Prevalence of Diagnosed Diabetes Among African-American and Non-Hispanic White Youth, 1999

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OBJECTIVE — To document diabetes prevalence among African-American and non-Hispanic white youth in a two-county region in South Carolina.

RESEARCH DESIGN AND METHODS — We conducted a population-based surveillance effort to identify case subjects aged 0–18.9 years with a physician diagnosis of diabetes residing in a two-county region in 1999. Case subjects were ascertained from hospitals, the sole office of pediatric endocrinology, and several smaller sources. Case subjects were classified according to the diagnosis made by a pediatric endocrinologist. As a completeness check, eight randomly selected physicians were queried for eligible case subjects. Capture-recapture provided an additional measure of completeness. Prevalence estimates used U.S. 2000 Census data for the two-county denominator.

RESULTS — Crude total diabetes prevalence was 1.7 cases per 1,000 youth and similar between African-American and non-Hispanic white youth. Among younger youth (0–9.9 years), non-Hispanic white total prevalence was 1.1 per 1,000 and African-American prevalence was 0.6 per 1,000. Among older youth (10.0–18.9 years), non-Hispanic white total prevalence was 2.5 per 1,000 and African-American prevalence was 3.1 per 1,000. Type 2 diabetes was only confirmed among older prevalent cases. Ascertainment completeness was estimated to be 98%.

CONCLUSIONS — Our estimates suggest that total diabetes prevalence among non-Hispanic white youth is similar to rates observed over 20 years ago. Among African-American youth, the difference in prevalence noted between younger and older age-groups was notably greater than that observed among the non-Hispanic white youth, potentially reflecting a more marked increase in diabetes incidence with age.

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The emergence of type 2 diabetes among youth in North America has recently been described (1). Population-based data suggest that the incidence of type 2 diabetes among older African-American and non-Hispanic white youth is increasing (2), and several studies conducted within specialty clinics have noted increasing numbers of youth diagnosed with type 2 diabetes (1,3). Additionally, indications of an increase in the incidence of type 1 diabetes have been reported among nonwhite children in the U.S. (4). However, we know very little about how these increases have affected the overall population burden or prevalence of diabetes in youth. There are no prevalence estimates for type 2 diabetes among youth with the exception of Native American populations (5–6), nor are there any recent estimates of prevalence of type 1 diabetes in the U.S. According to data collected primarily among non-Hispanic white youth before the mid-1980s, the median prevalence of type 1 diabetes was ~1.7 cases per 1,000 youth (7).

The lack of standard case definitions for type of diabetes in youth, differing case ascertainment methodologies, and the recent widespread awareness of type 2 diabetes among youth make comparisons of previously recorded prevalence estimates of childhood and adolescent diabetes very difficult. Currently it is not entirely clear whether the apparent increasingly frequent reports of type 2 diabetes among youth reflect true increases in incidence, the result of changing diagnosis patterns due to increasing physician awareness, increased screening, or some combination thereof. Until accurate case definitions for type 1 and type 2 diabetes can be applied to population-based surveillance efforts, type-specific prevalence estimates will be difficult to establish. Because both type 1 and type 2 diabetes can result in similar diabetes-related complications later in life, this study focused on overall diabetes burden in youth and considered type-specific estimation as a secondary aim. This study will help describe the burden of diabetes among non-Hispanic white and African-American youth.

RESEARCH DESIGN AND METHODS

— The Richland/Lexington County Childhood and Adolescent Diabetes Registry (RLDR) was a population-based effort that identified youth who had a physician diagnosis of diabetes, were a resident of Richland or Lexington county, and were aged <19 years (born on or after 1 January 1981, for the index year of 1999).

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Abbreviations: ADA, American Diabetes Association; RLDR, Richland/Lexington County Childhood and Adolescent Diabetes Registry.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

Case identification

Multiple sources of case identification were used, including *1*) area hospitals located within Richland and Lexington counties (emergency room services, inpatient services, and outpatient services), *2*) the sole pediatric endocrinology office, *3*) two large-area pediatric outpatient clinics (a university-affiliated pediatric clinic and a clinic that primarily serves youth who would otherwise not have access to basic health care), *4*) all adult endocrinology clinics within the two-county region, and *5*) a local diabetes camp registration list. The hospitals and the university-affiliated pediatric clinic used billing data to identify all potentially eligible youth who were billed with an ICD-9-CM code of 250.00–250.99 between the years 1995 and 1999. All other sources provided current lists of patients known to have diabetes. The only hospital of five that did not provide data was a local Veterans hospital that does not have a department of pediatrics. An adult endocrinologist at this location was included in our ascertainment efforts.

