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Mortality in Youth-Onset Type 1 and Type 2 Diabetes: the SEARCH for Diabetes in Youth Study

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Abstract

Aims—To estimate short-term mortality rates for individuals with type 1 or type 2 diabetes diagnosed before age 20 years from the SEARCH for Diabetes in Youth study.

Methods—We included 8358 individuals newly-diagnosed with type 1 (n=6840) or type 2 (n= 1518) diabetes from 1/1/2002–12/31/2008. We searched the National Death Index through 12/31/2010. We calculated standardized mortality ratios (SMRs) as observed divided by expected numbers of deaths based on age, sex, and race for the comparable US population in the geographic areas of the SEARCH study.

Results—Mean age at diabetes diagnosis was 10.7 years. During 44,893 person-years (PY) of observation (median follow-up=5.3 years), 41 individuals died (91.3 deaths/100,000 PY); 26 with

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type 1 (70.6 deaths/100,000 PY) and 15 with type 2 (185.6 deaths/100,000 PY) diabetes. The expected mortality rate was 70.9 deaths/100,000 PY. The overall SMR (95% CI) was 1.3 (1.0, 1.8) and was high among individuals with type 2 diabetes 2.4 (1.3, 3.9), females 2.2 (1.3, 3.3), 15–19 year olds 2.7 (1.7–4.0), and non-Hispanic blacks 2.1 (1.2, 3.4).

Conclusions—Compared to the state populations of similar age, sex, and race, our results show excess mortality in individuals with type 2 diabetes, females, older youth, and non-Hispanic blacks. We did not observe excess short-term mortality in individuals with type 1 diabetes. Studies of longer-term mortality in individuals with youth-onset diabetes are warranted.

Keywords

Type 1 Diabetes; Type 2 Diabetes; Mortality; Epidemiology; Youth

1. Introduction

Population-based studies in the US and territories,[1–4] as well as other countries [5–13] have reported increased mortality for individuals with youth-onset type 1 diabetes compared to the general population, with standardized mortality ratios (SMRs) varying from 1.7 to 12.9 [5, 8]. Although few studies have evaluated mortality risk among individuals with youth-onset type 2 diabetes, it has been suggested that their mortality experience is worse than the general population and worse than those with youth-onset type 1 diabetes.[7, 14]

There is a paucity of data from contemporary populations in the US that can be used to identify people with youth-onset diabetes and evaluate their mortality risk. Most published studies have been limited to persons with type 1 diabetes. Further, few studies have examined cause-specific mortality among youth-onset type 2 diabetes. Using data from the SEARCH for Diabetes in Youth (SEARCH) study, we sought to estimate all-cause and cause-specific mortality in individuals with incident type 1 and type 2 diabetes diagnosed before 20 years of age (“youth-onset”) and to determine if the short-term mortality experience among SEARCH study participants differs from that of the comparable US population in the geographic areas of the SEARCH study.

2. Participants

SEARCH is a multicenter, population-based observational study of youth with incident diabetes who are followed longitudinally. A detailed description of study methods has been published.[15] In brief, incident cases of physician-diagnosed diabetes in individuals aged <20 years were identified beginning in 2002. Diabetes type is based on physician report around the time of diabetes and categorized as type 1 (including type 1, type 1a, or type 1b) and type 2 diabetes. Cases were ascertained from geographically defined populations at sites in Ohio, Colorado, South Carolina and Washington, among enrollees in one health plan in California (Kaiser Permanente Southern California), and among Indian Health Service beneficiaries from American Indian populations in Arizona and New Mexico. Cases were identified through networks of pediatricians and endocrinologists, other healthcare providers, hospitals, community health centers, and health plans.Eligible cases were registered anonymously with the coordinating center at the Wake Forest School of Medicine.

Case ascertainment has been >90% for both type 1 and type 2 diabetes for the duration of the study.[15, 16]

Local institutional review boards with jurisdiction over local study populations approved the study.

3. Materials and Methods

3.1 Mortality ascertainment

Vital status (living, deceased, unknown) and underlying and contributing causes of death were determined from linkages of all registered diabetes cases with the National Death Index (NDI) Plus database [17] from the date of diabetes diagnosis through 12/31/2010 unless cases were known to be alive on or after that date. Records where cases were known to be deceased were submitted to the NDI to obtain cause of death. NDI records were searched for all years for which vital status could not be confirmed. Deaths were verified by matching name, social security number (if available), date of birth, and sex. Death certificates and reports of deaths by immediate family members or healthcare providers were also considered definitive evidence of death.

