Disparities in Hemoglobin A_{1c} Testing During the Transition to Adulthood and Association With Diabetes Outcomes in Youth-Onset Type 1 and Type 2 Diabetes: The SEARCH for Diabetes in Youth Study

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OBJECTIVE

To identify correlates of hemoglobin A_{1c} (HbA_{1c}) testing frequency and associations with HbA_{1c} levels and microvascular complications in youth-onset diabetes.

RESEARCH DESIGN AND METHODS

The SEARCH for Diabetes in Youth study collected data from individuals diagnosed with diabetes before age 20 at 8 years (n = 1,885 type 1, n = 230 type 2) and 13 years (n = 649 type 1, n = 84 type 2) diabetes duration. We identified correlates of reporting ≥3 HbA_{1c} tests/year using logistic regression. We examined associations of HbA_{1c} testing with HbA_{1c} levels and microvascular complications (retinopathy, neuropathy, or nephropathy) using sequentially adjusted linear and logistic regression.

RESULTS

For type 1 diabetes, odds of reporting ≥3 HbA_{1c} tests/year at 8 and 13 years diabetes duration decreased with older age at diagnosis (odds ratio [OR] 0.91 [95% CI 0.88–0.95]), longer duration of diabetes (OR 0.90 [0.82–0.99]), not having a personal doctor (OR 0.44 [0.30–0.65]), and lapses in health insurance (OR 0.51 [0.27–0.96]). HbA_{1c} testing ≥3 times/year over time was associated with lower HbA_{1c} levels (OR −0.36% [−0.65 to −0.06]) and lower odds of microvascular complications (OR 0.64 [0.43–0.97]) at 13 years' duration, but associations were attenuated after adjustment for HbA_{1c} testing correlates (OR −0.17 [−0.46 to 0.13] and 0.70 [0.46–1.07], respectively). For type 2 diabetes, not seeing an endocrinologist decreased the odds of reporting ≥3 HbA_{1c} tests/year over time (OR 0.19 [0.06–0.63]), but HbA_{1c} testing frequency was not associated with HbA_{1c} levels or microvascular complications.

CONCLUSIONS

We observed disparities in HbA_{1c} testing frequency predominately by health care–related factors, which were associated with diabetes outcomes in type 1 diabetes.

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**A complete list of the SEARCH for Diabetes in Youth Study Group can be found in the supplementary material online.*

The troubling increase in youth-onset type 1 and type 2 diabetes (1) is compounded by disparities in glucose control (2) and a high prevalence of complications and comorbidities in the first decade following diagnosis (3). In addition to self-monitoring of blood glucose levels, provider monitoring of glucose control over time is believed to facilitate individualized care and treatment adjustments to reach management goals. Accordingly, the American Diabetes Association recommends hemoglobin A_{1c} (HbA_{1c}) testing at least every 6 months for individuals meeting glycemic goals (generally $<7.0\%$) and every 3 months for individuals not meeting goals, with recent medication changes, and <18 years with type 2 diabetes (4,5).

However, only one-half of youth and young adults with youth-onset type 1 or type 2 diabetes report ≥ 3 HbA_{1c} tests/year (6,7), despite notably poor glycemic control (3,8). Testing frequency appears to decrease with age in the first 5 years postdiagnosis, especially among lower-income individuals (7). This is concerning given evidence that more frequent HbA_{1c} testing is associated with lower HbA_{1c} levels in youth-onset type 1 diabetes (6,9) and adult-onset type 2 diabetes (10). Maintaining glycemic control throughout the course of youth-onset diabetes is critical, as lifetime risk of complications is greater than adult-onset because of a longer duration of disease (11).

We examined factors potentially related to infrequent HbA_{1c} testing in youth-onset type 1 and type 2 diabetes at an average of 8 and 13 years postdiagnosis, a time when many individuals are transitioning to adulthood with an increased responsibility for their own health and health care. We considered socioeconomic and clinical factors with the potential to inform strategies for increasing testing frequency and, ultimately, successful disease management. To confirm the relevance of HbA_{1c} testing for diabetes-related outcomes during this transitional period, we also examined testing frequency in relation to HbA_{1c} levels and microvascular complications.