Case validation

Diabetes-related ICD-9-CM codes were not considered a definite indicator of diagnosed diabetes but served to identify potential cases of diabetes. A participant was considered a valid case subject if there was physician confirmation (written or verbal) of a diagnosis of diabetes or a subject's parent or the subject, if aged >18 years, confirmed in a survey (by phone or mail) that the subject has had a diagnosis of diabetes. Participating providers were asked to report cases of type 1 or type 2 diabetes only. During the validation effort, reports determined to be cases of gestational diabetes or diabetes secondary to another condition were excluded from this study.

Typology

Valid case subjects that were current patients of the local pediatric endocrinologist (n = 181) were assigned a specific diabetes type. Classification was based on the latest clinical impression of the pediatric endocrinologist. There were no widely accepted case definitions for diabetes in youth at the initiation of this study. The American Diabetes Association (ADA) has recently stated that specific diabetes type is best determined at onset in order to focus on disease etiology (8). As this was a prevalence study, many youth were diagnosed years ago, and helpful information such as diabetes autoantibody data or even information regarding symptoms at diagnosis was not available. Therefore, this study relied on the clinical acumen of a specialist. We made no attempt to assign diabetes type to valid cases that were not patients of the local pediatric endocrinologist due to lack of consistent information regarding diabetes type. These 64 case subjects remain classified as unknown diabetes type.

Denominator

Year 2000 population estimates from the U.S. 2000 Census (9) for the two counties were used as denominators rather than 1999 population projections, which were based on U.S. 1990 Census data. The U.S. 1990 Census is thought to have systematically underestimated minority populations (10). In 2000, an estimated 140,492 youth aged <19 years resided in Richland and Lexington Counties. Youth in Richland and Lexington counties are primarily African American (39%) or non-Hispanic white (56%). Therefore, race-specific prevalence was not calculated among youth who were not African American or non-Hispanic white. However, these youth were counted in the crude prevalence estimates.

Estimation of prevalence

Numerators for prevalence estimates were defined as the number of youth who at any time during 1999 were eligible and validated as case subjects. Total diabetes (type 1, type 2, and undetermined type) prevalence was calculated for the entire sample and according to race, sex, and age-group (young [0–9.9 years] and older [10–18.9 years]) and expressed as number of cases per 1,000 youth. The Poisson distribution was used to calculate 95% CIs for estimates of total prevalence. Proportions of youth with type 1, type 2, and unknown diabetes type were also determined according to race, sex, and age-group.

Completeness of case ascertainment

Two approaches were undertaken to evaluate completeness of ascertainment. First, we received a listing of all active physicians with a Richland or Lexington County address currently licensed in pediatrics or family/general practice (n = 316) from the South Carolina Department of Labor, Licensing and Regulation, Board of Medical Examiners. Four pediatricians and four family practice physicians were randomly selected for inclusion. Selected physicians were asked to provide a list of all eligible patients seen by his/her practice. Larger practices were more likely selected due to the greater number of physicians practicing within the facility. Two selected physicians refused to participate and were replaced by random selection.

Second, multiple-source capture-recapture methods using the log-linear approach described by Hook and Regal (11) were used to estimate the true number of cases within the two-county region. Three analytical sources were defined to adjust for potential dependencies between sources and include the pediatric endocrinologist, all participating hospitals (combined as one source), and the remaining sources (combined as one source). Capture-recapture estimates were calculated by race and for the entire population. The randomly selected physicians were not included in the capture-recapture analysis, as they were considered an independent means to assess completeness of ascertainment.

RESULTS

Initially 368 unique individuals were reported to the RLDR. Of these reports, 245 were eligible and valid diabetic case subjects, 71 were false-positive reports (validated as never diagnosed with diabetes), 8 were found ineligible due to moving from the catchment area, 2 were found to have diabetes secondary to another condition, and 1 had died before 1999. The remaining 41 reports were excluded because diabetes status could not be validated, even after medical record review. The large number of false-positive reports was largely the result of using billing data as an initial means to identify potential case subjects.

