

## Racial-Ethnic Disparities in Stroke Care: The American Experience

### A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

*The American Academy of Neurology affirms the value of this statement as an educational tool for neurologists.*

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**Purpose**—Our goal is to describe the effect of race and ethnicity on stroke epidemiology, personal beliefs, access to care, response to treatment, and participation in clinical research. In addition, we seek to determine the state of knowledge on the main factors that may explain disparities in stroke care, with the goal of identifying gaps in knowledge to guide future research. The intended audience includes physicians, nurses, other healthcare professionals, and policy makers.

**Methods**—Members of the writing group were appointed by the American Heart Association Stroke Council Scientific Statement Oversight Committee and represent different areas of expertise in relation to racial-ethnic disparities in stroke care. The writing group reviewed the relevant literature, with an emphasis on reports published since 1972. The statement was approved by the writing group; the statement underwent peer review, then was approved by the American Heart Association Science Advisory and Coordinating Committee.

**Results**—There are limitations in the definitions of racial and ethnic categories currently in use. For the purpose of this statement, we used the racial categories defined by the US federal government: white, black or African American, Asian, American Indian/Alaskan Native, and Native Hawaiian/other Pacific Islander. There are 2 ethnic categories: people of Hispanic/Latino origin or not of Hispanic/Latino origin. There are differences in the distribution of the burden of risk factors, stroke incidence and prevalence, and stroke mortality among different racial and ethnic groups. In addition, there are disparities in stroke care between minority groups compared with whites. These disparities include lack of awareness of stroke symptoms and signs and lack of knowledge about the need for urgent treatment and the causal role of risk factors. There are also differences in attitudes, beliefs, and compliance among minorities compared with whites. Differences in socioeconomic status and insurance coverage, mistrust of the healthcare system, the relatively limited

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The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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number of providers who are members of minority groups, and system limitations may contribute to disparities in access to or quality of care, which in turn might result in different rates of stroke morbidity and mortality. Cultural and language barriers probably also contribute to some of these disparities.

Minorities use emergency medical services systems less, are often delayed in arriving at the emergency department, have longer waiting times in the emergency department, and are less likely to receive thrombolysis for acute ischemic stroke. Although unmeasured factors may play a role in these delays, the presence of bias in the delivery of care cannot be excluded. Minorities have equal access to rehabilitation services, although they experience longer stays and have poorer functional status than whites. Minorities are inadequately treated with both primary and secondary stroke prevention strategies compared with whites. Sparse data exist on racial-ethnic disparities in access to surgical care after intracerebral hemorrhage and subarachnoid hemorrhage.

Participation of minorities in clinical research is limited. Barriers to participation in clinical research include beliefs, lack of trust, and limited awareness. Race is a contentious topic in biomedical research because race is not proven to be a surrogate for genetic constitution.

**Conclusions**—There are limitations in the current definitions of race and ethnicity. Nevertheless, racial and ethnic disparities in stroke exist and include differences in the biological determinants of disease and disparities throughout the continuum of care, including access to and quality of care. Access to and participation in research is also limited among minority groups. Acknowledging the presence of disparities and understanding the factors that contribute to them are necessary first steps. More research is required to understand these differences and find solutions. (*Stroke*. 2011;42:2091-2116.)

**Key Words:** AHA Scientific Statements ■ race ■ ethnicity ■ access to care ■ epidemiology ■ stroke

The present document is a comprehensive statement on racial and ethnic disparities in stroke care in the United States. This statement was developed by a panel of biostatisticians, epidemiologists, nurses, cardiologists, and vascular neurologists encompassing a broad range of expertise.

The intended audience for this statement includes physicians, nurses, other healthcare professionals, and policy makers. The goal of this statement is to provide an overview of the role of race and ethnicity in stroke care; their impact on the different rates of incidence, prevalence, and morbidity and mortality of stroke among minorities compared with whites; and their effect on personal beliefs, access to care, response to treatment, and participation in clinical research. In addition, we seek to determine gaps in knowledge about disparities in stroke care, propose solutions, and guide future research.

This statement is divided into sections selected by the chair of the writing group. Each section author searched the literature on the topic assigned and considered for inclusion papers based on observational (analytic or descriptive) or experimental studies that addressed racial-ethnic disparities in stroke. Because of the wide scope of the topic, the members of the writing group were responsible for primary reviews of individual sections, and the complete statement was assembled by the writing group chair. The statement underwent peer review and was approved by the American Heart Association Science Advisory and Coordinating Committee.

## Background

Racial and ethnic minorities now constitute 28% of the population in the United States, but that number is expected to reach nearly 40% by 2030. The percentage of non-Hispanic whites is now ≈67%. Among minority groups, it is estimated that Hispanic Americans, the fastest-growing group in the United States, now represent 14% to 15% of the US population; blacks or African Americans account for 12%; and Asian Americans and American Indian and Alaska Natives

represent ≈7%. The US Census Bureau estimates that the number of Asian Americans will probably reach 10% of the US population by 2050.<sup>1</sup> With the percentage of racial and ethnic minorities in the United States almost doubling by the year 2050, there is an increasing need to reduce racial-ethnic disparities in health care.<sup>1</sup>

With an ever-changing and diverse healthcare environment, healthcare providers must not only become knowledgeable in the rapidly growing field of pharmacogenomics and the reported racial differences of genetic polymorphisms,<sup>3</sup> but they must also possess knowledge about the effects of race and ethnicity on stroke epidemiology and access to care to help create cultural awareness and improve access to and quality of care for minorities. In fact, under the competency of professionalism outlined by the Accreditation Council for Graduate Medical Education, residents are expected to “demonstrate sensitivity and responsiveness to patients’ culture, age, gender and disabilities.”

Racial and ethnic disparities in health care exist and remain a growing concern.<sup>4</sup> A 2006 study found striking disparities in life spans between different racial-ethnic groups in the United States. The authors characterized their provocative observations as the “Eight Americas,” where life expectancy ranged from 86.7 years for Asian American women to 61.7 years for black or African American men.<sup>5</sup> They found that Asian Americans had an average life expectancy of 84.9 years; whites living in the rural northern plains/Dakotas, 79 years; mostly white “middle Americans,” 77.9 years; low-income whites in Appalachia and the Mississippi Valley, 75 years; black or African American “middle Americans,” 72.9 years; American Indians in the West, 72.7 years; blacks or African Americans in the South, 71.2 years; and high-risk urban-dwelling blacks or African Americans, 71.1 years.

Cardiovascular disease, including stroke, was the largest contributor to these disparities in life expectancy. More importantly, not only is the burden of stroke higher in blacks

or African Americans and Hispanics than in whites,<sup>6</sup> but a population-based study estimating the temporal trends in stroke incidence among different racial groups conducted in the greater Cincinnati (OH)/northern Kentucky area concluded that the incidence of first-ever ischemic strokes declined steadily over the study period (ascertainments were made in 1993–1994, 1999, 2005, and 2010) in whites,<sup>7</sup> even though the incidence remained unchanged among blacks or African Americans, which suggests a worsening of the racial disparity gap in stroke incidence. Although the study may not be generalizable to other regions of the country, other population-based studies have reported similar findings.<sup>8</sup> Therefore, further research and thoughtful debate are needed to understand why minority Americans have worse health outcomes. Some of the important issues to address include, but are not limited to, disparities in morbidity and mortality due to stroke; disparities in environmental, biological, socioeconomic, sociocultural, and dietary determinants of disease; major barriers in access to care; major differences in quality of care; the role of language and culture as barriers to compliance and access; and the potential presence of bias among healthcare providers. Determining the underlying reasons for disparities in stroke care could help find solutions to resolve these disparities.

### Definitions

The concepts of race and ethnicity are complex and difficult to define. The definition of race originally denoted physical and biological characteristics; however, this definition has been refined to incorporate social characteristics and their interactions.<sup>9,10</sup> Race encompasses a number of related factors, such as biological and geographic origins, ancestry, culture, economics, politics, and racism.<sup>11</sup> Indeed, racial categories may determine social, economic, and political disadvantages that may impact health status and well-being.

The concept of ethnicity has been proposed as a replacement category for race, because ethnic groups share common ancestry, history, or culture but highlight cultural and social characteristics rather than biological ones.<sup>11</sup> Ethnicity may also imply a common language or religious tradition.<sup>12</sup> Of note, assignment to a racial or ethnic category in census data or clinical studies is usually self-reported information. The number of factors considered in the definition of race is certainly responsible for the limitations in the current racial and ethnic categories found in the literature.

The racial and ethnic categories currently in use relate to those defined by the federal government.<sup>5,13,14</sup> At present, the race categories recognized by the government include white, a person having origins in any of the original peoples of Europe, North Africa, or the Middle East; black or African American, a person having origins in any of the black racial groups of Africa; American Indian or Alaskan Native, a person having origins in any of the original peoples of North and South America, including Central America, who maintains cultural identification through tribal affiliations or community attachment; Asian, a person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian Subcontinent, including Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, Philippine Islands, Thailand,

and Vietnam; and Native Hawaiian or other Pacific Islander, a person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific islands. In addition, 2 ethnic groups are defined: Hispanic/Latino origin, a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin, regardless of race; and not of Hispanic/Latino origin.<sup>14</sup> Despite the limitations associated with the use of these categories, they provide the framework to begin our discussion.

The federally defined categories stand in contrast to the definitions used in stroke studies. White race is usually defined in stroke studies by self-reported data using the federal racial and ethnic classifications.<sup>15</sup> In these classifications, whites are defined as people having origins in Europe, North Africa, or the Middle East.<sup>15</sup> The Northern Manhattan Stroke Study (NOMAS), a prospective study comparing the incidence of stroke among whites, blacks or African Americans, and Hispanics, used self-report methods and defined white race as being white without any Hispanic origin.<sup>16</sup>

Black or African American refers to a person having origins in a black racial group or Africa.<sup>15,17</sup> Yet some investigators have chosen to categorize these patients as individuals of “African descent”<sup>18</sup> or “black.”<sup>19</sup> More recently, the REasons for Geographic and Racial Differences in Stroke (REGARDS) investigators defined race by self-report methodology that requested participants to select their race from a list (white, black or African American, Asian, etc).<sup>20</sup>

The racial-ethnic groups American Indian and Alaskan Native are usually combined; however, these 2 groups are distinct in terms of geography, culture, and beliefs.<sup>21</sup> Hundreds of American Indian tribes are spread throughout the United States, many of which are not federally recognized.<sup>21</sup> Alaskan Natives are a diverse group with differences in diet, geographic location, lifestyle, and socioeconomic status (SES).<sup>22</sup> The stroke literature has not thoroughly examined stroke in American Indians and Alaskan Natives. In addition, racial and ethnic misclassification of American Indian and Alaskan Native groups has significantly limited assessment of national rates of cardiovascular disease mortality.<sup>23,24</sup> Few studies have specifically examined groups of American Indians or Alaskan Natives. The Strong Heart Study examined a population of American Indians, but only those in 13 specific tribes in southwestern Oklahoma, central Arizona, and North and South Dakota.<sup>25</sup> The Genetics of Coronary Artery Disease in Alaska Natives (GOCADAN) Study looked at Alaskan Natives, but only those from the Norton Sound region of Alaska.<sup>26</sup> The Alaska Native Stroke Registry, begun in 1995, is a surveillance system for patients within the Alaska Native health system.<sup>27</sup>

There is a paucity of data about Asians, Hawaiians, or Pacific Islanders in the stroke literature. Two studies focused specifically on Chinese immigrants in New York City,<sup>28,29</sup> whereas a few studies used data from the Nationwide Inpatient Sample (NIS) of the Healthcare Cost and Utilization Project to examine stroke in Asians/Pacific Islanders.<sup>30,31</sup> Several studies have used data from the Honolulu Heart Program to examine stroke in Japanese American men.<sup>32–37</sup>

There is no universally applied definition of Hispanic or Latino ethnicity in clinical or epidemiological research studies. Operationally, most studies use the terms Hispanic or

Latino interchangeably and refer to populations who self-identify in this manner. Most published reports involving Hispanic or Latino populations use the former term exclusively. The Hispanic Community Health Study/Study of Latinos, a National Institutes of Health–funded cohort study of cardiopulmonary disease begun in 2007, is recruiting 16 000 people who self-identify as Hispanic or Latino.<sup>38</sup> In this study, Hispanic or Latino ethnicity is defined as people or descendants of people from Cuba, Mexico, Puerto Rico, and other Spanish-speaking countries in the Caribbean (Dominican Republic), Central America (Costa Rica, Guatemala, Honduras, El Salvador, Nicaragua, or Panama), or South America (Argentina, Bolivia, Chile, Colombia, Ecuador, Paraguay, Peru, Uruguay, or Venezuela). People from Spain are not consistently categorized as Hispanic. Similarly, people from Portuguese-speaking countries, such as Brazil, have not been consistently categorized as Hispanic either.