RESEARCH DESIGN AND METHODS

Participants

The SEARCH for Diabetes in Youth (SEARCH) study population and protocol have been described previously (12). Briefly, SEARCH identifies individuals newly diagnosed with any type of diabetes before age 20 years through a population-based registry network covering 5.5 million youth from five sites in the U.S.: South Carolina; Cincinnati, Ohio, and surrounding counties; Colorado with southwestern U.S. American Indian sites; Seattle, Washington, and surrounding counties; and Kaiser Permanente Southern California membership in seven counties. Individuals diagnosed in 2002–2006 or 2008 were invited to join an observational study of the natural course of youth-onset diabetes. Baseline visits were conducted shortly after diagnosis (2002–2010: $n=4{,}095$, mean age 11.0 years, mean diabetes duration 9.9 months), with a first follow-up visit conducted ≥ 5 years after diagnosis (2011–2015: $n=2{,}777$, mean age 17.9 years, mean diabetes duration 8.0 years) and a second follow-up visit conducted ≥ 8 years after diagnosis (2015–2019: $n=2{,}668$, mean age 21.5 years, mean diabetes duration 11.2 years). The study was approved by the institutional review boards with jurisdiction in each study location. Written informed consent and/or assent were obtained from all participants and parents, as appropriate.

Data Collection

We abstracted date of birth and date of diagnosis from medical records and calculated age of diagnosis and diabetes duration for each visit. At the baseline visit, parents reported child sex, race, ethnicity, highest parental education, and annual household income. At follow-up visits, participants (or parents if the participant's age was <14 years) self-reported their diabetes treatment regimen, glucose self-monitoring practices, and number of HbA_{1c} tests in the prior year using categories of 0, 1, 2, or ≥ 3. Further, participants (or parents if participant's age was <18 years) reported type of diabetes provider, type of insurance, insurance status in the prior year, problems with cost of diabetes care in the prior year, occurrence of hypoglycemia events requiring hospitalization in the prior year, and meetings with a diabetes nurse or diabetes educator in prior year. Finally, participants were asked about the provider-patient relationship as follows: "A personal doctor or nurse is the health care provider who knows you best. This can be a general doctor, a specialist doctor, a nurse practitioner, or a physician assistant. Do you have one person you think of as your personal diabetes doctor or nurse?" At the second follow-up, the question was modified to ask about a personal diabetes doctor. Blood and urine samples were collected after an overnight, ≥ 8-h fast with no medications taken the morning of the visit (including short-acting insulin). Participants were asked to bring a first morning urine void; when not provided ($\sim 8\%$ of participants), a spot urine specimen was collected. Blood samples were analyzed for HbA_{1c} and urine for albumin, creatinine, and cystatin C at the Northwest Lipid Metabolism and Diabetes Research Laboratory (Seattle, WA).

Microvascular Complication Assessments

Complications were ascertained at both follow-up visits. Diabetic kidney disease was defined as moderate albuminuria (≥ 30 μg/mg of creatinine) or low glomerular filtration rate (≤ 60 mL/min/1.73 m^2 as estimated by the Chronic Kidney Disease Epidemiology equation with serum creatinine and cystatin C) (13). Diabetic retinopathy was assessed with 45° color digital fundus images taken by trained research staff using a nonmydriatic camera (Visucam Pro N; Carl Zeiss Meditech), centered on the disc and macula of both eyes. Photos masked to all clinical characteristics were graded by the Wisconsin Ocular Epidemiology Reading Center. Diabetic retinopathy was defined as mild, moderate, or proliferative retinopathy (codes of 30–80) in at least one eye (14). Our threshold for diagnosing retinopathy was set higher than typically used clinically to distinguish diabetic retinopathy from milder forms that may have an etiology other than diabetes retinopathy. Peripheral neuropathy was defined as a score >2 on the Michigan Neuropathy Screening Instrument (15), as described previously (16).

