



Original article

Factors influencing time to case registration for youth with type 1 and type 2 diabetes: SEARCH for Diabetes in Youth Study



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ABSTRACT

Purpose: The development of a sustainable pediatric diabetes surveillance system for the United States requires a better understanding of issues related to case ascertainment.

Methods: Using the SEARCH for Diabetes in Youth registry, we examined whether time from diabetes diagnosis to case registration differed by diabetes type, patient demographics, and the type of provider reporting the case to the study. Plots for time from diagnosis to registration were developed, and differences by key variables were examined using the log-rank test.

Results: Compared with time to registration for type 1 cases, it took 2.6 (95% confidence interval [CI], 2.5–2.6) times longer to register 50% of type 2 diabetes cases, and 2.3 (95% CI, 2.0–2.5) times longer to register 90% of type 2 cases. For type 1 diabetes cases, a longer time to registration was associated with older age, minority race/ethnicity, and cases, where the referring provider was not an endocrinologist. For type 2 diabetes cases, older age, non-Hispanic white race/ethnicity, and cases reported by providers other than an endocrinologist took longer to identify and register.

Conclusions: These findings highlight the need for continued childhood diabetes surveillance to identify future trends and influences on changes in prevalence and incidence.

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Introduction

Diabetes is one of the leading chronic diseases in youth [1], yet data on burden and trends of type 1 and type 2 diabetes in youth in the United States were scarce until the early 2000s. In the United States, surveillance for diabetes in adults relies predominantly on self-report and laboratory data from national surveys [2]. However, because the prevalence of diabetes in childhood is relatively low

(<1%) [3], national surveys do not have a large enough sample size to produce reliable estimates by diabetes type, within demographic groups or at the state level. From 1999 to 2010, the National Health and Nutrition Examination Survey only yielded 58 self-reported cases of diabetes among youth aged 12–19 years [4]. Before year 2000, limited data from North America existed on the incidence of type 1 and type 2 diabetes among individuals less than 20 years and existing data were from populations in limited geographic areas [5–7] or very selected populations (e.g., native populations) [8,9].

The SEARCH for Diabetes in Youth was designed and launched in 2000 as the largest ongoing registry of diabetes in U.S. youth to conduct a comprehensive assessment of the incidence and prevalence of type 1 and type 2 diabetes in youth less than 20 years across all racial/ethnic groups in geographically diverse and defined

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areas. From 2001 to 2009, SEARCH reported a 21.1% (95% CI, 15.6–27.0) increase in the prevalence of type 1 diabetes and a 30% (95% CI, 17.3%–45.1%) increase in the prevalence of type 2 diabetes in youth, and, from 2002 to 2009, a 2.7% annual increase in the incidence of type 1 diabetes in non-Hispanic white youth [3]. These findings highlight the need for continued childhood diabetes surveillance to identify future trends and influences on changes in prevalence and incidence. Understanding factors influencing time to registration of newly diagnosed cases of pediatric diabetes is essential for efficient and sustainable approaches to surveillance in the future and interpretation of the results. Therefore, we explored potential contributors to a delay in case registration after onset of diabetes including diabetes type, case demographic characteristics, and referring health care provider type.

Materials and methods

Study design and data collection

SEARCH is a multicenter epidemiologic surveillance study funded by the Centers for Disease Control and Prevention and the National Institutes for Diabetes and Digestive Kidney Diseases that conducts population-based case ascertainment of youth diagnosed with diabetes (excluding gestational diabetes) with onset before 20 years of age. A detailed description of the SEARCH study has been published elsewhere [10]. In brief, the catchment areas for the SEARCH study include four geographic sites based in Ohio (eight counties in the Greater Cincinnati area); the entire state of Colorado; five counties around Seattle, Washington; the entire state of South Carolina; and two membership-based locations: Kaiser Permanente Southern California (including members from seven counties) and Indian Health Service beneficiaries drawn from reservation-based populations in Arizona and New Mexico, recruited under the direction of the Colorado site. The study was approved by the institutional review boards with jurisdiction at each center. To identify a high proportion of individuals with childhood onset diabetes in the context of the complex structure of the U.S. health care system, SEARCH study investigators contact multiple primary and specialty care providers, hospitals, and ambulatory practices, and query electronic health records to identify cases. Local case identification relies heavily on pediatric and adult endocrinologists, with additional cases identified through a limited number of other primary care centers, hospitals, community health centers, review of clinical and administrative health data, and existing clinical registries. Case reports are validated based on physician diagnosis and eligibility based on age, county of residence, nonmilitary, noninstitutionalized, and health plan membership (California) or Indian Health Service membership (for Native American sites). Demographic information, date of diagnosis, and diabetes type are collected from medical record review. Case registration is performed under a waiver of consent from the Health Insurance Portability and Accountability Act, as approved at each site. Duplicate cases are removed using combinations of name or initials, date of birth, date of diagnosis, sex, and race/ethnicity. After validation and de-duplication, cases are registered with the coordinating center. Case ascertainment completeness is assessed using capture-recapture, which was shown to be consistently over 90% for both type 1 and type 2 diabetes over the study period of 2005 through 2009 [3].