Racial and ethnic health disparities occur around the world, but the conglomerate of different races and ethnic groups and the disparities in health care associated with them has been an especially important issue in the United States. In this statement, we focus on racial-ethnic disparities in the United States. Trimble and Morgenstern<sup>39</sup> divided disparity in terms of avoidable and unavoidable inequalities that lead to stroke. This approach provides a framework to establish priorities in service and research areas.<sup>39</sup> There are many possible explanations for why racial-ethnic disparities exist, including cultural variations in perceptions of health and the healthcare system, environmental exposures, genetic factors,<sup>40</sup> SES,<sup>41</sup> disadvantage in early childhood,<sup>42</sup> fear, mistrust, prejudice,<sup>39</sup> and educational level.<sup>43</sup> The goal of Healthy People 2010 was to eliminate these disparities.<sup>44</sup> Although it might not be possible to change unavoidable inequalities such as certain differences in biological determinants of disease (ie, age, sex, and genetics), we must strive to close the gap with regard to avoidable disparities such as access to care, mistrust, and bias, among others. To achieve that goal, we first need to establish and acknowledge the existence of disparities and to understand their determinants as a prerequisite to finding solutions.

## Summary

There are limitations to the operational definitions of racial and ethnic categories in use. For the purpose of this statement, we will use the categories defined by the federal government. Those racial categories are white, black or African American, Asian, American Indian/Alaskan Native, and Native Hawaiian/other Pacific Islander. Hispanic/Latino is considered an ethnic category.

## Epidemiology

### Differential Burden of Risk Factors

Although the reasons for racial and ethnic differences in stroke incidence and mortality are not entirely clear, the role of the distribution of risk factor burden across racial and ethnic groups must be considered an important contributor. Prevention of mortality, morbidity, and disability due to stroke requires a greater emphasis on the identification of people at high risk for stroke, especially vulnerable groups, and efforts to shift the levels of risk factors in the entire population.<sup>45</sup>

Hypertension is a well-established risk factor for stroke across all racial-ethnic groups. In NOMAS, hypertension was an independent risk factor for stroke in whites, blacks or African Americans, and Hispanics, but was more prevalent and associated with more strokes among blacks or African Americans.<sup>46</sup> Similarly, compared with whites, blacks or African Americans in national and regional survey samples have been shown to have a higher prevalence of other risk factors related to stroke, including diabetes mellitus, hypercholesterolemia, peripheral vascular disease, elevated C-reactive protein, left ventricular hypertrophy, heavy alcohol use, and current cigarette smoking and physical inactivity.<sup>20,47,48</sup> The greater risk factor burden in blacks or African Americans than in whites accounts for a significant proportion of the higher stroke incidence<sup>49,50</sup> and mortality<sup>51</sup> observed among blacks or African Americans.

Less is known about the stroke risk factor burden among Hispanics, American Indians/Alaskan Natives, and Asians. The etiologic fraction (ie, proportion of strokes due to the risk factor) of hypertension has been reported to be greater among Caribbean Hispanics than among whites. Although there are limitations to this estimate, it provides a sense of the impact of a risk factor.<sup>46</sup> In the San Antonio Heart Study, triglycerides, body mass index, and systolic and diastolic blood pressure were higher and high-density lipoprotein cholesterol level was lower in Hispanics (men and women) than in non-Hispanic whites.<sup>52</sup> A recent study found metabolic syndrome to be more common among Hispanics than among whites or blacks or African Americans.<sup>53</sup> Even after adjustment for sociodemographic variables, metabolic syndrome was a better predictor of stroke risk among Hispanics than among whites. In NOMAS, hypertension, diabetes mellitus, hypercholesterolemia, heavy alcohol use, and current cigarette smoking were more prevalent in Hispanics than in whites.<sup>45</sup> Although the San Antonio Heart Study included Hispanics mostly of Mexican origin and NOMAS included Hispanics of Caribbean ancestry, it is remarkable that the results are similar. Data from the Behavior Risk Factor Surveillance System (BRFSS) showed that the prevalence of  $\geq 2$  self-reported risk factors (among hypertension, high cholesterol, diabetes mellitus, current smoking, physical inactivity, and obesity) was highest among blacks or African Americans (48.7%) and American Indian/Alaskan Natives (46.7%) and lowest among Asians (25.9%).<sup>47</sup> In addition, data from the National Health and Nutrition Examination Survey (NHANES 1988 to 2006) showed that the prevalence of diabetes mellitus was more than twice as great among blacks or African Americans and Mexican Americans than among whites<sup>54</sup> (Table).

### Summary

The burden of risk factors is different among racial and ethnic groups. Blacks or African Americans have a higher prevalence of hypertension, diabetes mellitus, and left ventricular hypertrophy than whites. Hispanics have a higher prevalence of metabolic syndrome and diabetes mellitus than whites and blacks or African Americans. The prevalence of at least 2 risk factors for stroke is also higher in American Indians/Alaskan Natives than in whites.



**Table. Racial-Ethnic Disparities in Stroke Risk Factors**

Author, Year	Data Source, N	Topic Area	Results
Sacco et al, 2001 <sup>46</sup>	Northern Manhattan Stroke Study (n=688 cases and n=1156 controls)	Racial-ethnic disparities in impact of stroke risk factors	Hypertension: independent risk factor for whites, blacks or African Americans, and Hispanics, but greater prevalence and etiologic fraction among blacks or African Americans and Hispanics AF: greater prevalence in whites Coronary artery disease: most important for whites and least important for blacks or African Americans Prevalence of physical inactivity greater in Caribbean Hispanics
Bravata et al, 2005 <sup>48</sup>	NHANES III N=11 163 participants	Impact of SES in racial disparities in stroke risk factors	Blacks or African Americans had a higher prevalence of 5 risk factors related to stroke (hypertension, DM, claudication, elevated CRP, inactivity) Whites had a higher prevalence of 3 risk factors related to stroke (older age, MI, decreased HDL) Ethnicity was associated with increased stroke risk (OR 1.32, 95% CI 1.04–1.67) after adjustment for 8 risk factors but not after adjustment for income Income was independently associated with stroke (OR 0.89, 95% CI 0.82–0.95)
Mitchell et al, 1990 <sup>52</sup>	San Antonio Heart Study (n=3301 Mexican Americans and n=1877 whites)	Risk factors for CVD mortality in Hispanics and non-Hispanic whites	Triglycerides, BP, BMI, HDL were all lower in Mexican Americans Mexican Americans smoked fewer cigarettes per day on average
Heuschmann et al, 2008 <sup>55</sup>	South London Stroke Register (n=2874)	Ethnic disparities in stroke incidence and vascular risk factors	Stroke incidence declined over 10 years for white men, white women, and black or African American women, but not for black or African American men Hypertension, AF, and smoking decreased over time in whites, but there were no changes in blacks or African Americans Total stroke incidence was higher in blacks or African Americans (RR 1.27, 95% CI 1.10–1.46)
Hajat et al, 2001 <sup>56</sup>	South London Stroke Register (n=995 whites, n=203 blacks or African Americans, n=52 other)	Ethnic differences in stroke risk factors and subtypes	Age and previous CVD were associated with infarct rather than hemorrhage Blacks or African Americans had less AF and less excessive alcohol intake and were less likely to have ever smoked Blacks or African Americans are more likely to have hypertension and DM
CDC MMWR 2005 <sup>47</sup>	2003 BRFSS survey (n=103 191 total, n=79 891 whites, n=10 016 blacks or African Americans, n=6858 Hispanic, n=1070 Asian, n=1914 American Indian/Alaskan Native, n=3440 other)	Racial-ethnic disparities in stroke risk factors	Six risk factors were examined: high BP, high cholesterol, diabetes, current smoking, physical inactivity, and obesity Prevalence of having $\geq 2$ risk factors was highest among blacks or African Americans (48.7%) and American Indian/Alaskan Natives (46.7%) and lowest among Asians (25.9%) Prevalence of having $\geq 2$ risk factors differed by education status (25.9% among college graduates vs 52.5% among those with less than a high school diploma) Prevalence of having $\geq 2$ risk factors differed by income (28.8% for $> \$50 000/y$ vs 52.2% for $< \$10 000/y$ )
Thomas et al, 2005 <sup>51</sup>	N=300 647 whites and n=20 223 blacks or African Americans in MRFIT	Racial-ethnic disparities in CVD risk factors	More than 4 times as many blacks or African Americans as whites had elevated risk factor levels and low income Adjustment for age, income, and risk factor differences explained most of the 35% greater mortality in blacks or African Americans At all risk factor levels (low, medium, high) blacks or African Americans were at increased CVD risk compared with whites (HR 1.37, 95% CI 1.20–1.57 for stroke)
Cushman et al, 2008 <sup>20</sup>	REGARDS, n=23 940	Stroke risk by region and race	Higher stroke probability in Stroke Belt (10.7) followed by Stroke Buckle (10.4) and elsewhere (10.1) Blacks or African Americans had higher scores for Framingham Stroke Risk Score components of hypertension, SBP, DM, smoking, and LVH Blacks or African Americans had less history of heart disease, less AF
Giles et al, 1995 <sup>49</sup>	NHANES I, n=8203 whites and n=1362 blacks or African Americans	Determinants of black or African American–white risk differences for cerebral infarct	Blacks or African Americans were at increased risk for infarct RR decreased substantially for older blacks or African Americans but only slightly for younger blacks or African Americans after adjustment for age, sex, education, DM, SBP, hypertension therapy, hemoglobin, and heart disease
Howard et al, 2006 <sup>57</sup>	REGARDS, n=11 701 participants	Racial differences in hypertension	Blacks or African Americans were more aware of their hypertension than whites Among those treated, hypertension was less likely to be controlled in blacks or African Americans than in whites Trend for better treatment and control of hypertension in Stroke Belt
Ayala et al, 2001 <sup>58</sup>	National Vital Statistics records: n=507 256 ischemic, n=97 709 ICH, n=27 334 SAH	Racial differences in stroke-type mortality	Mortality rates for all stroke types higher among blacks or African Americans than whites All minority populations had higher mortality rates from SAH than whites
Albala et al, 2008 <sup>53</sup>	Northern Manhattan Stroke Study (n=3298 stroke-free residents)	Metabolic syndrome and stroke risk across racial groups	Metabolic syndrome was more common among Hispanics (50%) than whites (39%) or blacks or African Americans (37%) After adjustment for sociodemographics and risk factors, metabolic syndrome was associated with increased stroke risk (HR 1.5, 95% CI 1.1–2.2) Metabolic syndrome had a greater effect on stroke risk in women and Hispanics
Deleu et al, 2006 <sup>59</sup>	N=302 Arab and South Asian stroke patients admitted to Hamad Medical Corp in Qatar	Ethnic variations in risk factor profiles	Stroke recurrence and carotid artery lesions were more common in Arabs than among South Asians Hypertension and DM were much more common in both Arabs and South Asians than in Western populations
Hayes et al, 2006 <sup>60</sup>	N=153 466 women in 2003 BRFSS	Racial differences in multiple risk factors for CHD and stroke	Multiple risk factors ( $\geq 2$ risk factors), including diabetes, current smoking, high BP, high cholesterol, obesity, or physical inactivity Prevalence of multiple risk factors lowest in whites and Asians After adjustment for age and SES variables, OR of having multiple risk factors were greater in blacks or African Americans (OR 1.53, 95% CI 1.42–1.64) and American Indians (OR 1.36, 95% CI 1.11–1.67) and lower in Hispanics (OR 0.83, 95% CI 0.76–0.91) than in whites

