The Many Faces of Diabetes in American Youth: Type 1 and Type 2 Diabetes in Five Race and Ethnic Populations: The SEARCH for Diabetes in Youth Study

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DIABETES, a leading cause of nephropathy, retinopathy, neuropathy, and coronary and peripheral vascular disease, is the third most prevalent severe chronic disease of childhood in the U.S. (1). People with diabetes diagnosed before the age of 20 years have a life expectancy that is 15–27 years shorter than people without diabetes (1), although prospective data show improvements in mortality for those diagnosed in more recent years (2). Until only a decade ago, diabetes diagnosed in children and adolescents was almost entirely considered to be type 1 diabetes, most often due to the autoimmune destruction of the β-cells of the pancreas leading to an absolute deficiency of insulin. Diabetes in children and adolescents is now viewed as a complex disorder with heterogeneity in its pathogenesis, clinical presentation, and clinical outcome. The occurrence of what appears clinically to be type 2 diabetes in youth, particularly overweight minority youth, has been documented in several studies.

The SEARCH for Diabetes in Youth Study, funded by the Centers for Disease Control and Prevention, Division of Diabetes Translation, with support from the National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, began in 2000 with an overarching objective to describe childhood diabetes as it occurs among the five major race and ethnic groups in the U.S. These groups include non-Hispanic white, Hispanic, Asian/Pacific Islander, African American, and American Indian. Key aims of the study with a focus on race and ethnicity are the following:

- To estimate the prevalence and incidence of physician-diagnosed diabetes in youth aged <20 years by age, sex, race/ethnicity, and diabetes type; and
- To characterize key risk factors for diabetes complications, according to race/ethnicity and diabetes type.

As previously published by the SEARCH study, both type 1 and type 2 diabetes occur in each of the five major race/ethnic groups under surveillance (3,4). These publications, as well as other publications and presentations from the SEARCH study, have reported on findings related to critical aspects of diabetes in youth and have included data on race/ethnicity to the extent deemed appropriate. In this Diabetes Care supplement, we provide a set of five articles, each devoted to one of the five race/ethnic groups. These articles were designed to provide a comprehensive picture of the face of diabetes in the race/ethnic group of interest and to highlight important aspects of the epidemiologic, biochemical, quality-of-care, social, and behavioral aspects of diabetes in these youth. The articles also report on key findings relevant to the experience of diabetes that have not been published to date and that may advance our understanding of diabetes and generate new research. Here, we present the general philosophy of the SEARCH study with regard to race and ethnicity and highlight content of the five papers included in this supplement.

The constructs of race and ethnicity in biomedical research have been hotly debated in recent years (5–8), with concerns raised regarding the meaning of race in a biologic or genetic sense versus social and cultural aspects of race and ethnic self-identification. Some researchers have promoted a “race-neutral approach” in the absence of clear evidence for biological or genetic significance (9,10). However, particularly in the area of diabetes, marked differences in health outcomes and risk factors for health outcomes have been identified for subgroups of individuals defined according to U.S. Census-based self-identification of race and ethnicity. Accordingly, many researchers promote use of self-identified race and ethnicity as the most valid measure for most types of epidemiologic studies (11,12). This is the approach used by the SEARCH study. Although the U.S. Census accommodates reporting of multiple races, in the SEARCH study we did not have sufficient participant numbers to allow evaluation of separate categories of reported multiple race groups. Other than the specific combination of Asian and Pacific Islander who are included in the Asian and Pacific Islander article, only 5% of those who reported Hispanic ethnicity and 4% of non-Hispanic individuals selected more than one race. Rather than exclude these individuals, we uti-
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Table 1—Participants in the SEARCH for Diabetes in Youth Study, including cases prevalent in 2001 and cases with diabetes diagnosed in 2002–2005

|                          | Clinical type 1 diabetes (aged 0–19 years at diagnosis) | Clinical type 2 diabetes (aged 10–19 years at diagnosis) |
|--------------------------|--------------------------------------------------------|--------------------------------------------------------|
|                          | Cases for prevalence or incidence estimation | Subset for clinical characteristics | Cases for prevalence or incidence estimation | Subset for clinical characteristics |
| Prevalent 2001           |                                                      |                                                      |                                                      |                                                      |
| Non-Hispanic white       | 4,045                                                 | 1,691                                                 | 198                                                 | 37                                                   |
| African American         | 490                                                   | 178                                                   | 202                                                 | 77                                                   |
| Hispanic                 | 638                                                   | 290                                                   | 143                                                 | 41                                                   |
| Asian/Pacific Islander   | 167                                                   | 95                                                    | 88                                                  | 17                                                   |
| Navajo                   | 18                                                    | 12                                                    | 74                                                  | 40                                                   |
| All prevalent cases      | 5,359                                                 | 2,266                                                 | 705                                                 | 212                                                  |
| Incident 2002–2005       |                                                      |                                                      |                                                      |                                                      |
| Non-Hispanic white       | 2,800                                                 | 1,692                                                 | 241                                                 | 78                                                   |
| African American         | 450                                                   | 258                                                   | 298                                                 | 135                                                  |
| Hispanic                 | 448                                                   | 261                                                   | 187                                                 | 86                                                   |
| Asian/Pacific Islander   | 107                                                   | 82                                                    | 103                                                 | 51                                                   |
| Navajo                   | 10                                                    | 5                                                     | 56                                                  | 26                                                   |
| All incident cases       | 3,813                                                 | 2,298                                                 | 885                                                 | 376                                                  |
| Total cases              | 9,174                                                 | 4,564                                                 | 1,590                                               | 588                                                  |

Data are n.