Cause of death was derived from the NDI file and classified per International Classification Diseases, Tenth Revision (ICD-10). “Underlying cause of death” was used for cause-specific mortality. “Contributing cause of death” was used to identify deaths where diabetes was a significant condition contributing to death but not the underlying cause.

All 9213 individuals with incident type 1 or type 2 diabetes diagnosed between 1/1/2002 and 12/31/2008 were eligible for mortality surveillance. We excluded 855 (9.3%) cases because their vital status was unknown and we did not have sufficient individual-level data for NDI linkage, leaving 8358 for mortality surveillance. The excluded cases were older at diagnosis, more likely to have type 2 than type 1 diabetes and to be non-Hispanic black or of unknown race/ethnicity compared to cases who were known alive or whose data were submitted to the NDI.

3.2 Statistical Analysis

Person-years (PY) of follow-up were calculated from date of diabetes diagnosis to either 12/31/2010 or date of death, whichever occurred first. Age-, sex-, and race-standardized mortality rates were calculated using respective US state populations of the SEARCH study sites. Standardized mortality ratios (SMRs) were calculated as observed numbers of deaths in the SEARCH study divided by expected numbers of deaths based on age, sex, and race distributions for comparable US state populations of the study sites. For each year, we obtained population sizes and deaths in the corresponding US state populations from the Centers for Disease Control and Prevention (CDC) Wide-ranging Online Data for Epidemiologic Research (WONDER) online tool, which contains mortality and population counts for all US counties.[18] Poisson regression was used to model death rates and calculate 95% confidence intervals (CIs). Cause-specific mortality rates were not calculated because the numbers of deaths were too small for reliable estimates. Statistical analyses were performed using SAS software, version 9.3 (SAS Institute, Cary, NC).

4. Results

Demographic characteristics of the 8358 SEARCH cases stratified by diabetes type are shown in Table 1. Follow-up time was similar among those with type 1 and type 2 diabetes.

During a median follow-up of 5.3 years (44,893 PY of observation), 41 deaths occurred (crude rate of 91.3 deaths/100,000 PY); 26 with type 1 (70.6 deaths/100,000 PY) and 15 with type 2 diabetes (185.6 deaths/100,000 PY) (Table 2). The expected mortality rate was 70.9 deaths/100,000 PY. Mortality for all groups combined was slightly higher than that of the comparable age-, sex-, and race-specific US state populations of the SEARCH study sites (SMR=1.3, 95% CI=1.0, 1.8), and was not statistically significant (p=0.08) (Figure 1). Mean (SD) age at death among individuals with type 1 and type 2 diabetes was 15.2 (4.9) and 20.0 (3.5) years, respectively. The crude mortality rate was higher for type 2 versus type 1 diabetes. Compared to the US state populations, mortality in the SEARCH study was significantly higher than expected for individuals with type 2 diabetes (SMR=2.4, 95% CI=1.3, 3.9; p=0.001) but not for individuals with type 1 diabetes (SMR=1.1, 95% CI=0.7, 1.6; p=0.84) (Figure 1). Females had higher mortality rates than males, and non-Hispanic Blacks and Hispanics had higher mortality rates than non-Hispanic whites. Individuals aged 15–19 years at the time of death had the highest mortality rates compared to other age groups (Table 2). No deaths occurred among the 320 non-Hispanic whites with type 2 diabetes (data not shown). Compared to the US state populations, mortality in the SEARCH study was significantly higher than expected for females (SMR=2.2, 95% CI=1.3, 3.3; p<0.001), non-Hispanic blacks (SMR=2.1, 95% CI=1.2, 3.4; p=0.004) and those aged 15–19 years (SMR=2.7, 95% CI=1.7, 4.0; p<0.001) at the time of death or end of follow-up (Figure 1).

Among decedents with type 1 diabetes, diabetes was the most frequent underlying cause of death followed by accidental injury and intentional self-harm (Table 3). Diabetes was listed as the contributing cause of death for 2 of the 26 deaths among individuals with type 1 diabetes. Using the underlying or contributing cause of death due to diabetes, 50% of deaths among those with type 1 diabetes were related to their diabetes. Among decedents with type 2 diabetes, the leading underlying cause of death was attributed to transport/motor vehicle accidents followed by accidental poisoning and intentional self-harm. Among individuals with type 2 diabetes, diabetes was not listed as contributing cause of death for any of the deaths but it was the underlying cause of death for 1 individual.