(Continued)

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Author, Year	Data Source, N	Topic Area	Results
Hozawa et al, 2007 <sup>61</sup>	N=14 162 adults in ARIC	Attributable risk of CVD incidence among blacks or African Americans and whites	Proportion of subjects with optimal risk factor levels was lower in blacks or African Americans than in whites Proportion of subjects with at least 1 elevated risk factor was higher in blacks or African Americans (80%) than in whites (60%) Proportion of CVD events explained by elevated risk factors was high in blacks or African Americans (90%) compared with whites (65%)
McGruder et al, 2004 <sup>62</sup>	N=96 501 persons from NHIS	Racial and ethnic disparities in CVD risk factors in stroke survivors	Blacks or African Americans were 1.65 times as likely and Hispanics 0.73 times as likely as whites to report hypertension Hispanics and blacks or African Americans were more likely to report DM but less likely to report CHD than whites Overweight and physical inactivity were both higher in blacks or African Americans and Hispanics than in whites Stroke prevalence was highest in blacks or African Americans (2.8%), followed by whites (2.2%) and Hispanics (1.3%)
Mokdad et al, 2003 <sup>63</sup>	N=195 005 adults in BRFSS	Obesity and related risk factors across ethnic groups	Blacks or African Americans had higher rates of obesity and diabetes than Hispanics; Hispanics had higher rates than whites Decreasing education was associated with increasing prevalence of both obesity and DM
Winkleby et al, 1998 <sup>64</sup>	NHANES III: n=1752 blacks or African Americans, n=1481 Mexican Americans, n=2023 whites	Ethnic/SES differences in CVD risk factors	Most CVD risk factors were higher among minority women than whites After adjustment for education, differences in BP, BMI, physical inactivity, and DM remained for black or African American and Mexican-American women Women of low SES from all ethnic groups had a higher prevalence of smoking and physical inactivity

AF indicates atrial fibrillation; ARIC, Atherosclerosis Risk in Communities; BMI, body mass index; BP, blood pressure; BRFSS, Behavioral Risk Factor Surveillance System; CDC, Centers for Disease Control and Prevention; CHD, coronary heart disease; CI, confidence interval; CRP, C-reactive protein; CVD, cardiovascular disease; DM, diabetes mellitus; HDL, high-density lipoprotein; HR, hazard ratio; ICH, intracerebral hemorrhage; IRR, incidence rate ratio; LVH, left ventricular hypertrophy; MI, myocardial infarction; MMWR, *Morbidity and Mortality Weekly Report*; MRFIT, Multiple Risk Factor Intervention Trial; NHANES, National Health and Nutrition Examination Survey; NHIS, National Health Interview Survey; OR, odds ratio; REGARDS, REasons for Geographic And Racial Differences in Stroke; RR, relative risk; SAH, subarachnoid hemorrhage; SBP, systolic blood pressure; and SES, socioeconomic status.

## Differential Burden of Stroke Morbidity: Prevalence, Incidence, and Recurrence

### Whites

Among non-Hispanic whites, the prevalence of stroke is  $\approx 2.3\%$ .<sup>65</sup> The age-adjusted incidence of first ischemic stroke in whites was 88 per 100 000 in NOMAS.<sup>8</sup> Of those who have a first stroke, a recurrent stroke occurs within 5 years in 15% of men and 17% of women 40 to 69 years of age and in 23% of men and 27% of women  $\geq 70$  years of age.<sup>8</sup> In comparison, the incidence of ischemic stroke among whites was higher in the greater Cincinnati (OH) region at 130 per 100 000.<sup>66</sup>

### Blacks or African Americans

The overall prevalence of stroke is  $\approx 4.0\%$  among non-Hispanic blacks or African Americans,<sup>65</sup> with an age-adjusted incidence of first ischemic stroke of 191 per 100 000 in NOMAS and 194 per 100 000 in the greater Cincinnati region.<sup>8,67</sup> Blacks or African Americans tend to be more likely to report stroke symptoms,<sup>66</sup> to experience transient ischemic attacks,<sup>68</sup> and to be hospitalized for stroke,<sup>69</sup> and they have approximately twice the number of incident strokes as whites.<sup>67</sup> The disparity in stroke incidence is particularly prominent among younger adults.<sup>67</sup> For example, population-based data show that the risk ratio of first-ever stroke in blacks or African Americans compared with whites is 2.05 (95% confidence interval [CI] 1.49 to 2.69) in those  $< 34$  years of age, 4.18 (95% CI 3.96 to 4.41) in those 35 to 44 years of age, 2.02 (95% CI 1.90 to 2.15) in those 45 to 54 years of age, 1.74 (95% CI 1.65 to 1.84) in those 55 to 64 years of age, 1.66 (95% CI 1.60 to 1.72) in those 65 to 74 years of age, 1.33 (95% CI 1.28 to 1.38) in those 75 to 84 years of age, and 1.11 (95% CI 1.06 to 1.15) in those  $> 85$  years of age.<sup>67</sup>

Compared with the stroke risk of white children, black or African American children have a higher risk of stroke (relative risk [RR] 2.12), with sickle cell disease being the most important cause of ischemic stroke among black or African American children.<sup>70</sup> The increased stroke risk among black or African American children is not fully explained by the presence of sickle cell disease, but it is unclear what other factors may be at play.<sup>70</sup>

With regard to recurrent stroke, in a cohort of 299 patients admitted to a New York hospital, blacks or African Americans had an adjusted RR of recurrent stroke of 2.4 compared with whites.<sup>71</sup> In another study, among those 65 to 74 years of age, blacks or African Americans had a higher rate of readmission for stroke than whites, with an RR of 1.4.<sup>72</sup> Lower adherence to current standards of secondary stroke prevention in black or African American patients might help explain these discrepancies.<sup>73</sup>

With regard to functional outcome, a study showed that after an index stroke, black or African American stroke survivors had greater disability than white stroke survivors. However, from the data presented, it is unclear whether the disability is related to the subtype of stroke.<sup>74</sup> In contrast, in a more recent study, blacks or African Americans and Hispanics were more likely to be discharged home than whites. Although the reason is not entirely clear, it is possible that younger age in minorities with stroke or higher proportion of strokes secondary to small-vessel disease may contribute to explaining the results.<sup>74</sup>

### Hispanics

Among Hispanics (of any race), the prevalence of stroke is  $\approx 2.6\%$ .<sup>65</sup> The age-adjusted incidence of first ischemic stroke was 149 per 100 000 among primarily Caribbean Hispanics in NOMAS<sup>8</sup> in contrast to the Brain Attack Surveillance in

Corpus Christi (BASIC) Project, which showed a crude cumulative stroke incidence of 168 per 10 000 in Mexican Americans and 136 per 10 000 in non-Hispanic whites. Although incidence in these 2 studies may not be directly comparable, the BASIC Project showed a high risk ratio of stroke among Mexican Americans compared with whites; the risk ratio among Mexican Americans was similar to that among blacks or African Americans at a younger age (45 to 59 years of age: RR 2.04, 95% CI 1.55 to 2.69; 60 to 74 years of age: RR 1.58, 95% CI 1.31 to 1.91) but not at older ages ( $\geq 75$  years of age: RR 1.12, 95% CI 0.94 to 1.32).<sup>75</sup> The same group found a higher risk of recurrent stroke among Mexican Americans than among whites, with an RR of 1.57 after adjustment for demographic data, stroke risk factors, and severity of stroke.<sup>76</sup>

Also, Mexican Americans have a higher incidence of transient ischemic attack, intracerebral hemorrhage (ICH), and subarachnoid hemorrhage (SAH) than non-Hispanic whites when adjusted for age.<sup>75</sup> Conversely, compared with the stroke risk of white children, Hispanics have a lower RR of 0.76.<sup>70</sup>

#### **American Indians/Alaskan Natives**

The overall prevalence of stroke is  $\approx 6.0\%$  among American Indians/Alaskan Natives.<sup>65</sup> Data from the Strong Heart Study show that the prevalence of stroke in American Indian men 45 to 74 years of age ranges from 0.2% to 1.4%, whereas among women in the same age group, the prevalence is 0.2% to 0.7%.<sup>77</sup> Among those 65 to 74 years of age, the annual rates per 1000 population of new and recurrent strokes were 6.1 for men and 6.6 for women.<sup>77</sup>

#### **Summary**

The incidence and prevalence of stroke are higher among blacks or African Americans, Hispanics, and American Indians/Alaskan Natives than among whites. This difference is more marked at a younger age. Recurrent stroke risk is also higher among blacks or African Americans and Hispanics. The highest burden is among blacks or African Americans. In addition, blacks or African Americans have greater impairment after a stroke.

#### **Differential Burden of Stroke Mortality**

Between 1950 and 1996, the age-standardized death rate for stroke declined 70% in the general US population.<sup>78</sup> The mean age of stroke decedents is 79.6 years, and 11.9% of strokes occur in people  $< 65$  years of age.<sup>79</sup> However, racial and ethnic minorities have excess deaths from stroke and also experience greater years of potential life lost than non-Hispanic whites.<sup>79</sup> The risk ratio for stroke mortality in all racial and ethnic minorities is higher in the 35-to-64-year-old age group and decreases with aging, becoming equivalent to non-Hispanic whites after the age of 64 years in Hispanics and American Indian/Alaskan Natives and after age 85 years in blacks or African Americans.<sup>80</sup>

Although one of the goals of Healthy People 2010 was to eliminate racial disparities in stroke mortality,<sup>44</sup> little progress has been made. Stroke risk factors are more common in racial and ethnic minorities,<sup>39</sup> and poor understanding of socioeconomic factors and social networks also hinders the development of effective interventions to reduce these disparities.<sup>44</sup>

Therefore, risk factor control and removal of barriers to early and effective treatment are crucial to reduce disparities in stroke mortality.