Statistical Analyses

Analyses were conducted separately by diabetes type. We included SEARCH participants aged ≥ 10 years at the first follow-up visit with a provider diagnosis of type 1 (excluding 19 reporting no insulin

use) or type 2 diabetes and data for HbA_{1c} testing frequency, HbA_{1c} levels and/or microvascular complications, and all socioeconomic and clinical variables of interest (Supplementary Fig. 1). We conducted a cross-sectional analysis in participants with complete data from the first follow-up ($n=1,885$ type 1 and $n=230$ type 2) and a longitudinal analysis in the subset of participants from the cross-sectional analysis also having sufficient data from the second follow-up ($n=649$ type 1 and $n=84$ type 2). We dichotomized HbA_{1c} testing frequency as reporting three or more versus fewer than three times in the prior year. For the cross-sectional analysis, we classified participants as reporting $\geq$3 versus $<$3 tests/year in the year prior to the first follow-up. For the longitudinal analysis, we classified participants as reporting $\geq$3 tests in the year prior to both visits versus $<$3 tests in the year prior to either visit.

We examined socioeconomic and clinical factors associated with HbA_{1c} testing using logistic regression, modeling the odds of reporting $\geq$3 tests/year at the first follow-up and the odds of reporting $\geq$3 tests/year at both follow-ups. Models included core variables of age at diagnosis, diabetes duration at the visit, sex, race/ethnicity, SEARCH clinical site, and (for the longitudinal analysis only) time interval between the follow-up visits. Additional socioeconomic and treatment-related variables were considered via stepwise selection, whereby variables were retained in the model only when statistically significant ($P < 0.05$). Because of the small sample size in the type 2 diabetes longitudinal analysis, all core and candidate variables were subject to stepwise selection. Candidate variables included parental education at baseline, household income at baseline, diabetes treatment, diabetes care provider, having a personal doctor, having problems with the cost of care in the prior 12 months, type of health insurance, and having continuous health insurance in the prior year. For the longitudinal models, levels of the candidate variables reflected status over time (e.g., having a consistent regimen vs. a change in regimen in diabetes treatment between visits).

We evaluated HbA_{1c} testing frequency in relation to diabetes outcomes using linear regression for HbA_{1c} levels and logistic regression for microvascular complications. For complications, we used a composite variable reflecting the manifestation of one or more microvascular complications. The cross-sectional analysis modeled the HbA_{1c} level or odds of having one or more complications at the first follow-up among those reporting $\geq$3 tests/year at the first follow-up relative to those reporting $<$3 tests/year. The longitudinal analysis modeled the HbA_{1c} level or odds of having one or more complications at the second follow-up among those reporting $\geq$3 tests/year at either follow-up relative to those reporting $<$3 tests/year at both follow-up visits. For both analyses, we adjusted for covariates sequentially as follows: Model 1 was unadjusted, model 2 was adjusted for core variables, and model 3 was additionally adjusted for candidate variables that passed stepwise selection for the analysis of HbA_{1c} tests per year as well as for the variables of frequency of glucose self-monitoring and receipt of diabetes education. Sociodemographic and clinical characteristics are presented as mean (SD) or count (%). Linear and logistic regression model estimates are presented as β and odds ratio (OR), respectively, with 95% CI. All analyses were conducted with a two-sided α of 0.05 for statistical significance.

RESULTS

Participant characteristics of the analytic cross-sectional sample ($n=1,885$ type 1 and $n=230$ type 2) and longitudinal subset ($n=649$ type 1 and $n=84$ type 2) are presented in Tables 1 and 2. On average, the first follow-up occurred at 8.0 years diabetes duration (range 3.3–13.0 years) and the second follow-up at 12.6 years' duration (range 7.8–17.4 years). These descriptive data suggest a decline in quality of diabetes care and management over time, which was affirmed in the longitudinal subset (Supplementary Table 1).

Socioeconomic and clinical factors significantly related to HbA_{1c} testing frequency cross sectionally at 8 years diabetes duration are presented in Fig. 1. Participants with type 1 diabetes were less likely to report $\geq$3 HbA_{1c} tests/year if they had been older at diagnosis (OR 0.88 [95% CI 0.86–0.91] per 1-year increase), had a greater duration of diabetes (OR 0.85 [0.80–0.90] per 1-year increase), did not have a personal doctor (OR 0.46 [0.36–0.59]), did not have continuous health insurance in the prior year (OR 0.64 [0.43–0.96]), were not seeing an endocrinologist for their diabetes care (OR 0.71 [0.55–0.92]), had problems with the cost of care in the prior year (OR 0.78 [0.64–0.97]), or were not using an insulin pump (OR 0.67 [0.54–0.84]). Odds of reporting $\geq$3 tests/year also differed by household income ($P=0.02$), although only the comparison between higher income households and those not reporting their income (i.e., declined to report or did not know) was statistically significant (OR 1.68 [1.08–2.62] for those without income data). No differences in HbA_{1c} tests per year were observed by sex or race/ethnicity for participants with type 1 diabetes (data not shown). Participants with type 2 diabetes were less likely to report $\geq$3 tests/year when they were not seeing an endocrinologist for their diabetes care (OR 0.18 [0.08–0.41]), were using noninsulin medications (OR 0.33 [0.15–0.73] vs. insulin), or were not using medication for their diabetes treatment (OR 0.06 [0.01–0.32] vs. insulin). No differences in HbA_{1c} testing frequency were observed by age at diagnosis, diabetes duration, sex, or race/ethnicity for type 2 diabetes (data not shown).

