need for ongoing epidemiological and intervention studies in black communities. Such studies must strike a balance between describing the epidemiology and health-related behavior of blacks with diabetes and providing a genuine service to the communities in which the studies are conducted. The best way to ensure that both the scientific and service goals of such projects are met is to involve representatives from the black community in the earliest planning stages for such projects. Institutions and programs that seek to improve diabetes care in African-American communities must be and be perceived as genuine partnerships between those communities and the institutions sponsoring the programs. As stated by Gavin (16), "Greater sensitivity and awareness among providers must be a high priority for all of us. If we are ineffective in sensitizing communities and educating them about the seriousness of diabetes and if community and cultural barriers to such efforts are not appropriately identified and accommodated (and this will take some focused well-funded research), then we will ultimately fail in attempts to curb the impact of this most debilitating disease" (16).

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