The SEARCH study is uniquely positioned to provide the picture of the many faces of childhood diabetes, collected under a standardized protocol, in this large cohort of youth from five major racial and ethnic groups in the U.S. Because the goal of this supplement is to provide information regarding the burden of childhood diabetes from a public health surveillance perspective (hence reporting of the prevalence and incidence data) and to describe childhood diabetes in a clinically relevant manner, we have chosen to present data according to the type of diabetes as diagnosed by the treating physician. We have previously shown that using this approach results in grouping of youth with a clinical diagnosis of type 1 diabetes who are much more likely to have a positive diabetes autoantibody, with much lower fasting C-peptide concentrations, than youth with a clinical diagnosis of type 2 diabetes (3). Table 1 shows the number of youth with clinically diagnosed type 1 and type 2 diabetes, according to race/ethnicity, who are included in analyses presented in this supplement.

The SEARCH study methods have been published previously (14), and further details regarding the protocol are available online at www.searchfordiabetes.org. To provide valid information on prevalence and incidence, case ascertainment must be high. Based on capture-recapture analyses, completeness of ascertainment was >90% for prevalence and incidence (3,4). We have recently systematically evaluated response rates to the SEARCH study in-person research visit (15) and reported that older, nonwhite individuals and those with type 2 diabetes were less likely to attend the research visit than younger, non-Hispanic white individuals and those with type 1 diabetes. However, in a previous report from the SEARCH study, estimating prevalence of elevated albumin-to-creatinine ratio in SEARCH study youth with type 1 and type 2 diabetes, we provided evidence that selection bias did not impact on the prevalence estimate of this important clinical outcome (16).

The SEARCH study is ongoing with collection of prospective data in a subset of the cohort and ongoing ascertainment of incident cases and related data collection. It is anticipated that the study in general, and this supplement, will inspire new ideas for clinical or public health practice and will inspire new research to-
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References

1. Diabetes in America. Bethesda, MD, National Diabetes Data Group, 1995
2. Pambianco G, Costacou T, Ellis D, Becker DJ, Klein R, Orchard TJ: The 30-year natural history of type 1 diabetes complications: the Pittsburgh Epidemiology of Diabetes Complications Study experience. Diabetes 55:1463–1469, 2006
3. Dabelea D, Bell RA, D’Agostino RB Jr, Imperatore G, Johansen HM, Linder B, Liu LL, Looting B, Marcorina S, Mayer-Davis EJ, Pettitt DJ, Waitzfelder B, the Writing Group for the SEARCH for Diabetes in Youth Study Group: Incidence of diabetes in youth in the United States. JAMA 297: 2716–2724, 2007
4. Liese AD, D’Agostino RB Jr, Hamman RF, Kilgo PD, Lawrence JM, Liu LL, Looting B, Linder B, Marcorina S, Rodriguez B, Standiford D, Williams DE: The burden of diabetes mellitus among US youth: prevalence estimates from the SEARCH for Diabetes in Youth Study. Pediatrics 118: 1510–1518, 2006
5. Cooper RS: Race, genes, and health: new wine in old bottles? Int J Epidemiol 32:23–25, 2003
6. Rotimi CN: Genetic ancestry tracing and the African identity: a double-edged sword? Devel World Bioeth 3:151–158, 2003
7. Burchard EG, Ziv E, Coyle N, Gomez SL, Tang H, Karter AJ, Mountain JL, Perez-Stable EJ, Sheppard D, Rissh N: The importance of race and ethnic background in biomedical research and clinical practice. N Engl J Med 348:1170–1175, 2003
8. Borak J, Fiellin M, Chemerynski S: Who is Hispanic? Implications for epidemiologic research in the United States. Epidemiol 15:240–244, 2004
9. Cooper RS, Kaufman JS, Ward R: Race and genomics. N Engl J Med 348:1166–1170, 2003
10. Fullilove MT: Comment: abandoning “race” as a variable in public health research—an idea whose time has come. Am J Public Health 88:1297–1298, 1998
11. Karter AJ: Commentary: Race, genetics, and disease: in search of a middle ground. Int J Epidemiol 32:26–28, 2003
12. Lin SS, Kelsey JL: Use of race and ethnicity in epidemiologic research: concepts, methodological issues, and suggestions for research. Epidemiol Rev 22:187–202, 2000
13. Ingram DM, Parker JD, Schenker N, Weed JA, Hamilton B, Arias E, Madans JH: United States Census 2000 population with bridged race categories. Vital Health Stat 2 135:1–55, 2003
14. SEARCH Study Group: SEARCH for Diabetes in Youth: a multicenter study of the prevalence, incidence and classification of diabetes mellitus in youth. Control Clin Trials 25:458–471, 2004
15. Liese AD, Liu L, Davis C, Standiford D, Waitzfelder B, Dabelea D, Bell R, Williams D, Imperatore G, Lawrence JM: Participation in pediatric epidemiologic research: the SEARCH for Diabetes in Youth Study experience. Contemp Clin Trials 29:829–36, 2008
16. Maahs DM, Snively BM, Bell RA, Dolan L, Hirsch I, Imperatore G, Linder B, Marcorina SM, Mayer-Davis EJ, Pettitt DJ, Rodriguez BL, Dabelea D: Higher prevalence of elevated albumin excretion in youth with type 2 than type 1 diabetes: the SEARCH for Diabetes in Youth Study. Diabetes Care 30:2939–2938, 2007

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