Sociodemographic and clinical factors significantly associated with HbA_{1c} testing frequency longitudinally from 8 to 13 years diabetes duration are presented in Fig. 2. Participants with type 1 diabetes were less likely to report $\geq$3 tests/year across this period if they were older at diagnosis (OR 0.91 [95% CI 0.88–0.95] per 1-year increase), had a greater duration of diabetes (OR 0.90 [0.82–0.99] per 1-year increase), did not have a personal doctor at one or more visits (OR 0.44 [0.30–0.65]), or did not have continuous health insurance in the year prior to one or more visits (OR 0.51 [0.27–0.96]). Odds of reporting $\geq$3 tests/year over time also differed by household income ($P=0.01$), although only the comparison between higher income households and those not reporting their income (i.e., declined to report or did not know) was statistically significant (OR 2.06 [1.03–4.11] for those without income data). No differences were observed in HbA_{1c} tests per year over time by sex or race/ethnicity for type 1 diabetes (data not shown).

Table 1—Sociodemographic characteristics of participants in SEARCH

	Cross-sectional sample		Longitudinal subsample	
	Type 1 (*n* = 1,885)	Type 2 (*n* = 230)	Type 1 (*n* = 649)	Type 2 (*n* = 84)
Female, *n* (%)	948 (50)	149 (65)	363 (56)	62 (74)
Race/ethnicity, *n* (%)				
Non-Hispanic White	1,444 (77)	62 (27)	425 (65)	23 (27)
Non-Hispanic Black	188 (10)	102 (44)	84 (13)	41 (49)
Hispanic, any race	213 (11)	47 (20)	119 (18)	16 (19)
American Indian, Alaskan Native	7 (0)	14 (6)	4 (1)	3 (4)
Asian, Pacific Islander	28 (1)	4 (2)	14 (2)	1 (1)
Other	5 (0)	1 (0)	3 (0)	0 (0)
Age at diagnosis (years)	9.5 (4.1)	14.1 (2.8)	9.6 (4.3)	14.4 (2.7)
Diabetes duration at baseline visit (years)	0.8 (0.5)	0.9 (0.6)	0.8 (0.5)	0.8 (0.5)
Age at first follow-up visit (years)	17.5 (4.2)	22.1 (3.6)	17.7 (4.5)	22.5 (3.5)
Diabetes duration at first follow-up (years)	8.0 (1.9)	8.0 (2.0)	8.0 (1.9)	8.1 (1.8)
Interval between first and second follow-up (years)	—	—	4.6 (1.1)	4.4 (0.9)
Parental education at baseline visit, *n* (%)				
High school graduate or less	340 (18)	111 (48)	118 (18)	38 (45)
Some college or higher	1,545 (82)	119 (52)	531 (82)	46 (55)
Annual household income at baseline visit, *n* (%)				
<$50,000	606 (32)	156 (68)	214 (33)	55 (65)
≥$50,000	1,152 (61)	49 (21)	389 (60)	19 (23)
Do not know, refused	127 (7)	25 (11)	46 (7)	10 (12)

Data are mean (SD) unless otherwise indicated.

For type 2 diabetes, where all core and candidate variables were subject to stepwise selection because of the small sample size, only type of diabetes provider was retained in the model. Participants were less likely to report ≥3 tests/year over time when they were not seeing an endocrinologist for their diabetes care at one or more visits (OR 0.19 [0.06–0.63]). Sensitivity analyses using ordinal HbA_{1c} testing categories (0, 1, 2, or ≥3 tests/year) yielded similar results (Supplementary Table 2).