#### **Blacks or African Americans**

Blacks or African Americans bear the highest burden of mortality attributable to stroke. A study showed that for people between 45 and 64 years of age, the age-specific stroke mortality in blacks or African Americans is approximately 3 times that of non-Hispanic whites,<sup>74</sup> whereas others found higher mortality due to ischemic stroke, ICH, and SAH in all age groups than in non-Hispanic whites<sup>58</sup>; there were 6370 excess deaths in blacks or African American compared with non-Hispanic whites in 1997.<sup>78</sup> Most of the excess burden is attributed to the higher stroke mortality occurring in relatively young (35 to 64 years of age) blacks or African Americans.<sup>80</sup> Stroke mortality is also higher among blacks or African Americans in the southeastern United States, where the incidence of stroke is higher in all racial groups.<sup>82</sup> Although the Southeast has a lower socioeconomic level than nonsoutheastern states, and SES is less favorable for blacks or African Americans, the higher mortality risk remains after adjustment for SES.<sup>83</sup>

With regard to in-hospital mortality and case fatality rates, there do not appear to be differences among different racial groups. In a recent report, in-hospital mortality was lower among black or African American patients than whites (odds ratio [OR] 0.90, 95% CI 0.85 to 0.95) in hospitals participating in the Get With The Guidelines–Stroke program between 2003 and 2008.<sup>73</sup> Population-based studies have shown comparable results, with a similar 30-day case fatality in minorities and in whites.<sup>7,67</sup> Because people with lacunar infarctions have better survival rates,<sup>84</sup> it has been argued that a greater propensity for less-severe strokes of lacunar subtype among blacks or African Americans is one reason for the lower short-term mortality rate. However, this may not be the only explanation, because blacks or African Americans have a higher incidence of all subtypes of ischemic stroke than whites, with a predominance of strokes secondary to intracranial atherosclerosis and lacunar strokes.<sup>8,85</sup> Another potential explanation is a lower rate of withdrawal of life support among black or African American patients.<sup>86</sup>

#### **Hispanics**

Hispanics have a lower or similar age-specific mortality from stroke compared with non-Hispanic whites.<sup>79,87</sup> In a population-based study in Corpus Christi, TX, between 2000 and 2002, risk ratios for all-cause mortality after stroke in Hispanics were 0.58 at 28 days and 0.79 at 36 months compared with non-Hispanic whites, despite similar stroke subtypes and severity between the 2 groups. A previous nationwide study found 242 excess deaths due to stroke in Hispanics  $< 65$  years of age in 1997.<sup>78</sup> These studies suggest that although all-cause mortality after stroke may be lower in Hispanics, younger Hispanics (25 to 45 years of age) may have disproportionately high rates of stroke mortality. Hispanics tend to have more diabetes mellitus, higher rates of obesity, lower income, lower education, and less physical activity than non-Hispanic whites. The cause of the higher survival beyond 45 years of age is unknown.<sup>88</sup>

**American Indians and Alaskan Natives**

Compared with blacks or African Americans and Hispanics, American Indians/Alaskan Natives appear to have a lower age-specific mortality due to stroke. Excess death is the difference between the number of deaths observed in a racial-ethnic group and the number of deaths that would have occurred in that group if it had the same death rate as the white population. In 1997, American Indians and Alaskan Natives had 41 excess deaths compared with non-Hispanic whites in the 35-to-64-year-old age group.<sup>78</sup> No excess deaths were observed for American Indians/Alaskan Natives >65 years of age. When Alaskan Natives are considered separately, their stroke mortality patterns are similar to some American Indian tribes. Between 1999 and 2003, there were 47 excess deaths in Alaskan Natives compared with non-Hispanic whites.<sup>89</sup> The greater mortality due to stroke in Alaskan Natives appears to be true for all stroke subtypes for ages 35 to 65 years.<sup>90</sup> The reason for and extent of this stroke mortality disparity are not clear. Problems with misclassification of race in the past have resulted in underestimation of stroke in American Indians.<sup>24,91</sup>

**Summary**

Racial-ethnic minorities have higher rates of stroke mortality in the United States. The differences are more marked among blacks or African Americans and people <64 years of age. They appear to be related at least in part to variation in distribution of biological risk factors, although the reasons for these disparities in stroke mortality in Hispanics, Alaskan Natives, and American Indians remain under investigation.

**Differences in Disease Awareness**

Knowledge of stroke warning signs among the general population is poor, with 30% to 60% of the population being unable to recognize a single stroke warning sign<sup>92</sup> and only 20% to 40% capable of recognizing 5 symptoms and indicating that they would call 9-1-1 if they thought someone was having a stroke.<sup>93,94</sup> There are racial-ethnic disparities in awareness and understanding of the nature of stroke, its signs and symptoms, the need for urgency of treatment, and risk factors. Blacks or African Americans and Hispanics from the central Harlem (NY) area were noted to achieve a substantially lower score than whites on a questionnaire about basic stroke knowledge.<sup>95</sup>

In a Centers for Disease Control and Prevention analysis of a survey from the 2005 BRFSS conducted among almost 72 000 people in 13 states and Washington, DC, the proportion of respondents who were able to identify 5 stroke warning signs and recognize the need to call 9-1-1 was 41.3% among whites compared with only 29.5% among blacks or African Americans and 26.8% among Hispanics.<sup>93</sup> These proportions were improved from a similar multistate study in 2001, when the percentages were closer to 19% for whites and 9% for minority groups.<sup>94</sup> In a study conducted in the greater Cincinnati region, blacks or African Americans were 28% less likely to be familiar with stroke warning signs than whites.<sup>96</sup> Surveys among men have found that blacks or African Americans have lower scores on tests of knowledge about stroke and heart disease.<sup>97</sup>

Hispanic women (32%) were more likely to feel uninformed than white women (22%) and expressed greater

fatalism about their ability to prevent vascular disease. In data from the BRFSS among women 45 to 54 years of age, Hispanics were more than 4 times as likely and blacks or African Americans 2.5 times as likely as whites to have low scores on scales of stroke knowledge, even after adjustment for education, income, and type of medical insurance.<sup>98</sup> In addition, poor stroke awareness among black or African American women appears to correlate with lower income and lack of insurance.<sup>99</sup> Among Hispanics, non-English speakers have less knowledge about stroke than those who also speak English.<sup>100</sup>

Even among those with a history of prior stroke, the ability to recognize stroke symptoms and the need to activate emergency medical services remains poor, with lower performance among non-Hispanic blacks or African Americans (22.3%) and Hispanic/other group members (16.7%) than among whites (28.9%).<sup>101</sup> Hispanic ethnicity remained an independent predictor of lack of awareness in multivariate models. These data indicate that all groups, but particularly minority populations, fall short of the 83% rate of stroke symptom recognition targeted by Healthy People 2010.<sup>44</sup>

Racial-ethnic disparities in awareness of stroke risk factors also exist. In a 1999 survey in Michigan, blacks or African Americans were 61% more likely than whites to be unable to report any stroke risk factors.<sup>102</sup> Among 3271 participants in the 4-city Coronary Artery Risk Development in Young Adults (CARDIA) Study, blacks or African Americans had lower scores for knowledge of cardiovascular risk factors than whites, even after adjustment for education.<sup>103</sup> Blacks or African Americans may be more aware of hypertension, which perhaps reflects educational efforts about hypertension in black or African Americans communities. Of note, in the REGARDS study, blacks or African Americans were 30% more likely to be aware of their hypertension than whites and 70% more likely to be treated when aware, although they were still less likely to have their hypertension controlled.<sup>57</sup> According to Centers for Disease Control and Prevention data for adults with hypertension, the proportion aware of having hypertension was also higher among non-Hispanic blacks or African Americans (70.3%) than non-Hispanic whites (62.9%), although it was lowest among Mexican Americans (49.8%).<sup>104</sup>

Education appears to be associated with awareness of the benefits of physical exercise. Among urban women, 42% did not meet suggested levels of physical activity, and physical inactivity was associated with lower levels of education.<sup>105</sup> Among Caribbean Hispanic women in New York, level of education was also strongly correlated with physical activity.<sup>106</sup>

The literature on awareness of stroke warning signs and risk factors has methodological limitations. In 1 study, use of closed-ended questions led to higher scores of knowledge than use of open-ended questions.<sup>107</sup> Earlier studies have not consistently shown an effect of race on stroke knowledge, possibly because of low survey response rates,<sup>107</sup> smaller numbers of patients interviewed and inclusion of patients with acute stroke,<sup>108</sup> and limitation to a single community with active public stroke education programs.<sup>109</sup>

Educational efforts improve knowledge about stroke symptoms among minority populations. Some interventions and a



randomized clinical trial using creative educational programs effectively taught school children to recognize stroke symptoms and the need for urgency of treatment.<sup>110–112</sup> In communities in which children live with grandparents, these strategies may have particularly important health implications. In Cincinnati, a group of black or African American beauticians were educated about stroke risk factors and warning symptoms and were instructed to transmit this newly acquired knowledge to their clientele. This education resulted in a significant improvement in knowledge of stroke symptoms.<sup>113</sup> These data also suggest that educational programs conducted in native languages and using culturally appropriate methods may be more successful.

### Summary

Lack of awareness of stroke symptoms and signs, the need for urgent treatment, and the role of risk factors is common among minority groups. This lack of awareness persists even after a stroke and is particularly prominent in women. Education improves such knowledge and awareness, but the long-term effects of educational campaigns are unknown. There is a need for further research to establish whether educational efforts with appropriate sociocultural interventions decrease the morbidity and mortality of stroke.

### Differences in Attitudes, Beliefs, and Compliance

Minority groups have poorer control of stroke risk factors that is attributable in part but not in full to lower compliance with treatment recommendations. These disparities exist for practically every major stroke risk factor, including hypertension,<sup>114,115</sup> diabetes mellitus,<sup>116,117</sup> smoking,<sup>118,119</sup> identified carotid plaque,<sup>120</sup> and lipid control.<sup>121</sup> Studies show that blacks or African Americans have poorer hypertension control despite having greater awareness of their hypertension and receiving adequate antihypertensive treatment.<sup>57,122–125</sup> Still, some data show that the OR of uncontrolled hypertension among blacks or African Americans decreases from 1.8 (95% CI 1.3 to 2.5) to 1.5 (95% CI 1.0 to 2.1) after adjustment for confounding factors, most notably a higher lack of adherence to taking medical prescriptions in these patients.<sup>114</sup> In another study, blacks or African Americans had an OR of adherence to hypertension medications of less than half that of whites.<sup>115</sup> However, other studies have suggested that adherence has little effect on blood pressure control in blacks or African Americans.<sup>126</sup> In addition, although whites and blacks or African Americans were equally likely to initiate oral therapy for diabetes mellitus, blacks or African Americans were nearly twice as likely to discontinue medication as their white counterparts (hazard ratio 1.8, 95% CI 1.2 to 1.7).<sup>117</sup> Interestingly, a study of low-income people showed that 85% of whites were adherent to self-monitoring of blood glucose levels compared with 79% of blacks or African Americans and only 78% of Hispanics.<sup>116</sup> Finally, among new statin users with dyslipidemia, blacks or African Americans were 36% less likely to achieve low-density lipoprotein goals over time (hazard ratio 0.64, 95% CI 0.61 to 0.68); however, this disparity persisted after adjustment for statin adherence and low-density lipoprotein testing (hazard

ratio 0.60, 95% CI 0.57 to 0.63).<sup>121</sup> Other researchers have shown that not only are there racial disparities in receiving treatment, but these disparities also exist in the aggressiveness of treatment delivered. For example, blacks or African Americans were less likely than whites to be switched between lipid-lowering agents (OR 0.68, 95% CI 0.60 to 0.78), to have treatment augmented (OR 0.53, 95% CI 0.43 to 0.66), or to be prescribed upward titration of treatment (OR 0.75, 95% CI 0.67 to 0.84).<sup>127</sup>

It has been argued that there is an association between health literacy and compliance that may arise from those with low literacy having “a complex array of problems, including difficulty with oral as well as written communication, limited problem solving abilities, lack of self empowerment, trouble following instructions and complying with treatments, and distrust of new information.”<sup>128</sup> For example, those with lower health literacy have an OR of 1.37 (95% CI 1.08 to 1.74) for low refill adherence, although this association was substantially attenuated by adjustment for covariates, including race and income.<sup>129</sup> Health literacy (and particularly numeracy skills) has an inconsistent association with anticoagulation control. A study showed that variability in international normalized ratio was 32% higher among those with the lowest literacy level than among those at the highest level ( $P=0.009$ ).<sup>130</sup> Others found no association between literacy and the proportion of time with the international normalized ratio in the therapeutic range (OR 1.0, 95% CI 0.7 to 1.4), but no genetic factors influencing response to anticoagulation were included in the analysis.<sup>131</sup>

There is a rich literature on misunderstandings of the causes and treatment of stroke and stroke risk factors. For example, a study showed that there was high attribution of the risk of hypertension to high-fat diet and stress but less awareness of the role of lack of exercise, salt intake, and obesity.<sup>132</sup> The heavy attribution of increased risk mainly to diet and at the exclusion of obesity and exercise was also encountered in another study.<sup>133</sup> In interviews with 12 groups of blacks or African Americans ( $\approx 9$  people per group) in the Dallas, TX, area, the most frequently reported perceived causes of hypertension were stress (100% of groups interviewed), heredity (83%), consumption of pork (67%), salt intake (67%), excessive use of alcohol (67%), overweight (67%), and evil spirits (42%). The most commonly perceived treatments for hypertension included garlic (92% of groups), herbs/vitamins (92%), physician-prescribed medications (83%), vinegar (75%), and diet or weight loss (67%).<sup>134</sup>

There are also insights from a qualitative research study on the pathways of beliefs and attitudes about compliance among 106 blacks or African Americans who had hypertension.<sup>135</sup> The results indicate that the factors that contribute to this lack of compliance can be classified into the domains of patient-specific barriers, medication-specific barriers, disease-specific barriers, and logistical barriers.