All incident type 1 diabetes (types 1, 1a, and 1b) and type 2 diabetes cases diagnosed from 2005 through 2009 and registered within 30 months of diagnosis were included in our analysis. Cases registered with a diabetes type attributed to a single-gene mutation affecting beta-cell function, historically referred to maturity onset diabetes of youth ($n = 23$), as well as those with uncertain type ($n = 89$) were excluded from this analysis.

Statistical analysis

Plots for time from diagnosis to registration were developed by diabetes type and within-diabetes type by: age group (0–4, 5–9, 10–14, 15–19 years for type 1 diabetes and 10–14 and 15–19 years for type 2 diabetes), race/ethnicity (non-Hispanic white [NHW] vs. “other”) and type of referring provider (adult or pediatric endocrinologist and other type of provider). Differences in the overall curves by key variables were tested using the log-rank test. The time to registration of 50% and 90% of all identified and registered cases (based on 100% of those known to the study) were calculated by diabetes type and within-diabetes type by the above variables. The ratio of time to 50% and 90% registration for type 2 compared to type 1 diabetes was calculated by the key variables above along with the 95% confidence intervals using a Taylor series expansion to generate the variance. Statistical analyses were conducted using SAS 9.4 (SAS Institute, Cary, NC).

Results

Type 1 diabetes

A total of 5264 incident cases of type 1 diabetes among youth less than 20 years at diagnosis were registered between 2005 and 2009. The proportion of cases by age group was 16.1% for 0–4 years, 32.6% for 5–9 years, 36.5% for 10–14 years, and 14.8% for 15–19 years. Non-Hispanic white youth comprised 68.4% of the type 1 diabetes cases, and the referring provider was an endocrinologist for 91.3% of cases (Table 1). Figure 1 shows the time from diagnosis to registration for 2005–2009 incident cases by diabetes type. The median time from diagnosis to registration was 2.2 months for type 1 diabetes cases, and the median time to 90% registration was 11.2 months (Fig. 1). Time to registration increased significantly for older age groups ($P < .0001$), as illustrated in Figure 2. Time to registration of 90% of cases was 9.6, 10.1, 10.9, and 16.9 months for cases diagnosed at 0–4, 5–9, 10–14, and 15–19 years, respectively (Fig. 2). Figure 3 shows that the overall time to registration according to race/ethnicity. Time to 90% registration was 11.5 months for racial/ethnic minorities compared to 10.6 months for NHW cases ($P = .03$). Figure 4 shows that the overall time to registration was shorter when the referring provider was an endocrinologist compared to all other provider types (9.1 months compared to 22.5 months to register 90% of the cases, $P < .0001$).

Type 2 diabetes

A total of 1266 incident cases of type 2 diabetes among youth less than 20 years were registered by SEARCH between 2005 and 2009.

Table 1

Total incident cases of type 1 and type 2 diabetes among youth less than 20 years of age in the SEARCH for Diabetes in Youth Study, 2005–2009

	Diabetes type	
	Type 1, $n = 5264$	Type 2, $n = 1266$
	N (%)	N (%)
Age at diagnosis (y)		
0–4	849 (16.1)	3 (0.2)
5–9	1715 (32.6)	66 (5.2)
10–14	1923 (36.5)	583 (46.1)
15–19	777 (14.8)	614 (48.5)
Race/ethnicity		
NHW	3603 (68.4)	243 (19.2)
All others	1661 (31.6)	1023 (80.8)
Type of referring provider		
Endocrinologist	4805 (91.3)	852 (67.4)
All others	459 (8.7)	413 (32.6)

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