5. Discussion

In the SEARCH study, mortality for both types of diabetes together did not differ significantly from the comparable general US population in the geographic areas of the SEARCH study. However, compared to the general population, mortality was two-fold higher among those with type 2 diabetes, females, non-Hispanic Blacks, and those aged 15–19 years at the time of death.

We identified 41 deaths during 44,893 person-years (91.3 deaths/100,000 PY) of observation over a median follow-up of 5.3 years; 26 deaths occurred in youth-onset type 1 diabetes

(70.6 deaths/100,000 PY) and 15 deaths occurred in youth-onset type 2 diabetes (185.6 deaths/100,000 PY). The mortality rates we observed were substantially lower than what has been reported in other studies in the US [1, 19] and many other countries.[10] However, few studies have reported on short-term mortality risk in youth-onset diabetes and comparisons of our findings to previous studies should be made with caution, due to differences in methods, study populations (including type of diabetes, age at diagnosis, diabetes duration, and historical versus contemporary cohorts), and the background population mortality. During 7.8 years of follow-up in the Chicago Diabetes Registry of 1238 individuals with diabetes onset before age 18 between 1985–2000, 30 individuals were reported to have died (250 deaths/100,000 PY).[1] In the population-based Western Australia Children's Diabetes Database, mortality among individuals with type 1 diabetes diagnosed before age 18 between 1987–2011 was 74.5 deaths/100,000 PY during 7.6 years of follow-up.[8] The lower mortality rates seen in the Western Australia Children's Database and the SEARCH cohort could be due to a shorter duration of diabetes as well as the focus on more contemporary cohorts, which may have benefited from advances in diabetes treatment.

After a median 5.3 years of follow-up, we found that the crude mortality rate was higher for individuals with type 2 versus type 1 diabetes. Further, mortality for youth-onset type 2 diabetes was higher than expected compared to the similar age, sex, and race state populations of the SEARCH study sites. Several studies have suggested that youth-onset type 2 diabetes is associated with more severe chronic diabetes complications and greater mortality.[7, 20–22] Over a median 21 years of follow-up in the Royal Prince Alfred Hospital Diabetes Clinical Database in Australia, the adjusted hazard ratio for mortality was two-fold higher in type 2 versus type 1 diabetes (diabetes onset between ages 15–30 years).[7]

Mortality was higher in females compared to males in the SEARCH study and higher than expected in females compared with the general population (SMR=2.2; 95% CI: 1.3, 3.3). Similarly, the Western Australian Children's Diabetes Database study found that mortality for females with type 1 diabetes was 10 times that of the general population, while no statistically significant elevated mortality risk was observed in males [8]. Similar observations have been reported from studies conducted in Japan [23], Europe [6], and the US;[19] however, some studies have observed higher mortality in males compared to females.[24] The higher SMR among females may reflect the death rate in the general population for this age group where young males have a two-fold higher death rate than females.

We found that mortality in non-Hispanic blacks in the SEARCH study was 2.1 times higher than the mortality in the similar age, sex, and race state populations of the SEARCH study sites. These findings are supported by other studies in the US and territories.[1, 25, 26] We previously reported that a substantial proportion of non-Hispanic black youth with diabetes have adverse socioeconomic profiles,[27] which may be associated with barriers to care and contribute to the increased mortality.

There are several limitations to our study. We could not conduct detailed cause-specific mortality analyses due to the small number of deaths. Therefore, although it is interesting to note that only one death was attributed to diabetes in those with youth-onset type 2 diabetes, we were unable to determine whether this is related to socioeconomic, psychosocial or other

risk factors of acute deaths. The mortality estimates for youth-onset type 2 diabetes are based on a very small number of deaths over a very short time period and may not reflect the true mortality rates across the US. In addition, we could not ascertain vital status for 9.3% of the cohort. These individuals were older at diabetes diagnosis, more likely to have type 2 diabetes and to be non-Hispanic black; therefore, it is possible that our mortality findings are underestimated in these populations and the SMRs are higher than reported here. Further, we were unable to confirm cause of death through medical record review or death certificates. However, previous studies have demonstrated that the NDI is an accurate source for ascertaining vital status even in the absence of social security numbers. Sensitivity of the NDI ranges from 87% to 98% [28] and use of different combinations of personal identifiers can correctly identify 83% to 92% of decedents and 92% to 99% of living individuals.[29] Strengths of our study include the large sample size and racial/ethnic and geographic diversity, which makes our findings generalizable, although not necessarily generalizable to the entire US. Moreover, SEARCH is a unique and valuable resource for conducting mortality surveillance since it includes individuals with youth-onset type 1 and type 2 diabetes. Few contemporary cohorts of incident type 1 and type 2 diabetes in children and young adults in the US are available; therefore, these results likely provide the most comprehensive and current estimates of the mortality experience of youth-onset diabetes in the US.