- Patient-specific barriers included (1) forgetfulness; (2) beliefs that medications were associated with impotence or drug dependence/addiction or are not needed when one feels well; and (3) attitudes such as denial or feelings that medications are not needed if there is no family history of

hypertension and that medications are associated with other poor outcomes such as development of kidney disease or diabetes mellitus, as well as being required to take medications for the rest of one's life.

- Medication-specific barriers included side effects such as allergies, hives, dizziness, headaches, and loss of sexual desire.
- Disease-specific barriers included the absence of symptoms, which was interpreted as implying the lack of need for treatment.
- Logistical barriers included the burden of filling prescriptions, obtaining clinic visits, having to use the restroom while away from home, and having to carry extra medications to avoid missing a dose.

In a review of 11 qualitative research studies that examined lay beliefs about hypertension, the authors found that the perceptions described previously are consistently found in the black or African American population, including the perceived causes of hypertension (stress, racism, and poor diet), as well as the symptoms and side effects of treatment (headache, increased heart rate, dizziness, sluggishness, and sweating).<sup>136,137</sup> Likewise, in 60 other interviews, the believed causes of hypertension were further classified into 4 broad categories: inherited, stress related, behavioral, and biologically mediated.<sup>138</sup>

However, there are clearly other nonbelief pathways that are likely contributing to racial differences in compliance. In addition to health literacy, analyses adjusted for potential confounders show that a lack of adherence resulted from an inability to afford medications, which was more likely among blacks or African Americans (OR 1.38, 95% CI 1.08 to 1.78) and Hispanics (OR 1.35, 95% CI 1.02 to 1.78).<sup>139</sup> Among diabetic people with poor glucose control, blacks or African Americans were least likely to cite positive healthcare experiences and were most likely to cite stress, depression/mood, and diet temptations as barriers.<sup>140</sup>

Some authors suggest that perceived racial bias may be playing a substantial role as a barrier to good compliance. One study found that a belief that the healthcare system treats people unfairly based on race is associated with delays in filling prescriptions (OR 2.02, 95% CI 1.11 to 3.17), and perceived discrimination in the community is associated with delays in medical testing (OR 2.42, 95% CI 1.09 to 5.36).<sup>141</sup> Likewise, another study showed an increasing likelihood of failure to adhere to medical care subjects with 1 to 2 discrimination experiences (OR 1.8, 95% CI 1.2 to 2.6) and those with  $\geq 2$  discrimination experiences (OR 2.6, 95% CI 1.7 to 4.1) were compared with people with no discrimination experiences.<sup>142</sup>

### Summary

There are definite differences in attitudes, beliefs, and compliance among minorities. Denial of disease, concern for potential or experienced side effects of medications, absence of symptoms, hierarchy of need, burden of filling prescriptions, and attending doctor visits influence compliance with treatment. Lower health literacy also plays a significant role. In addition, there is limited evidence to support the idea that

appropriate sociocultural interventions can improve communication, education, and awareness among minorities. Finally, the perceived or true presence of racial discrimination during interaction with the healthcare system has a negative impact on compliance.

## Disparities in Access to Care

### Disparities in Access to Acute Stroke Treatment

Access to care is a complex concept that incorporates availability, accommodation, affordability, and acceptability.<sup>143</sup> Causes of racial disparities in access to emergency care include differences in insurance coverage, potential racial biases by caregivers, and the relative small number of minority physicians available to care for minorities.<sup>144</sup> In addition, undocumented Hispanic immigrants may be more reluctant to use health services.<sup>145</sup> However, specific data on ethnic disparities in access to acute stroke care are incomplete and often present conflicting results.<sup>41</sup>

Disparities in access have been reported at different levels of acute stroke care. There is less stroke symptom recognition by blacks or African Americans.<sup>97</sup> Delay in arrival at the emergency department (ED) decreases the odds of receiving acute stroke treatment.<sup>146</sup> A study in New Jersey showed that blacks or African Americans and Hispanics with acute stroke were less likely to use ambulance services, which was associated with delayed arrival at the ED.<sup>147</sup> Intrahospital disparities in delays of care have also been reported. One study showed that Hispanics had longer waiting times to see a physician after arriving at an ED with stroke symptoms.<sup>147</sup> In contrast, blacks or African Americans, but not Hispanics, had significantly longer waiting times in the ED in a study using data from the National Hospital Ambulatory Medical Care Survey (1997–2000 and 2003–2005).<sup>148</sup> The difference persisted after adjustment for other factors associated with longer waiting time, such as arrival by means other than ambulance, urban location of the hospital, and nonemergency triage. Longer waiting time in the ED leads to treatment delays that include administration of thrombolytic therapy. More research is needed to understand the reasons for this discrepancy in emergency care.

### Summary

Minorities are less likely to use emergency medical services. In addition, they have delayed arrival at the ED. Blacks or African Americans and possibly Hispanics have longer waiting times in the ED, which may contribute to their lower likelihood of receiving thrombolysis for acute ischemic stroke. Although some of these disparities are the result of lack of awareness, language barriers, and reluctance to seek attention because of immigration status, the role of unmeasured factors on these differences cannot be excluded, and the evidence suggests the potential existence of bias in the delivery of care.

### Disparities in Access to Stroke Rehabilitation

Few studies have examined racial-ethnic disparities in stroke rehabilitation, and the available evidence is unclear and somewhat contradictory. With regard to access, a study of the Veterans Health Administration found no racial-ethnic differ-

ences in referral to or receipt of inpatient rehabilitation services,<sup>149</sup> whereas another study examining acute stroke patients in Maryland revealed that blacks or African Americans living in urban areas were more likely than urban-dwelling whites to be discharged from the hospital to inpatient rehabilitation.<sup>150</sup>

In terms of time between stroke onset and admission to rehabilitation, several studies showed no difference between different racial groups,<sup>151,152</sup> except for 1 study that found blacks or African Americans had a slightly longer time to initiation of rehabilitation than whites (4.4 days versus 3.8 days;  $P < 0.05$ ).<sup>149</sup>

The effect of the Functional Independence Measure (FIM) score on admission to rehabilitation is equally contradictory. A retrospective cohort study found no racial-ethnic differences in admission FIM scores,<sup>151</sup> whereas others found significant differences in FIM scores. One study of a large urban county hospital reported that Hispanics had lower admission FIM scores than blacks or African Americans,<sup>152</sup> and another study found that unadjusted FIM scores were highest for whites compared with other racial groups.<sup>153</sup>

A few studies reported no racial-ethnic differences in length of stay for inpatient rehabilitation<sup>151–153</sup>; however, 1 study of Veterans Affairs (VA) and non-VA inpatient rehabilitation facilities reported significantly longer average lengths of stay for blacks or African Americans than for whites.<sup>154</sup> No racial-ethnic differences have been seen in the intensity of inpatient rehabilitation therapies, such as occupational therapy and physical therapy.<sup>151,155</sup> A study using data from the BRFSS found that blacks or African Americans had a higher prevalence of outpatient rehabilitation than whites (adjusted OR 1.49, 95% CI 1.1 to 2.0).<sup>156</sup> Results on the delivery of outpatient occupational therapy and physical therapy services are conflicting. A telephone survey reported that whites were more likely than nonwhites to receive occupational therapy and physical therapy services after stroke,<sup>157</sup> whereas another study examining data from the Health and Retirement Study did not find racial differences in receipt of these services.<sup>158</sup>

### Summary

Information on access to rehabilitation services offers conflicting findings. Current evidence shows that minorities have equal access to rehabilitation services and that they have longer stays and poorer functional status than whites.

### Disparities in Access to Stroke Prevention Services

Differences in access to and use of stroke prevention resources is poorly documented and understudied. The few well-done studies available point to the need for further research. In a study of 5840 stroke survivors as part of the National Health Interview Survey, researchers found that women, blacks or African Americans, and the poor were significantly less likely to fill prescriptions because of cost.<sup>159</sup> One report suggests that blacks or African Americans are less likely to have thorough diagnostic evaluations after a first stroke and are less likely to receive guideline-concordant stroke preventive medication.<sup>160</sup> In another study, which used the 2005 BRFSS in 11 862 stroke survivors, little difference was found among blacks or African Americans and non-

Hispanic whites with respect to secondary prevention measures. The study found that secondary prevention resources were underused by both racial groups.<sup>161</sup> In a community-based study examining Mexican Americans and non-Hispanic whites, no difference in preventive therapies was found for patients having their first or second stroke.<sup>75</sup> In this same community, it was found that access-to-care variables were strongly associated with first stroke in both Mexican Americans and non-Hispanic whites, which suggests the need to remedy these barriers for all populations.<sup>88</sup>

The possibility of behavioral intervention programs to improve stroke prevention efforts appears promising. One study showed that 84% of subjects demonstrated a willingness to participate in a church-based primary stroke prevention project focused on diet and exercise.<sup>162</sup> Similarly, another study of a practice-based stroke prevention project reported greater improvement in stroke prevention behaviors among black or African American participants than among non-Hispanic white participants.<sup>163</sup>

### Summary

Although secondary prevention treatments are underused by all races and ethnic groups, minorities are less likely to receive medications for secondary prevention. Some of these differences may be confounded by SES, education, and insurance coverage. Behavioral modification programs may be effective in minority populations.

### Potential Contributing and Confounding Factors

Several factors could influence racial-ethnic disparities in access to care for those with or at risk for stroke, thereby complicating study design, interpretation of results, and ability to compare results across studies. These factors include SES, public awareness, perception of resource availability, literacy, mistrust of the healthcare system, language barriers, religious and cultural beliefs, cultural isolation, access to transportation, immigration status, and healthcare provider issues. More importantly, these factors may also be mediators for or barriers to intervention.

