HHS Public Access

Author manuscript

Epidemiology. Author manuscript; available in PMC 2015 September 08.

Published in final edited form as:

Epidemiology. 2013 September ; 24(5): 773–774. doi:10.1097/EDE.0b013e31829ef01a.

The Prevalence of Type 1 Diabetes in the United States

Andy Menke,
Social & Scientific Systems, Inc, Silver Spring, MD

Trevor J. Orchard,
Department of Epidemiology, Graduate School of Public Health, University of Pittsburgh Pittsburgh, PA

Giuseppina Imperatore,
Division of Diabetes Translation, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA

Kai McKeever Bullard,
Division of Diabetes Translation, National Center for Chronic Disease Prevention and Health Promotion, Centers for Disease Control and Prevention, Atlanta, GA

Elizabeth Mayer-Davis, and
Department of Nutrition, University of North Carolina, Chapel Hill, NC

Catherine C. Cowie
National Institute of Diabetes and Digestive and Kidney Diseases, National Institutes of Health, Bethesda, MD

Andy Menke: amenke@s-3.com

To the Editor

There are few data on the prevalence of type 1 diabetes mellitus[1,2] and no estimates for the entire US population. The National Health and Nutrition Examination Survey (NHANES) is a representative cross-sectional survey of the civilian, noninstitutionalized US population. Although NHANES does not explicitly collect information on type 1 diabetes mellitus, we estimated the prevalence based on age of diabetes diagnosis, the age of insulin initiation, and current use of insulin.[3]

The protocol for the 1999–2010 NHANES was approved by the National Center for Health Statistics of the Centers for Disease Control and Prevention Ethics Review Board. All participants gave written informed consent. After excluding 2955 infants for whom diabetes data were not collected and 75 children and adults who were missing diabetes data, 59,130 participants remained in the analytic sample.[4] We considered participants to have type 1 diabetes mellitus if they started insulin within 1 year of diabetes diagnosis, were currently

The contents of this article are solely the responsibility of the author and do not necessarily represent the official views of the Centers for Disease Control and Prevention and the National Institute of Diabetes and Digestive and Kidney Diseases.

The authors report no conflicts of interest.

using insulin and were diagnosed with diabetes under age 30 (definition 1) or under age 40 (definition 2).

Data were analyzed using SUDAAN, version 10.0 (Research Triangle Institute, Research Triangle Park, NC), accounting for the complex sampling design used in NHANES. The prevalence of diabetes (by each definition) was calculated overall and by age, race/ethnicity, and sex. The sum of sample weights was used to estimate the total number of the US population with type 1 diabetes. We calculated the percentage of diagnosed diabetes and all diabetes (diagnosed diabetes, or hemoglobin A1c ≥6.5%, or fasting glucose ≥126 mg/dL) that was type 1.

The overall fractions (weighted number) with type 1 diabetes mellitus based on definitions 1 and 2 were 2.6/1000 (740,000 people) and 3.4/1000 (970,000 people), respectively (Table). The proportions of diagnosed diabetes that were type 1 were 4.6% and 6.0%, respectively. The proportions of all diabetes that were type 1 were 3.6% and 4.8% for definitions 1 and 2, respectively. Prevalence of type 1 diabetes mellitus increased an average of 0.08% per 4 years for both definitions during the 12-year period 1999–2010 (test for trend, $P = 0.02$ for definition 1 and 0.06 for definition 2).

In previous estimates, the SEARCH for Diabetes in Youth Study[2] had identified a prevalence of 1.5/1000 (95% confidence interval [CI] = 1.5 to 1.6/1000) among youth under the age of 20—lower than our estimate of 2.4/1000 for this age group. The National Survey of Children's Health found 3.2/1000 (95% CI = 2.6 to 3.7/1000) of children under the age of 18 had diabetes, although diagnosis was based on self-report and included both type 1 and type 2 diabetes.[1]

Although type 1 diabetes mellitus may develop at any age,[5] estimates of the prevalence or incidence in older adults are limited.[6,7] By definition, our estimates missed cases starting after the age of 40, while including some younger people with type 2 diabetes who required insulin within a year of diagnosis. Using a higher age cutpoint for diabetes diagnosis in our study would likely result in an even greater misclassification of type 2 diabetes as type 1. When age of diagnosis was not included in the definition (ie, when we include everyone with diabetes who started taking insulin within 1 year of diagnosis), the prevalence was 5.7/1000, representing an upper bound of prevalence. Ideally, diabetes status should be determined based on data collected at or before diagnosis, particularly data on diabetes autoantibodies.[8]

Our prevalence estimates of type 1 diabetes mellitus in the entire civilian noninstitutionalized US population (2.6/1000 for definition 1 and 3.4/1000 for definition 2) are reasonable given current available data. However, the limitations of these data highlight the need for more comprehensive national data collection, both to fully understand the burden of diabetes and to plan healthcare response.