6. Conclusions

Among individuals with type 1 or type 2 diabetes, our results show excess short-term mortality risk in individuals with type 2 diabetes, non-Hispanic blacks, females and those aged 15–19 years compared to youth of similar age, sex, and race in the corresponding US states. We did not observe excess mortality in individuals with type 1 diabetes. Our findings begin to shed light on the epidemiology of short-term risk of mortality of youth-onset type 1 and type 2 diabetes in the US. A longer follow-up in this well-characterized and contemporary cohort would allow for further examination of cause-specific mortality outcomes, which could help in developing focused strategies aimed to increase survival in youth-onset diabetes.

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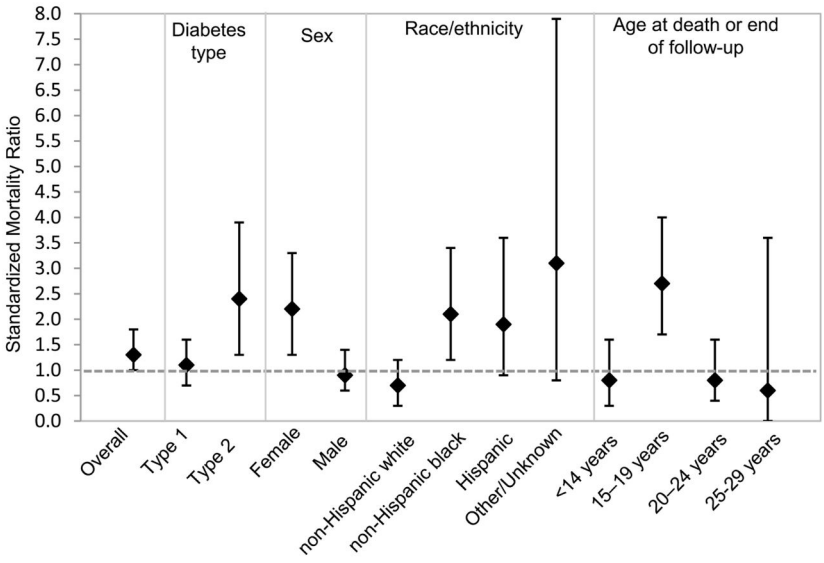

Figure 1.

Age-, Sex-, and Race-Standardized Mortality Ratios Overall and by Diabetes Type, Sex, Race/Ethnicity, and Age at Death or End of Follow-up

Table 1

Characteristics of the 8,358 Diabetes Cases in the SEARCH for Diabetes in Youth Study, Overall and by Type, 2002–2008

Characteristics	Total (N=8,358)	Diabetes Type	
		Type 1 (N=6,840)	Type 2 (N=1,518)
Age at diabetes diagnosis (years)	10.7±4.7	9.8±4.5	14.7±2.8
Age group at diagnosis (years), N (%)			
0–4	1228 (14.7)	1224 (17.9)	4 (0.3)
5–9	2221 (26.6)	2155 (31.5)	66 (4.3)
10–14	3230 (38.6)	2517 (36.8)	713 (47.0)
15–19	1679 (20.1)	944 (13.8)	735 (48.4)
Sex, N (%)			
Female	4186 (50.1)	3278 (47.9)	908 (59.8)
Male	4172 (49.9)	3562 (52.1)	610 (40.2)
Race/Ethnicity, N (%)			
Non-Hispanic White	5132 (61.4)	4812 (70.4)	320 (21.1)
Non-Hispanic Black	1296 (15.5)	781 (11.4)	515 (33.9)
Hispanic	1360 (16.3)	908 (13.3)	452 (29.8)
Other/Unknown	570 (6.8)	339 (5.0)	231 (15.2)
Year of diagnosis, N (%)			
2002	1132 (13.5)	924 (13.5)	208 (13.7)
2003	1087 (13.0)	888 (13.0)	199 (13.1)
2004	1102 (13.2)	910 (13.3)	192 (12.6)
2005	1196 (14.3)	990 (14.5)	206 (13.6)
2006	1249 (14.9)	1021 (14.9)	228 (15.0)
2007	1286 (15.4)	1047 (15.3)	239 (15.7)
2008	1306 (15.6)	1060 (15.5)	246 (16.2)
Follow-up time from diagnosis, years *	5.3 (0–9)	5.3 (0–9)	5.2 (0–9)
Age at death/censor (years)	16.0±5.0	15.2± 4.9	20.0±3.5
Age group at death/censor (years), N (%)			
< 14	3449 (41.3)	3328 (48.6)	121 (8.0)
15–19	2904 (34.7)	2295 (33.6)	609 (40.1)
20–24	1795 (21.5)	1121 (16.4)	674 (44.4)
25–29	210 (2.5)	96 (1.4)	114 (7.5)

Data are means ± standard deviation, N (%), or median (range), as appropriate.