### Income

Low SES is associated with an average lifespan that is 10 years less than that of people with high SES.<sup>164</sup> In particular, evidence from observational studies using large administrative data sets indicates that being poor is associated with greater prevalence of stroke risk factors, higher stroke incidence, lower quality of life after stroke, and higher mortality after stroke.<sup>165,166</sup> Lack of access to medical care is likely one mediator of the relationship between poverty and undesirable stroke outcomes. In the United States, blacks or African Americans have lower average SES than whites. For instance, 9.1% of white families lived below the poverty level in 1999, compared with 24.9% of black or African American families.<sup>39</sup> Indeed, many studies have compared racial-ethnic differences in stroke occurrence or stroke mortality and observed that SES accounted for a proportion of the observed racial-ethnic differences. Within a large biracial population of blacks or African Americans and whites in greater Cincinnati/northern Kentucky, it was observed that 39% of the racial disparity in stroke incidence for blacks or African Americans



was associated with lower SES as defined by the proportion of subjects below the poverty line.<sup>167</sup> Furthermore, in a sample of community-dwelling stroke survivors, lower income appeared to explain the higher association of black or African American race with stroke prevalence after adjustment for clinical risk factors.<sup>48</sup>

Lower level of education, a variable often related to lower SES, may contribute to exacerbating the difference in stroke incidence between blacks or African Americans and whites. Data from the Atherosclerosis Risk in Communities study showed that the black or African Americans–versus-white age-adjusted rate ratio for ischemic stroke was 2.41 (95% CI 1.85 to 3.15) but was attenuated to 1.38 (95% CI 1.01 to 1.89) after additional adjustment for baseline hypertension, diabetes mellitus, smoking status, coronary artery disease, and, notably, education level.<sup>50</sup>

### **Insurance**

Because cerebrovascular disease is a chronic, often progressive condition that reflects long-term exposures to vascular risk factors, lack of health insurance may compound the effects of low income or education on health risk behaviors by limiting access to primary and secondary prevention. Individuals without health insurance tend to be more likely to forgo routine physical examinations; to be unaware of a personal diagnosis of hypertension, diabetes mellitus, or hyperlipidemia; and to have higher levels of neurological impairment, a longer average length of hospital stay, higher rates of stroke, and a higher risk of death.<sup>168,169</sup> A cohort study of stroke survivors noted that being of black or African American race was associated with less ability to afford medication.<sup>159</sup> Moreover, NOMAS showed that those with no insurance or Medicaid are more likely than those with Medicare or private insurance to experience declines in function and quality of life after stroke, starting  $\approx 3$  years after the stroke.<sup>170,171</sup> Conversely, there are also substantial racial disparities among veterans with equal access to health care through the VA systems. For example, blacks or African Americans and Hispanics were less likely to use inpatient therapy services after a stroke than their white counterparts.<sup>172</sup>

### **Mistrust**

For black or African American and Hispanic patients, racial beliefs and preferences may affect the quality of interaction with their healthcare provider and may be a contributor to racial disparities.<sup>173</sup> One study found an association between patients' beliefs about discrimination in health care and specific preferences for the race or ethnicity of their physician.<sup>174</sup> Patients with racial preferences for their physician appear to be more likely to rate their regular physician highly if they are in a race-concordant relationship, with approximately one quarter of blacks or African Americans and one third of Hispanics preferring that their personal physician be of similar race or ethnicity.<sup>173</sup> In fact, racially concordant visits appear to be longer and have more favorable communication characteristics.<sup>175</sup> Importantly, the number of minority physicians is limited, which makes it difficult for minority patients to reach minority physicians all the time. However, there is a paucity of data that specifically examined mistrust

of care providers among minority patients with or at risk for stroke. This issue certainly deserves further exploration.

### **Providers**

It was shown that most of the care for black or African American patients is provided by relatively few primary care providers compared with care for white patients. In addition, physicians caring for blacks or African Americans are more likely to report having great difficulty accessing subspecialty support for their patients and feel that they are unable to provide high-quality care for their patients.<sup>176</sup> Furthermore, it has been suggested that in many cases, physicians treating black or African American patients may be less well trained clinically, less likely to be board certified in their primary specialty, less knowledgeable about preventive-care practices, less surgically competent, and less likely to have access to important clinical resources than physicians treating whites.<sup>176–179</sup> However, relatively little else is known about the effect of knowledge, training, and qualifications of healthcare providers on racial disparities in access to appropriate stroke care.

### **Healthcare System**

The healthcare system may lend itself to care disparities. Stroke registry studies evaluating routine clinical practice have indicated that being of black or African American race is associated with significant delays from 911 call to arrival in the ED<sup>180</sup> and time to a computed tomography scan of the head after hospital arrival.<sup>181,182</sup> Blacks or African Americans also appear less likely than their white counterparts to receive intravenous thrombolytic treatment<sup>183</sup> and to undergo cardiac monitoring, noninvasive cerebrovascular testing,<sup>184</sup> dysphagia screening, or smoking cessation counseling.<sup>181</sup> Recent data from the American Heart Association–sponsored Get With The Guidelines–Stroke program, which included 397 257 patients at 1181 hospitals, provided evidence that blacks or African Americans with stroke received fewer evidence-based care processes than Hispanic or white patients. Quality of care improved substantially over time for all 3 racial/ethnic groups, perhaps because of participation in quality-improvement measures.<sup>73</sup> However, not all studies that investigated this issue have shown racial disparities among routinely treated stroke patients. A study of patients with stroke at VA hospitals noted that a patient's race was not associated with having invasive carotid imaging or carotid endarterectomy (CEA), echocardiography, or noninvasive cerebrovascular testing.<sup>185</sup> Notably, the VA healthcare system is an open-access program. Further studies are required to better delineate the reasons behind these management disparities, where they occur, and how to resolve them.

### **Awareness**

Lack of stroke knowledge is a barrier to appropriate care and likely contributes to racial disparities in access to care. For instance, Mexican Americans in Texas were less likely than non-Hispanic whites to know that therapy for acute stroke existed, to recognize a time window for treatment, to indicate that they would call 911 for stroke symptoms, and to recall stroke symptoms.<sup>186</sup> Language impediments may exacerbate this issue. In fact, lack of English proficiency is strongly



associated with lack of stroke knowledge among Hispanics and highlights the need for educational interventions about stroke emergencies and preventive care targeted to Spanish-speaking communities.<sup>100</sup> Although these findings were limited to Texas, it does highlight the importance of language and communication as a barrier for awareness. Further studies are needed to confirm these findings.

### Summary

Several factors may contribute to racial and ethnic disparities in access to stroke care. They include SES, insurance coverage, mistrust of the healthcare system, a relatively limited number of providers belonging to minority groups, system limitations, and poor awareness. Large proportions of minorities have lower SES, no health insurance, and lower education levels than non-Hispanic whites. In addition, language barriers may limit stroke awareness and understanding of the options available for prevention and treatment of cerebrovascular disease.

## Disparities in Quality of Stroke Care

### Differences in Testing

Information on disparities in testing is scant. Carotid angiography has been reported to be performed more commonly in white patients than in blacks or African Americans in the VA healthcare system,<sup>187</sup> although this difference could be related to higher rates of carotid atherosclerosis in whites. Similarly, noninvasive cerebrovascular testing and comprehensive evaluations for the cause of a first stroke occur less often in black or African American patients.<sup>130,158</sup> In contrast, a recent study of the North Carolina Stroke Care Collaborative found no significant association between receiving a computed tomography scan within 25 minutes of hospital arrival and race.<sup>188</sup>

### Summary

There is limited evidence showing that minorities are less likely to receive evaluation or testing for cardiovascular disease and stroke than whites. However, more research on this topic is clearly necessary.

### Differential Referral to Neurologists

Apart from differences in use of diagnostic tests or application of treatments, discrepancies in stroke care can occur because the proportion of minorities evaluated by specialists is different as compared with whites. Neurological consultations could improve the accuracy of acute diagnosis in selected cases and increase the effectiveness of secondary prevention treatments by allowing a more accurate determination of the mechanism of brain ischemia. Patients treated by neurologists have lower rates of early mortality.<sup>8</sup> Unfortunately, there is a paucity of research assessing the frequency of neurological consultations in multiethnic stroke populations.

A study from the BASIC Project reported that Mexican Americans were less likely to have a neurology consultation in the ED than non-Hispanic whites (OR 0.58, 95% CI 0.35 to 0.98)<sup>189</sup>; however, the clinical significance of this finding is unknown. The absolute difference between neurological consultations in the ED for Mexican Americans and non-Hispanic whites, although statistically significant, was very

modest, because most patients in both groups did not have a neurological consultation. In addition, well-trained emergency physicians can accurately identify patients with stroke,<sup>190</sup> and the study did not assess whether there was any persistent discrepancy between the 2 groups in the rate of neurological consultations after admission to the hospital.

In a study of acute stroke patients treated across 137 community hospitals, patients treated by attending physicians who were neurologists were 3.7 times more likely to receive intravenous thrombolysis. This finding was consistent among black or African American and white patients, but only 10.6% of black or African American patients had a neurologist as their attending physician compared with 20.3% of white patients.<sup>152</sup> Thus, this study indicates a discrepancy in delivery of care with possible direct consequences on treatment and patient outcome.

### Summary

Minority patients with stroke are less likely to be evaluated by a neurologist. The causes for this disparity are not clear, and further research is needed to better understand the differences and to identify practical solutions.

## Disparities in Treatment With Thrombolytic Therapy

Data on disparities in treatment with thrombolytic therapy in patients with acute ischemic stroke are limited. Understanding the elements required in the various steps to achieve successful administration of thrombolytic therapy to patients with acute ischemic stroke provides a means to understanding the barriers and sources of disparities. The links in the stroke Chain of Survival<sup>190a</sup> are rapid recognition of stroke warning signs and activation of the emergency response system (call 911); rapid emergency medical services dispatch, transport, and prehospital notification; triage to a stroke center; and rapid diagnosis, treatment, and disposition in the hospital.

With regard to the administration of thrombolysis, 1 study analyzed the NIS database for 1999 to 2004, which showed that thrombolysis was used in 1.12% of patients hospitalized for ischemic stroke. Higher use of thrombolysis was noted among whites and patients with private, self-pay health insurance, which suggests a discrepancy; however, these associations were not controlled for SES and are limited in that they cannot discern whether other patient characteristics (particularly the presence of contraindications) or patient preferences could have accounted for the differences noted.<sup>191</sup> In a prospective study of the use of recombinant tissue plasminogen activator in acute ischemic stroke in a sample of US academic centers, investigators found that recombinant tissue plasminogen activator was used fewer times in blacks or African Americans even after controlling for delays to presentation.<sup>183</sup> Although the reason for that finding was unclear, physician biases, cultural barriers, and patient mistrust are possibilities that should be considered for additional study. No data are available in relation to access to endovascular acute stroke interventions. More recently, the Get With The Guidelines–Stroke program showed that blacks or African Americans with stroke were less likely to receive

thrombolysis than Hispanic or white patients (OR 0.84, 95% CI 0.77 to 0.91).<sup>73</sup>

### Summary

There are disparities in access to and treatment with thrombolysis among minorities compared with whites. The discrepancies appear to exist at several levels of acute stroke care as outlined in the stroke Chain of Survival. Research has not sufficiently analyzed the effects of SES and coverage by health insurance, which could represent sources of systematic biases in healthcare delivery.

### Disparities in Prevention

There are several possible reasons for disparities in risk factor control among minority groups, including access to care, physician inertia, adherence and compliance with treatment, and severity of disease. After a stroke and in situations in which barriers to access are reduced, such as in the VA and Medicare systems, disparities might be lessened.