Total diabetes prevalence

Table 1 shows prevalence and 95% CIs of all diabetes, regardless of type classification, by race, age, and sex. Total diabetes prevalence for all youth was 1.7 cases per 1,000. Total prevalence among non-Hispanic white youth was identical to that of African-American youth (1.8 cases per 1,000). Among the younger children (aged 0–9.9 years), non-Hispanic white prevalence (1.1 per 1,000) was approximately twice that noted among African-

Table 1—*Number of case subjects and prevalence of diabetes (type 1, type 2, and undetermined type) and 95% CIs per 1,000 youth aged 0–18.9 years, the RLDR*

	Total			Male			Female		
	N	PE	95% CI	*n*	PE	95% CI	*n*	PE	95% CI
All races									
Total	245	1.7	(1.5–2.0)	126	1.8	(1.5–2.1)	119	1.7	(1.4–2.1)
0–9.9 years	64	0.9	(0.7–1.1)	35	1.0	(0.7–1.3)	29	0.8	(0.6–1.2)
10–18.9 years	181	2.6	(2.3–3.0)	91	2.6	(2.1–3.2)	90	2.7	(2.2–3.3)
Non-Hispanic white									
Total	140	1.8	(1.5–2.1)	77	1.9	(1.5–2.4)	63	1.6	(1.3–2.1)
0–9.9 years	44	1.1	(0.8–1.5)	25	1.2	(0.8–1.8)	19	1.0	(0.6–1.5)
10–18.9 years	96	2.5	(2.0–3.0)	52	2.6	(2.0–3.4)	44	2.3	(1.7–3.1)
African American									
Total	100	1.8	(1.5–2.2)	48	1.7	(1.3–2.3)	52	1.9	(1.4–2.5)
0–9.9 years	18	0.6	(0.4–1.0)	10	0.7	(0.3–1.3)	8	0.6	(0.2–1.1)
10–18.9 years	82	3.1	(2.4–3.8)	38	2.8	(2.0–3.8)	44	3.4	(2.4–4.5)
Other									
Total	5	—	—	1	—	—	4	—	—
0–9.9 years	2	—	—	0	—	—	2	—	—
10–18.9 years	3	—	—	1	—	—	2	—	—

PE, prevalence.

American youth (0.6 per 1,000). Conversely, among the older youth (aged 10–18.9 years) the prevalence among non-Hispanic white youth was lower than among African-American youth (2.5 per 1,000 vs. 3.1 per 1,000). The highest prevalence of diabetes was found among older African-American females (3.4 per 1,000).

Proportion of youth with type 1, type 2, and unknown diabetes type

Among those seen by a pediatric endocrinologist ($n = 181$) and therefore assigned diabetes type, 152 were classified as type 1 diabetic case subjects and 29 were classified as type 2 diabetic case subjects. Within every race, sex, and age subgroup we identified and validated case subjects that had not been seen by the pediatric endocrinologist and therefore remained of unknown type for this study. Figures 1 and 2 show proportions of youth with type 1, type 2, and unknown diabetes type among youth with diagnosed diabetes.

Among those aged <10 years, 14 of 64 case subjects were not assigned a specific diabetes type (Fig. 1). Proportions of youth with undetermined diabetes type ranged from 8% (non-Hispanic white males) to 40% (African-American males). Among the others, we found no prevalent cases of diagnosed type 2 diabetes. However, four individuals who were aged >10 years and currently classified as having type 2 diabetes were initially diagnosed with type 2 diabetes before their 10th birthday.

Among the older youth, diabetes type was not assigned to 50 (28%) of the identified case subjects. Among those for whom type was assigned, older African-American females formed the largest proportion diagnosed with type 2 diabetes (Fig. 2). Approximately one-half (44.8%) of all older African-American females diagnosed with type 1 or type 2 diabetes were diagnosed with type 2 diabetes. The proportion was lower for African-American males, non-Hispanic white males, and non-Hispanic white females (19.2, 14.3, and 12.1%, respectively).

Case ascertainment completeness

The random sample of primary care practices identified 20 eligible case subjects, all of whom had been previously identified by the registry, which suggests adequate completeness of ascertainment. Multiple-source capture-recapture analysis estimates that the degree of ascertainment for the entire registry was ~98%. Estimates calculated separately by race suggest that RLDR identified 99% of non-Hispanic white and 94% of African-American case subjects. We observed a high level of dependency between the referral sources. In fact, 80% of the case subjects included in this report were reported to the registry by two or more sources and approximately one-half (49%) were reported from three or more sources.