Associations of frequency of HbA_{1c} testing with HbA_{1c} levels and microvascular complications cross sectionally at 8 years diabetes duration are presented in Supplementary Fig. 2. For type 1 diabetes, participants reporting ≥3 HbA_{1c} tests/year had significantly lower HbA_{1c} levels than those reporting <3 tests/year (unadjusted model 1: 9.03% vs. 9.36%, $P < 0.001$; adjusted model 3: 9.67% vs. 9.83%, $P=0.07$)). In model 3, covariates that were statistically significant included age at diagnosis (β=−0.05 [95% CI −0.07 to −0.03] per 1-year increase), sex (β=0.27 [0.12–0.43] for females vs. males), race/ethnicity (overall $P < 0.001$; only non-Hispanic Black vs. non-Hispanic White, β=1.24 [0.97–1.52], was statistically significant), not using an insulin pump (β=0.59 [0.42–0.76]), household income <$50,000/year (β=0.32 [0.14–0.49] vs. ≥$50,000/year), not having a personal doctor (β=0.29 [0.09–0.49]), and glucose self-monitoring <4 times/day (β=0.61 [0.45–0.78]). Participants who reported ≥3 tests/year also had a lower odds of any microvascular complication (unadjusted model 1: OR 0.53 [95% CI 0.41–0.69]), but this was attenuated to nonsignificance after covariate adjustment (adjusted model 2: OR 0.82 [0.62–1.09]; additionally adjusted model 3: OR 0.97 [0.72–1.31]). In model 2, covariates that were statistically significant included age at diagnosis (OR 1.13 [1.09–1.17] per 1-year increase) and duration of diabetes (OR 1.34 [1.25–1.45] per 1-year increase). In model 3, covariates that were statistically significant included age at diagnosis (OR 1.11 [1.07–1.15]), duration of diabetes (OR 1.33 [1.23–1.43]), using an insulin pump (OR 0.67 [0.49–0.90]), and not having a personal doctor (OR 1.59 [1.16–2.18]). For type 2 diabetes, no significant association was observed between HbA_{1c} testing and HbA_{1c} levels or microvascular complications at 8 years' duration in any model. Again, sensitivity analyses using ordinal HbA_{1c} testing categories (0, 1, 2, or ≥3 tests/year) yielded similar results (Supplementary Table 3).

Associations of HbA_{1c} testing longitudinally with HbA_{1c} levels and microvascular complications at 13 years diabetes duration are presented in Supplementary Fig. 2. For type 1 diabetes, participants reporting ≥3 tests/year at both visits had lower HbA_{1c} levels than those reporting <3 tests/year at either or both visits, although the comparison was statistically significant only in model 2 (8.78% vs. 9.13%, $P=0.02$). Participants reporting ≥3 tests/year also had a lower odds of any microvascular complication (unadjusted model 1: OR 0.51 [95% CI 0.35–0.75]; adjusted model 2: OR 0.64 [0.43–0.97]), but this was attenuated to nonsignificance after additional adjustment (model 3: OR 0.70 [0.46–1.07]). In model 3, covariates that were statistically significant included age at diagnosis (OR 1.06 [1.01–1.12]), duration of diabetes (OR 1.29 [1.16–1.44]), race/ethnicity (overall $P=0.05$; only non-Hispanic Black vs. non-Hispanic White, OR 2.23 [1.25–3.99] was statistically significant), non-continuous health insurance (OR 2.15 [1.22–3.79]), and glucose self-monitoring <4 times/day (OR 1.78 [1.19–2.66]). For type 2 diabetes, HbA_{1c} testing over time

Table 2—Clinical and health care characteristics of participants at the SEARCH follow-up visits