In primary prevention, disparities in blood pressure control are significant. Among men >60 years of age, Hispanics and non-Hispanic blacks or African Americans have worse rates of blood pressure control, even among those treated for hypertension, compared with whites.<sup>192</sup> Middle-aged Hispanic women have the lowest rates of blood pressure control among those treated. In an early analysis from the nationwide REGARDS study, blacks or African Americans were less likely than whites to have their blood pressure controlled (OR 0.73, 95% CI 0.64 to 0.83), despite greater awareness of their hypertension and greater likelihood of receiving treatment if aware of their diagnosis (OR 1.69, 95% CI 1.40 to 2.05).<sup>57</sup> Interestingly, there is no difference between the Stroke Belt and other regions with regard to awareness of hypertension (OR 0.95, 95% CI 0.79 to 1.14), and in fact, there is a trend for better treatment (OR 1.15, 95% CI 0.97 to 1.37) and control (OR 1.11, 95% CI 0.98 to 1.30) in the Stroke Belt region.<sup>193</sup>

Prophylactic use of aspirin is higher among whites than blacks or African Americans. In REGARDS, among 16 908 participants  $\geq 45$  years of age, 34.7% of whites used prophylactic aspirin compared with only 27.2% of blacks or African Americans ( $P < 0.0001$ ).<sup>194</sup> Aspirin use was also higher among men and higher socioeconomic groups.

Analyses of temporal trends from 1999 to 2006 using repeated NHANES questionnaires indicate that there has been overall progress in improving the rates of control of blood pressure and diabetes mellitus, but there are persistent disparities between whites and minorities.<sup>195</sup> For example, over the period of the study, differences in blood pressure control and glucose control between whites and blacks or African Americans have remained, and those between whites and Hispanics in glucose control have increased slightly. Although overall from 1999 to 2006, the proportion of patients with blood pressure controlled to a target <140/90 mm Hg increased from 45.7% to 56.0%, the pooled 8-year control rates were 52.8% among whites, 44.4% among blacks or African Americans, and 42.5% among US-born Hispanics. For diabetes mellitus control, pooled rates were 58.1% for whites, 41.6% for blacks or African Americans, and only

37.8% for US-born Hispanics. Of note, disparities were less marked among patients >65 years of age, perhaps because of their access to Medicare coverage. For instance, blood pressure differences between blacks or African Americans and whites decreased from 7.0 (95% CI 5.4 to 8.6) mm Hg before age 65 years to 2.8 (95% CI -0.1 to 5.7) mm Hg after age 65 years.

Previous data suggest that there were also differences among racial-ethnic groups in the use of secondary stroke prevention treatments. In an analysis among 19 051 nursing home residents with recent ischemic stroke, Asian Americans and Pacific Islanders were less likely to receive an antithrombotic agent than non-Hispanic whites, whereas American Indians/Alaskan Natives were more likely to receive treatment.<sup>196</sup> Asian Americans and Pacific Islanders, blacks or African Americans, and Hispanics were less likely to receive warfarin when indicated than non-Hispanic whites.<sup>196</sup> In REGARDS, investigators found that blacks or African Americans were less likely than whites to be aware they had atrial fibrillation or to be treated with warfarin.<sup>161</sup>

Recent cross-sectional evidence from nationwide health surveys suggests that once patients have a stroke, the use of most risk-reduction strategies does not differ markedly by race, although most prevention strategies are underused by all groups.<sup>161</sup> For example, data from the 2005 BRFSS show that black or African American stroke survivors are less likely to engage in regular exercise than whites but that they are no less likely to be prescribed aspirin and antihypertensive agents, to have cholesterol and glycosylated hemoglobin measurements when appropriate, and to be counseled to stop smoking and consume a low-fat or low-salt diet. Still, the proportion of those who participated in regular exercise was low among both blacks or African Americans (48%) and whites (58%). In an analysis of 1045 patients from the VA, rates of intervention for smoking cessation and use of aspirin were similar for blacks or African Americans and whites, although both interventions were underused; only 56% of both groups received interventions to quit smoking, and  $\approx 74\%$  received aspirin.<sup>197</sup> In data from the National Health Interview Survey, Hispanic stroke survivors and blacks or African Americans were more likely to be physically inactive and overweight than whites.<sup>62</sup> Screening for hypertension and hyperlipidemia among patients during outpatient office visits does not appear to differ by race.<sup>198</sup> A recent analysis of 4864 stroke survivors  $\geq 45$  years of age who responded to the National Health Interview Survey in 2000 to 2006 revealed that Mexican Americans and blacks or African Americans  $\geq 65$  years of age had reduced access to primary care providers and were less able to afford medications when compared with whites.<sup>199</sup> There was no difference in access to primary care providers or medications among those <65 years of age. However, Mexican Americans and blacks or African Americans in any age group had worse access to evaluation by specialists.

Yet racial disparities may exist, at least in the early phase of secondary stroke prevention. In hospitals participating in the Get With the Guidelines-Stroke program between 2003 and 2008, adherence to evidence-based performance mea-

asures aimed at reducing the risk of secondary strokes was significantly lower in blacks or African Americans than in whites and Hispanics.<sup>73</sup> These differences were noted in smoking cessation counseling, prescription of antithrombotic medications on discharge, prescription of anticoagulant medications for atrial fibrillation, and prescription of lipid therapy for atherosclerosis-related strokes. Although the differences were generally modest, they showed a consistent pattern and remained significant—or became even more prominent—after controlling for patient-related and hospital-related confounding variables. Such discrepancies could lead to increased risk of recurrent strokes in black or African American patients. The good news is that adherence to these guideline-recommended quality measures improved over the study period among patients of all racial groups in participating hospitals.<sup>73</sup>

### Summary

Minorities are inadequately treated with both primary and secondary stroke prevention strategies. Disparities are reduced when people have health insurance and ready access to care. Physical activity rates are particularly low among minority groups. Community healthcare workers and other lay providers may help diminish disparities by providing basic preventive care and education to people with otherwise limited access to health care.<sup>200,201</sup>

### Disparities in the Use and Outcomes of CEA

Randomized trials demonstrated that CEA can reduce the risk of stroke in patients with symptomatic carotid artery disease. As a result, screening for carotid disease, as well as subsequent CEA among appropriate patients, is recommended as an effective means of secondary stroke prevention.<sup>202,203</sup> Studies, however, have consistently demonstrated that blacks or African Americans are less likely to receive CEA than whites.<sup>187,204–210</sup> The magnitude of these differences varies slightly among study populations, but on average, results show that blacks or African Americans are 2 to 4 times less likely than whites to have CEA even after risk adjustment. Blacks or African Americans were also at higher risk of stroke after endarterectomy (OR 1.7,  $P=0.013$ ). Potential reasons for these racial differences in the use of CEA include less carotid artery screening among blacks or African Americans than whites<sup>187,211</sup>; racial differences in the distribution of carotid disease and appropriateness for CEA<sup>212–214</sup>; clinical characteristics<sup>206,212</sup>; differential risks for carotid surgery<sup>215–219</sup>; differential patient preferences for surgery<sup>220</sup>; and racial disparities in care.<sup>221</sup> Interestingly, among patients admitted to VA hospitals in the 1990s, there was no significant difference in use of CEA (1.5% among whites versus 0.8% among nonwhites,  $P=0.38$ ).<sup>185</sup>

### Summary

There is a differential use of CEA among blacks or African Americans relative to whites; however, these studies have several limitations. They lack the clinical detail necessary for risk adjustment and are relatively dated (pre-2000), focused on specific patient populations, and do not sufficiently consider potential confounders of CEA use. Future studies should be undertaken to determine whether racial disparities in use of CEA continue to exist, to delineate the underlying

causes of such differences, and to identify effective interventions designed to reduce these disparities in care.

### Differences in Access to Surgery in ICH or SAH

Epidemiological data on racial-ethnic disparities in the surgical treatment of patients with ICH or SAH are surprisingly limited, especially when one considers the often devastating consequences of these forms of cerebrovascular disease,<sup>222,223</sup> their higher incidence among ethnic minorities,<sup>224–227</sup> and the comparative abundance of studies evaluating ethnic disparities in procedures for other disease entities, including cardiovascular disease,<sup>179</sup> and studies on access to surgical management of ischemic cerebrovascular disease, including CEA.<sup>185,187</sup> The impact of advanced directives about restricting aggressive care on access to or performance of surgical procedures for these acute conditions is not well established. This is important because there is evidence indicating that blacks or African Americans are less likely to have withdrawal of life support measures as compared with whites.<sup>86</sup>

Relatively little information was found in a comprehensive review of the literature about racial-ethnic disparities in the United States in terms of surgical treatment and outcome of various cerebrovascular disease entities, including intracranial aneurysms and cerebral arteriovenous malformations, from 1966 through 2005.<sup>228</sup> The available data, which were generally retrospective and greatly confounded, showed no information on ethnic disparities in access to actual surgical treatment of these conditions.<sup>228</sup> A study of adult patients with SAH in the greater Cincinnati area prospectively identified from 1997 through 2005 did not find race to be associated with rates of time to treatment or case fatality.<sup>229</sup> To date, there is no information on racial-ethnic disparities in the care of patients with ICH.

### Summary

There is a marked paucity of data on racial-ethnic disparities in accessing surgical care after ICH and SAH. Future research should focus on looking at broad measures of processes of care, the impact of these care processes on clinical outcomes, and the potential contributors and confounders to any differential access to surgical care by race or ethnicity.

## Differences in Access to Research

### Rates of Participation of Minorities in Clinical Research

Minorities have usually been underrepresented in most major medical trials in general and stroke trials in particular.<sup>230–234</sup> According to figures from the National Institutes of Health, the percentage of minorities who took part in clinical trials funded by the federal government steadily fell from 41.3% to 29.5% between 1997 and 2001. Although the figure rose the following 2 years, reaching 35.8% by 2003, enticing the participation of patients belonging to racial-ethnic minorities remains challenging.

Personal beliefs and preconceived attitudes such as mistrust of medical research appear to be crucial to defining participation in clinical studies.<sup>235</sup> Mistrust of the medical care system may present a barrier to enrollment of minority



patients in research studies.<sup>236</sup> Yet the degree of mistrust among blacks or African Americans, Hispanics, and whites appears to vary depending on sociodemographic characteristics (sex, educational attainment, insurance status, and city of residence).<sup>237</sup> Moreover, a comprehensive literature review appears to contradict assumptions that minority subjects are more reluctant to consent to participate in clinical research by showing only very small differences in the willingness of minorities (mostly blacks or African Americans and Hispanics in the United States) to participate in health research compared with non-Hispanic whites.<sup>238</sup> Because racial and ethnic composition of the patient population may impact clinical trial results and their wide applicability by skewing the proportion of patients enrolled with different stroke subtypes, this issue is of major importance to stroke researchers.

### **Barriers to Participation of Minorities in Clinical Research**

Although ethnic minorities are interested in improving their health and, when given appropriate information, appear willing to participate in clinical research, data indicate that evaluation, study compliance, retention (remaining in the study), and follow-up of ethnic minorities is a challenging process that requires culturally relevant strategies to ensure optimal efficacy.<sup>239</sup> Racial disparities in access to clinical research have been observed in clinical trials, which constitute the major experimental approach to develop safe and effective state-of-the-art treatments, as well as population-based studies. Indeed, it has been suggested that there might be a “recruitment triangle” that is essential to the enrollment and retention of subjects in clinical research, especially clinical trials.<sup>240</sup> This triangle is composed of the subject, vital family members and friends, and the primary medical personnel involved in treatment and care of the subject.<sup>241</sup> The triangle is bound by social support, education about the nature of the research, and trust in study personnel.<sup>241</sup>

Potential barriers to maximal participation of ethnic minorities in clinical research can be divided into 2 main categories: cultural characteristics and structural factors.