CONCLUSIONS— Recent studies describe increasing numbers of youth classified as having type 2 diabetes (1,3). Most studies reporting on prevalence in the U.S. were conducted primarily among non-Hispanic white youth >20 years ago, when childhood diabetes was considered to be type 1 diabetes. Interestingly, total diabetes prevalence for all races in this study (1.7 cases per 1,000 youth) was similar to previously reported rates of type 1 diabetes among youth, which also cluster around 1.7 cases per 1,000 youth (7). Since there is no evidence of decreasing incidence of type 1 diabetes among the young, this could suggest that changing diagnostic patterns account for some of the increased numbers of youth diagnosed with type 2 diabetes. Alternatively, this may suggest that diagnosis of type 2 diabetes among the general population is still very rare relative to the existing num-

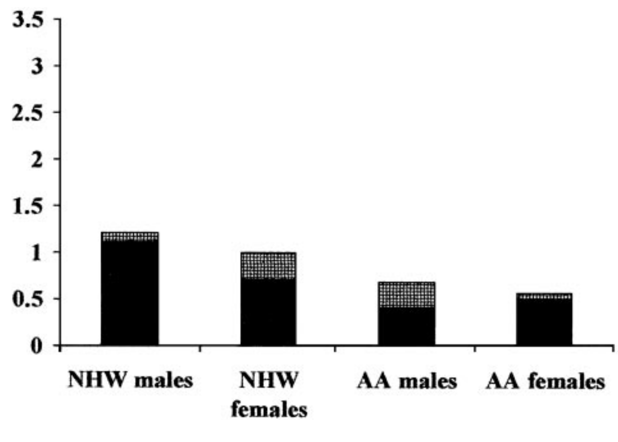

Figure 1—*Number of cases per 1,000 youth aged 0–9.9 years by diabetes type and race/sex subgroup. NHW, non-Hispanic white; AA, African American; ▦, unknown diabetes type; ■, type 1 diabetes.*

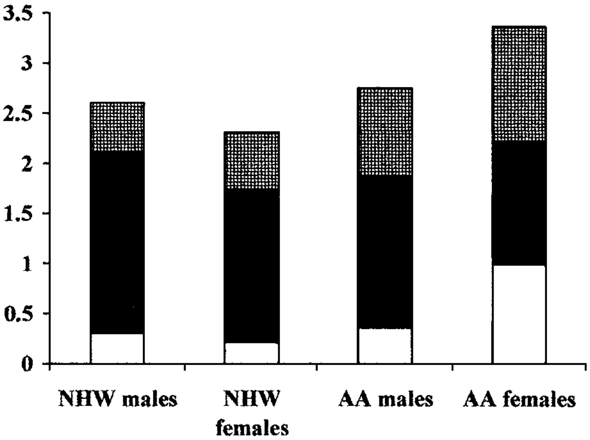

Figure 2—*Number of cases per 1,000 youth aged 10–18.9 years by diabetes type and race/sex subgroup. NHW, non-Hispanic white; AA, African American;* ▦, *unknown diabetes type;* ■, *type 1 diabetes;* □, *type 2 diabetes.*

ber of cases of childhood type 1 diabetes and therefore has had little effect on the population prevalence of diabetes.

However, further examination regarding specific diabetes type within age and race subgroups suggests that if type 2 diabetes among youth in our general population is epidemic, it appears to affect older African-American youth more often than their non-Hispanic white peers. Thus, our population-based findings are consistent with previous studies that found that nonwhite youth account for the majority of cases of type 2 diabetes (1). We found that type 2 diabetes accounts for 26% of prevalent African-American case subjects and only 10% of prevalent non-Hispanic white case subjects who were classified by type. Similar to findings from a nearby clinic-based study in coastal South Carolina in which almost one-half (46%) of African-American youth aged 10–19 years with new-onset diabetes was classified as having type 2 diabetes (12), we found that almost one-half of the older African-American females with diagnosed type 1 or type 2 diabetes were classified as having type 2 diabetes.

Two studies of prevalence conducted among school-aged youth in the 1970s suggested that prevalence rates of type 1 diabetes among non-Hispanic white youth were approximately twice as high as those noted among minority populations (13–14). This is consistent with what we observed for total diabetes prevalence among youth aged <10 years, the age-group in which no prevalent cases of type 2 diabetes was noted.

In contrast, among the older youth we found that total diabetes prevalence among African-American youth is now higher than that of non-Hispanic white youth. In Chicago, increasing incidence of childhood diabetes among minority youth is driven by an increase in youth with type 2 diabetes (15), which may explain the relatively high total diabetes prevalence among older African-American youth noted in this study.

Currently there are no widely used case definitions for classifying diabetes type among youth. Although most youth diagnosed with type 2 diabetes are older at diagnosis, belong to a minority population, and are overweight or obese (1), these factors cannot be used to rule out type 1 diabetes. The ADA recommends classification based on pathogenic criteria (8). However, this recommendation is very difficult to apply to population-based efforts that focus on prevalence. We found that many youth, especially those diagnosed years ago, did not undergo a thorough pathophysiological evaluation and classification was therefore limited to clinical impression. Further complicating the estimation of type-specific rates are those case subjects whose clinical information is not readily available or unobtainable. This study suffered from the lack of laboratory data needed to better assign diabetes type for the entire cohort and the lack of clinical data for those who ultimately were classified as type unknown.