* Time is from diabetes diagnosis to death or censoring on 12/31/2010.

Table 2

Crude Mortality Rates among 8,358 Diabetes Cases in the SEARCH for Diabetes in Youth Study, 2002–2008 and the 2014 Comparable State Populations

	Number of Person-Years	Number of Deaths		Crude Mortality Rate	
		Observed	Expected	SEARCH*	US*
Overall	44,893	41	31	91.3	70.9
Diabetes type					
Type 1	36,810	26	25	70.6	70.9
Type 2	8,083	15	6	185.6	70.9
Sex					
Female	22,489	22	10	97.8	48.1
Male	22,404	19	21	84.8	91.8
Race/Ethnicity					
Non-Hispanic White	27,766	12	17	43.2	63.9
Non-Hispanic Black	6,897	16	8	232.0	127.9
Hispanic	7,138	9	5	126.1	67.8
Other/Unknown	3,091	4	1	129.4	46.3
Age at death/censor (years)					
< 14	16,436	8	10	48.7	62.6
15–19	15,481	23	9	148.6	58.3
20–24	11,283	9	11	79.8	89.7
25–29	1,693	1	2	59.1	87.4

* per 100,000 person-years

Table 3

Underlying and Contributing Cause of Death by Diabetes Type among 8,358 Diabetes Cases in the SEARCH for Diabetes in Youth Study, 2002–2008

Cause of Death	ICD-10 Code	Total No. (%)	Type 1 Diabetes No. (%)	Type 2 Diabetes No. (%)
Total number of deaths		**41 (100.0)**	**26 (63.4)**	**15 (36.6)**
Underlying cause of death				
Infection and parasitic disease	A00-B99	1 (2.4)	0	1 (6.7)
Diseases of the blood	D50-D89	1 (2.4)	0	1 (6.7)
Endocrine, nutritional and metabolic diseases				
Diabetes mellitus (DM)	E00-E69	12 (29.3)	11 (42.3)	1 (6.7)
Insulin-dependent DM, with ketoacidosis	E10.1	2	2	0
Insulin-dependent DM, without complications	E10.9	1	1	0
Unspecified DM, with coma	E14.0	1	0	1
Unspecified DM, with ketoacidosis	E14.1	6	6	0
Unspecified DM, without complications	E14.9	2	2	0
Metabolic disorders	E70-E89	1 (2.4)	1 (3.8)	0
Mental and behavioral disorders	F01-F99	1 (2.4)	0	1 (6.7)
Diseases of the nervous system	G00-G98	3 (7.3)	2 (7.7)	1 (6.7)
Diseases of the circulatory system	I00-I99	2 (4.9)	1 (3.8)	1 (6.7)
Diseases of the respiratory system	J00-J98	2 (4.9)	2 (7.7)	0
Diseases of the digestive system	K00-K92	0	0	0
Pregnancy, childbirth and puerperium	O00-O99	0	0	0
Congenital malformations	Q00-Q99	0	0	0
External causes of morbidity and mortality	V00-Y89			
Transport/motor vehicle accidents	V13-V89	5 (12.2)	2 (7.7)	3 (20.0)
Other external causes of accidental injury	W00-X59	3 (7.3)	3 (11.5)	0
Accidental poisoning	X40-X49	2 (4.9)	0	2 (13.3)
Intentional self-harm	X60-X84	5 (12.2)	3 (11.5)	2 (13.3)
Sequelae of motor vehicle accident	Y85	1 (2.4)	0	1 (6.7)
Unknown		2 (4.9)	1 (3.8)	1 (6.7)
Contributing cause of death				
Diabetes	E10-E14	2 (4.9)	2 (7.7)	0
Underlying or contributing cause of death *				
Diabetes	E10-E14	14 (34.1)	13 (50.0)	1 (6.7)

* Underlying cause of death when diabetes mellitus is a contributing cause: Other external causes of accidental injury and Transport/motor vehicle accident