#### ***Cultural Characteristics (Attitudes, Beliefs, Perceptions, and Awareness)***

Regardless of race or ethnicity, the most frequently reported barriers to minority patients' acceptance of clinical trials tends to be mistrust of medical research and the medical system.<sup>239</sup> Mistrust of physicians and the healthcare system among minorities has been supported by studies in recent history in which an effective treatment was withheld as part of the study, as well as documented deficiencies in the delivery of health care to minorities, including unfavorable disparities in the use of diagnostic testing and treatment procedures by physicians.<sup>239</sup> In fact, enrollees in a double-blind, randomized clinical trial of black or African American stroke patients who subsequently withdrew or refused to participate consistently stated that they were worried about being used as “guinea pigs” and that these feelings were reinforced by their family and friends.<sup>240</sup>

Other pervasive notions among ethnic minorities that may impede their full involvement in clinical research are a fatalistic attitude about their chances of recovery from a

disease, specific research questions that may be perceived by minority subjects as irrelevant, negative personal experience with a local hospital/medical personnel, or an injury caused by the application of a treatment perhaps taken incorrectly.<sup>241</sup>

#### ***Structural Factors (Health and Research Systems and Economic Issues)***

Although several studies have highlighted barriers to minority patients' increased participation in clinical research, healthcare professional barriers have received relatively less attention, even though care provider perceptions and attitudes play an important role in study enrollment of underrepresented populations.<sup>242</sup> In fact, care providers, especially physicians, tend to act as gatekeepers and provide the majority of patient education and coordination regarding clinical trials.<sup>243,244</sup>

Evaluations of medical researchers' opinions about low minority recruitment have identified a perception of lower interest in clinical trials among minority patients (due to mistrust of researchers and lack of awareness/information and resources), a lack of investigator confidence in explaining clinical trials in culturally appropriate terms as probable barriers, and the paucity of collegial relationships between university-based physicians and many community physicians caring for minority patients.<sup>245</sup> Other data indicate that a large proportion of study principal investigators do not set a priori recruitment goals for racial-ethnic minorities, even though the number of minority participants needed for hypothesis testing may differ substantially from the numbers needed for more exploratory analyses aimed at generating new hypotheses.<sup>244</sup> The limitations in care among minority populations and the relative lack of resources in these communities leads these populations<sup>236</sup> to seek care in different settings from clinics to EDs or to never have access to medical care, making recruitment of minorities into stroke population-based studies difficult to achieve.<sup>241</sup>

Some investigators have created challenges for themselves by blindly using approaches to recruit subjects that may have been effective among nonminority groups, such as the use of mailed surveys, individual appeals, and reliance on individuals' basic trust in healthcare providers.<sup>241</sup> For instance, telephone reminder interventions in minority-rich urban populations are often unsuccessful, largely because up to 20% of the samples cannot be reached by telephone. Failure to network with local organizations, to pilot test to ensure that questions are culturally sensitive, to use bilingual recruiters (for subjects who speak only Spanish), or to provide ancillary services (eg, hiring social workers to help obtain other health and social services to show genuine interest in community welfare) could adversely affect the most well-meaning attempts to enroll and retain minority subjects in experimental studies.<sup>239</sup>

The race/ethnicity of a physician may also affect participation of minority patients in clinical research. Hispanic/Latino physicians tend to be significantly less likely than their non-Hispanic white counterparts to find clinical trials to be of scientific value, which probably determines whether they recommend them to their patients.<sup>243</sup>

There is relatively limited information in the literature on the enrollment and retention of minority women in clinical



trials. However, available data indicate that the factors that greatly influence the participation of women in clinical research are SES and educational level.<sup>247</sup>

### External Validity of Current Evidence

In the United States, there has been a long history of underrepresentation of racial and ethnic minorities in biomedical research.<sup>11,39,248–251</sup> Minorities were underrepresented in many types of clinical research, including stroke and other cardiovascular diseases.<sup>11,231,251,252</sup> In response to these observations, the US Congress mandated that the National Institutes of Health enroll more women and minorities in clinical trials.<sup>253</sup> Furthermore, the US Food and Drug Administration made specific recommendations that included standardized race and ethnicity categorization in studies to create a level of consistency in the evaluation of drug differences according to these demographic parameters.<sup>254</sup> These recommendations raised practical study design challenges. In the case of enhancement of enrollment of minorities in randomized controlled trials, the absolute number of minority enrollees usually was not sufficient to draw substantial conclusions about drug efficacy and safety.<sup>255</sup> Post hoc subgroup analyses of such data served to promote formulation of a hypothesis but were not adequate for direct testing of the hypothesis, because there might be uncontrolled or uncontrollable confounding.<sup>256</sup>

The latter potential shortcoming led to the recommendation that large targeted trials be funded to yield meaningful and usable data in relation to women and racial-ethnic minorities. In stroke research to date, there have been few such exclusive randomized controlled trials in racial-ethnic minorities. Thus far, the African-American Antiplatelet Stroke Prevention Study (AAASPS) and the Stroke Prevention Trial in Sickle Cell Anemia (STOP I and II trials) have been the prime examples of this type of study.<sup>11,257,258</sup> These trials are landmark studies and have shown that minority patients are interested in biomedical research and can be successfully recruited and retained for such trials.

Assessment of the external validity of the current evidence is very important. Results of clinical trials may not be generalizable to racial-ethnic minorities not represented in the clinical trial because of the potentially different response to treatment related to different prevalence and severity of disease and different genomic or metabolic profiles in specific racial-ethnic subgroups. For instance, there has been recent interest in the cytochrome P-450 superfamily of enzymes responsible for drug metabolism.<sup>259,260</sup> Specifically, within this superfamily of enzymes, there has been recent study of the CYP2C19 variant that is involved in the conversion of clopidogrel from its prodrug to its active metabolite.<sup>261,262</sup> It is estimated that this genetic variant, which prevents adequate conversion of clopidogrel to its active form, is common and may occur in 40% of people of African ancestry, 50% of people of East Asian ancestry, and 30% of people of European ancestry.<sup>262</sup> Similarly, variant alleles in the genes CYP2C9 and VKORC1 that affect

warfarin metabolism may have a higher frequency of occurrence in some racial-ethnic minorities.

These findings, although not specific to 1 race or ethnic minority group, are important to patients who are being treated and their healthcare providers because the results may predict the success or failure of therapy. Without focused study of racial-ethnic minorities, it will be difficult to predict excess risk among these people.<sup>263</sup> Overall, such information may provide the opportunity to reduce disparities in health care and health outcomes and help us to better understand disease-response variations among racial-ethnic groups.<sup>4,264</sup>

### Summary

There is limited participation of minorities in clinical research. Adequate participation of all racial-ethnic groups is necessary to comply with the ethical principles of justice (ie, fair distribution of risk and benefits related to research), fair subject selection, societal value, and scientific validity.<sup>265</sup> There are barriers to participation in clinical research. These barriers include cultural aspects, such as beliefs, trust, and awareness, as well as healthcare system and economic issues. Moreover, race is a contentious topic in biomedical research.<sup>266</sup> Although race has not been shown to act as a surrogate for genetic constitution in medicine or public health or to necessarily provide a definitive categorization of genetic information about the response to drugs, diagnosis, or cause of disease,<sup>266</sup> information about a patient's race and ethnic background is important for the identification, tracking, and investigation of the rationale for differences in the prevalence and severity of disease and responses to treatment. This is especially important when genetic factors may be involved, because race is associated with social and environmental factors that affect disease prevalence and severity, as well as response to treatment.<sup>264</sup> Thus, it is crucial that we enhance our understanding of the reasons that deter minorities from participating in research studies.

### Future Directions

Further efforts are needed to clarify the complex relationship between race-ethnicity, stroke burden, and stroke outcomes. Although available evidence is often limited and not always consistent, it does suggest the existence of disparities and the possibility of a bias in the care provided to minorities with stroke. Strategies aimed at reducing racial-ethnic disparities in stroke care require a better understanding of responsible factors and must start by acknowledging that discrepancies exist and need to be addressed. Support for programs such as the Racial and Ethnic Approaches to Community Health (REACH) program created by the Centers for Disease Control and Prevention should continue and expand.<sup>267</sup> Funds for research in this field should be made available to enhance our knowledge by making possible the design of solid scientific studies. We present our specific recommendations at the end of this statement.

In addition, a universal nomenclature is needed to account for the common characteristics of each group. Although each ethnic group is unique, blanket terms such as "Hispanic" may not be helpful in explaining the disparities in health and

health care among different communities given the existence of many subgroups and heterogeneity within blanket terms. An alternative definition, such as Americans who identify themselves with a Spanish-speaking community or ancestry, should be considered.

### Conclusions

Biological determinants may explain differences in the prevalence and incidence of stroke and stroke risk factors and in the morbidity and mortality due to stroke among racial and ethnic minorities compared with whites. However, racial-ethnic disparities in stroke care exist. The disparities appear more marked among people <65 years of age, which suggests that Medicare ameliorates the problem by providing equal access to care. SES and low education are barriers to delivering effective health care. Current literature focuses on the influence of sociocultural factors in access to care by minority populations. However, little attention has been paid to the deficiencies in the healthcare system, which may also limit effective treatment to reach minorities.

Closing the gap generated by these disparities in stroke care will require system changes to facilitate education and access to available resources. Appropriate culturally adjusted programs should be designed to allow prompt identification and modification of vascular risk factors, consistent recognition of stroke symptoms, and ready access to immediate treatment among minorities. If Medicare indeed diminishes the disparities in stroke care among different racial and ethnic populations, it would be reasonable to expect that healthcare reform could contribute to closing the gap in stroke care among minorities of all ages.

Further research is needed to understand the current deficiencies in the healthcare system that allow the occurrence of racial-ethnic disparities and to monitor the effects of healthcare reform as it takes effect. Based on our interpretation of the available information summarized in this document, our recommendations are a general call for future research and public health policy development that should include the following:

- Establish standardized definitions for racial and ethnic groups that reflect common features that may include, but are not limited to, biological, cultural, and social determinants.

- Implement educational programs to promote lifestyle modifications and increase stroke awareness in racial and ethnic minority populations.<sup>268–270</sup> These programs must incorporate the following educational objectives:
  - Recognition of vascular risk factors, their true causes, their impact on chances of having a stroke, and treatments available to control them
  - Identification of symptoms of stroke and understanding that stroke is a treatable emergency that should prompt calling 9-1-1 for immediate evaluation
  - Emphasis on physical activity as a means to reduce stroke risk
- Involve community resources outside of the medical system, such as churches, schools, and community centers, in the implementation of educational programs.
- Target educational programs toward young members of minority populations, because disparities in stroke rates and stroke burden are more prominent in young blacks or African Americans and Hispanics than in young whites.
- Establish programs for provider education to address cultural competence training.
- Prioritize the design of stroke prevention programs for the Hispanic population, because Hispanics are the fastest-growing minority group in the United States and presently constitute a relatively young population. Thus, it can be expected that the burden of stroke in this population will rise substantially in the near future.
- Increase access to health care by broadening the access to insurance coverage in minority populations.
- Expand national strategies for hospital-based implementation of quality improvement in acute stroke care.
- Promote more research to better define factors that contribute to the occurrence of racial-ethnic disparities in stroke care and to assess interventions designed to eliminate these disparities.
- Conduct clinical trials to find interventions to reduce existing disparities.
- Incorporate measures in large stroke trials to ensure adequate representation of all major racial-ethnic groups.
- Expand federal support for trials targeted to minority populations.
- Conduct more research on minority groups other than black or African American and Hispanics, such as American Indians, Asian Americans, and Pacific Islanders.

Disclosures

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\*Modest.  
†Significant.

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†Significant.

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## Racial-Ethnic Disparities in Stroke Care: The American Experience: A Statement for Healthcare Professionals From the American Heart Association/American Stroke Association

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