The majority of children included in this study (73%) were assigned diabetes type by their pediatric endocrinologist according to clinical presentation and clinical course. According to the ADA Consensus Statement "Type 2 Diabetes in Children and Adolescents" (16), most cases can be accurately classified based on disease presentation and course; we therefore feel that misclassification of case subjects seen by the pediatric endocrinologist is minimal. The remaining 27% of case subjects were not current patients of the local pediatric endocrinologist; therefore, reliable and consistent data regarding diabetes type were not available. It is important to note that a larger percentage of non-Hispanic white youth were identified by the local pediatric endocrinologist than their African-American peers (80 and 66%, respectively), and therefore a greater proportion of African-American youth were not classified according to diabetes type. This was an unfortunate finding considering this is the population subgroup in which diabetes typology is perhaps most critical.

To provide at least a tentative estimate of prevalence of type 2 diabetes among both African-American and non-Hispanic white youth, we applied the race/sex-specific proportion of case subjects diagnosed with type 2 diabetes (noted among the patients of the local pediatric endocrinologist) to those whose diabetes type is unknown. From this exercise we estimate the following number of cases of type 2 diabetes per 1,000 youth aged >10 years: 0.6 total, 0.4 non-Hispanic white males, 0.3 non-Hispanic white females, 0.5 African-American males, and 1.5 African-American females. Among all youth aged 0–18.9 years, prevalence of type 2 diabetes is estimated to be as low as 0.3 per 1,000. Assuming these estimates of type 2 diabetes are correct, we can estimate that the numbers of type 1 diabetes cases per 1,000 youth aged >10 years are: 2.0 total, 2.2 non-Hispanic white males, 2.4 non-Hispanic white females, 2.3 African-American males, and 1.9 African-American females. While type 2 diabetes among the young has received a great amount of attention recently, this study suggests that type 1 diabetes remains the much larger burden for both African-American and non-Hispanic white youth in our general population of youth <19 years of age.

Regardless of specific diabetes type, overall rates presented here appear to be sound according to two completeness checks. Both suggest that RLDR approached completeness of ascertainment, thus strengthening our prevalence estimates. Several ascertainment biases were considered that could not be evaluated through capture-recapture analysis or the random selection of physician practices. Most importantly, this study describes prevalence of diagnosed diabetes, and no screening effort was undertaken to determine the amount of undiagnosed cases. Additionally, this study describes diagnosed case subjects that receive care. It is possible that some youth/young adults do not receive care regularly, therefore detection with our system would be unlikely. Finally, it is possible that eligible diagnosed case subjects travel outside of these two counties for care and would therefore remain undetected. However, the counties surrounding Richland and Lexington counties are extremely rural, and the nearest urban centers with large medical centers and endocrinology departments are between a 1- to 2-h drive away. While we cannot determine the number of patients who seek care exclusively outside Richland or Lexington counties, we do not feel that this led to severe underascertainment.

The proportion of those diagnosed with type 2 diabetes has been shown to be increasing among those diagnosed with diabetes; however, data showing increasing prevalence or even increasing numbers of youth with diabetes of any type is sparse among African-American and non-Hispanic white populations. Although we were unsuccessful in estimating type-specific rates, this is to the best of our knowledge the first study to suggest that the overall burden or prevalence of diabetes is similar between African-American and non-Hispanic white youth aged 0–18.9 years. While crude rates are similar across race, perhaps the most important observation from this study is noted after stratification by age-group and race. Among African-American youth, the difference in prevalence noted between younger and older age-groups was notably greater than that observed among the non-Hispanic white youth, potentially reflecting a more marked increase in diabetes incidence with age.

Estimation of type-specific rates presents epidemiologists with major challenges. While this study classified youth as having type 1, type 2, and unknown diabetes type, youth with clinical features of type 2 diabetes and metabolic features more typically seen in type 1 diabetic patients may further blur the lines of diabetes typology. As the prevalence of overweight youth in our nation continues to increase, particularly among non-Hispanic, African-American, and Mexican-American youth (17), a larger proportion of true type 1 diabetic patients will be overweight, presenting clinicians with even greater diagnostic challenges without the help of laboratory data. Complete understanding of the recently labeled epidemic will require multiracial population-based studies that consistently collect autoimmune markers and clinical characteristics at onset to assign diabetes type.

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