	Type 1			Type 2		
	n	*n* or mean	% or SD	*n*	*n* or mean	% or SD
First follow-up (cross-sectional sample)	1,885			230		
Diabetes provider is endocrinologist	1,885	1,468	78	230	96	42
Cost of care is not a problem	1,885	961	51	230	106	46
Type of insurance	1,885			230		
Private		1,356	72		83	36
Medicare/Medicaid		373	20		86	37
Other		87	5		17	7
None		60	3		44	19
Continuous insurance for past year	1,885	1,743	92	230	159	69
Has a personal doctor	1,885	1,503	80	230	107	47
Received diabetes education in past year	1,885	1,376	73	230	112	49
Type 1 diabetes treatment	1,885					
Insulin pump		1,081	57		—	—
Other insulin		804	43		—	—
Type 2 diabetes treatment				230		
Insulin (any administration)		—	—		107	47
Noninsulin medications only		—	—		70	30
No medications		—	—		53	23
Glucose monitoring	1,885			230		
<4 times/day (including none)		305	32		165	72
≥4 times/day (including continuous monitoring)		1,275	68		65	28
No severe hypoglycemic episodes in past 6 months	1,885	1,747	93	230	224	97
Reported HbA_{1c} tests in past year	1,885			230		
0		57	3		52	23
1		236	13		50	22
2		413	22		65	28
≥3		1,179	63		63	27
HbA_{1c} (%), mean SD	1,855	9.2	1.8	227	8.7	2.8
HbA_{1c} (mmol/mol), mean SD	1,855	76.5	19.9	227	71.7	31.1
Optimal HbA_{1c} (<7% [53 mmol/mol])	1,855	154	8	227	85	37
Warrants quarterly HbA_{1c} testing*	1,855	1,701	92	228	156	68
Any microvascular complication	1,883	273	14	230	75	33
Diabetic kidney disease	1,654	105	6	181	32	18
Peripheral neuropathy	1,857	118	6	223	42	19
Diabetic retinopathy	1,842	83	5	224	18	8
Second follow-up (longitudinal subsample)	649			84		
Diabetes provider is endocrinologist at both visits	649	425	65	84	22	26
Cost of care is not a problem at both visits	649	188	29	84	25	30
Continuous insurance in past year at both visits	649	576	89	84	54	64
Type of insurance the same at both visits	649	477	73	84	51	61
Has a personal doctor at both visits†	649	433	67	84	27	32
Received diabetes education in past year at both visits	649	336	52	84	30	36
Diabetes treatment the same at both visits‡	649	533	82	84	56	67
Glucose monitoring ≥4 times/day (including continuous monitoring) at both visits	649	348	54	84	10	12
No severe hypoglycemic events in past 6–12 months at both visits§	649	545	84	84	81	96
Reported ≥3 HbA_{1c} tests/year at both visits	649			84		
Testing ≥3 times/year at both visits		266	41		14	17
Testing ≥3 times/year at first follow-up only		128	20		9	11
Testing ≥3 times/year at second follow-up only		105	16		16	19
Testing ≥3 times/year at neither visit		150	23		45	54
HbA_{1c} (%), mean SD	638	8.9	1.9	83	9.4	2.8
HbA_{1c} (mmol/mol), mean SD	638	73.5	20.9	83	79.6	30.3
Optimal HbA_{1c} (<7% [53 mmol/mol]) at both visits	626	37	6	82	15	18
Warrants quarterly HbA_{1c} testing at both visits*	626	514	82	82	48	59
Any microvascular complication	649	166	26	84	42	50
Diabetic kidney disease	579	63	11	71	20	28
Peripheral neuropathy	644	53	8	83	17	20
Diabetic retinopathy	626	95	15	80	25	31

Data are *n* (%) unless otherwise indicated. *Per the American Diabetes Association (4,5), quarterly HbA_{1c} testing is warranted when HbA_{1c} >7% (53 mmol/mol) in any individual with type 1 or type 2 diabetes or when age <18 years for those with type 2 diabetes. †Second follow-up asked specifically about a personal diabetes doctor. ‡Type 1: pump (yes/no) consistent across visits; type 2: treatment categories consistent across visits. §First follow-up asked about hypoglycemic episodes in past 6 months; second follow-up asked about past 12 months.

