

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 In-

stitute 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	3,815	2,298	885	376
Total cases	9,174	4,564	1,590	588

Data are *n*.

lized the National Center for Health Statistics plurality approach, in which data from a study designed to address multiple-race reporting was used to determine which single-race category should be assigned for specific combinations of multiple races reported (13).

For each of the five articles in this supplement, estimates of prevalence, incidence, and selected demographic and clinical characteristics of youth with diabetes are reported. Because diabetes is unique in many ways across the race/ethnic groups, each article presents additional data accordingly and provides discussion points as appropriate. A preview of the areas of focus for each article is as follows:

Non-Hispanic whites

- Incidence of type 1 diabetes is compared with results from other studies conducted around the world in other white populations.
- Characteristics of non-Hispanic white youth with type 2 diabetes, albeit quite rare in this group, are described.

African Americans

- Type 1 diabetes in African American adolescents, generally not the focus in recent literature, is described.
- Prevalence of poor metabolic status and

unhealthy lifestyle behaviors for African American youth with either type 1 or type 2 diabetes is highlighted.

- Key demographic factors related to socioeconomic status are considered.

Hispanics

- The burden of diabetes related to both type 1 and type 2 diabetes in Hispanic youth is described and differences by sex are reported.
- Poor glycemic control and adverse cardiovascular disease risk profile in youth with both type 1 and type 2 diabetes are highlighted.

Asians and Pacific Islanders

- Characteristics of diabetes, including weight status, are compared across subgroups of Asian/Pacific Islanders and those who are of both Asian and Pacific Island descent.

Navajo

- The occurrence of type 1 diabetes and the heavy burden of type 2 diabetes among Navajo youth is described.
- Poor glycemic control, adverse cardiovascular disease risk factors, and unhealthy health behaviors are described.

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-

ward advancing our understanding of diabetes and its complications in youth.

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