Acknowledgments

This work was supported by a contract from the National Institute of Diabetes and Digestive and Kidney Diseases (GS10F0381L).

References

1. Lee JM, Herman WH, McPheeters ML, Gurney JG. An epidemiologic profile of children with diabetes in the U.S. Diabetes Care. 2006; 29:420–421. [PubMed: 16443899]
2. Liese AD, D'Agostino RB Jr, Hamman RF, et al. The burden of diabetes mellitus among US youth: prevalence estimates from the SEARCH for Diabetes in Youth Study. Pediatrics. 2006; 118:1510–1518. [PubMed: 17015542]
3. Klein R, Knudtson MD, Lee KE, Gangnon R, Klein BE. The Wisconsin Epidemiologic Study of Diabetic Retinopathy XXIII: the twenty-five-year incidence of macular edema in persons with type 1 diabetes. Ophthalmology. 2009; 116:497–503. [PubMed: 19167079]
4. Centers for Disease Control and Prevention. National Health and Nutrition Examination Survey Questionnaire. Hyattsville, MD: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; National Center for Health Statistics; p. 1999-2010.
5. Daneman D. Type 1 diabetes. Lancet. 2006; 367:847–858. [PubMed: 16530579]
6. Gorham ED, Garland FC, Barrett-Connor E, Garland CF, Wingard DL, Pugh WM. Incidence of insulin-dependent diabetes mellitus in young adults: experience of 1,587,630 US Navy enlisted personnel. Am J Epidemiol. 1993; 138:984–987. [PubMed: 8256783]
7. Melton LJ 3rd, Palumbo PJ, Chu CP. Incidence of diabetes mellitus by clinical type. Diabetes Care. 1983; 6:75–86. [PubMed: 6839925]
8. Dabelea D, Pihoker C, Talton JW, et al. SEARCH for Diabetes in Youth Study. Etiological approach to characterization of diabetes type: the SEARCH for Diabetes in Youth Study. Diabetes Care. 2011; 34:1628–1633. [PubMed: 21636800]

TABLE

Percentage of Participants with Type 1 Diabetes Mellitus Overall and by Age, Race/Ethnicity, and Sex, NHANES 1999–2010 (n = 59,130)

	Definition 1		Definition 2	
	No.	**% (95% CI)**	**No.**	**% (95% CI)**
Overall[a]	123	0.26 (0.20–0.33)	160	0.34 (0.27–0.43)
Current age[a] (years)				
1–19	51	0.24 (0.17–0.33)	51	0.24 (0.17–0.33)
20–39	38	0.34 (0.22–0.49)	49	0.42 (0.30–0.57)
40–59	27	0.31 (0.16–0.55)	47	0.49 (0.30–0.75)
≥60	7	0.08 (0.02–0.18)	13	0.12 (0.05–0.23)
Race/ethnicity				
Non-Hispanic white	65	0.30 (0.21–0.42)	77	0.37 (0.27–0.49)
Non-Hispanic black	35	0.29 (0.19–0.44)	51	0.47 (0.32–0.66)
All Hispanic	21	0.12 (0.06–0.23)	29	0.23 (0.12–0.38)
Mexican–American[b]	16	0.11 (0.05–0.19)	22	0.18 (0.11–0.27)
Sex[a]				
Male	63	0.30 (0.21–0.42)	84	0.40 (0.29–0.54)
Female	60	0.22 (0.14–0.32)	76	0.28 (0.19–0.39)

Definition 1: Previous diagnosis of diabetes before age 30 years, now taking insulin, started taking insulin within 1 year of diagnosis.

Definition 2: Previous diagnosis of diabetes before age 40 years, now taking insulin, started taking insulin within 1 year of diagnosis.

[a] All participants including those who self-reported other races were included.

[b] Insufficient numbers of individuals in other Hispanic groups were available.