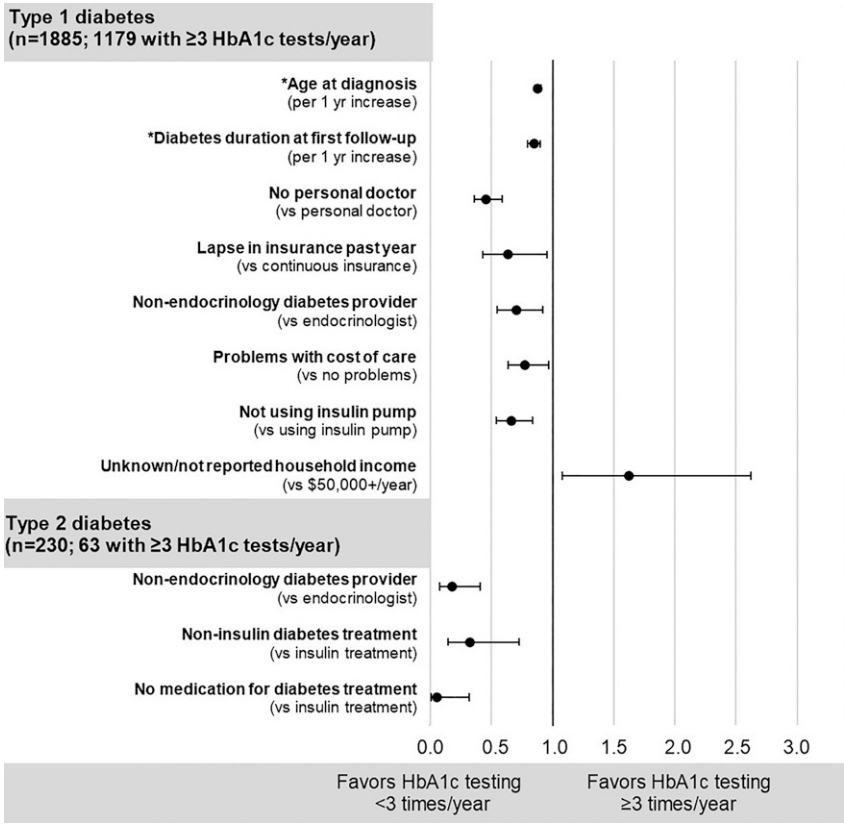

Figure 1—Sociodemographic and clinical correlates of HbA_{1c} testing cross sectionally at the first SEARCH follow-up visit for type 1 diabetes (top) and type 2 diabetes (bottom). Data are OR (95% CI) for reporting ≥3 tests/year relative to those reporting <3 tests/year. *Core variables of age at diagnosis, diabetes duration, sex, race/ethnicity, and clinical site were not subject to stepwise selection. Candidate variables included parental education at baseline, household income at baseline, diabetes treatment, diabetes care provider, having a personal doctor, having problems with the cost of care in the prior 12 months, type of health insurance, and having continuous health insurance in the prior year. Nonsignificant core variables and nonselected candidate variables are not shown.

was not observed to be related to HbA_{1c} levels or microvascular complications at 13 years' duration in any model. For microvascular complications, models 2 and 3 did not converge (no data shown).

CONCLUSIONS

Our data demonstrate disparities in HbA_{1c} testing frequency among individuals with youth-onset type 1 and type 2 diabetes, predominately according to health care–related factors. We previously reported that participant-reported receipt of three or more HbA_{1c} tests per year and screening for complications at 6 years' duration of youth-onset diabetes occurred less frequently among young adults, those from lower-income households, and those receiving diabetes care from general practitioners (7). Our present analysis extends this work to 8 and 13 years postdiagnosis, when individuals with youth-onset diabetes are increa-singly responsible for their own health care (17). Again, HbA_{1c} testing decreased with age and diabetes duration in type 1 diabetes, aligning with national reports of notably poor adherence to diabetes care goals in young adults (18). Considered alongside the other correlates of HbA_{1c} testing we identified, this is likely due to a reduction in clinic visits driven by multiple health care–related factors.

For both diabetes types, not receiving care from an endocrinologist reduced odds of reporting ≥3 HbA_{1c} tests/year. Endocrinologists are most familiar with diabetes management recommendations and more likely to be in clinics where quarterly visits with HbA_{1c} testing (point of care or venipuncture) is standard care (19). Yet, fewer participants reported seeing an endocrinologist after 13 years of diabetes duration: only two in three individuals with type 1 diabetes and one in four individuals with type 2 diabetes were consistently receiving care from an endocrinologist. Others have similarly reported that ~70% of young adults with type 1 diabetes visit an endocrinologist in a 1-year period, which further decreases with age (20). Barriers to specialty care for young adults with type 1 diabetes include inconvenient scheduling, perceived lack of need or benefit of specialty care, and prior negative experiences (21). Adults with type 2 diabetes are typically treated by general practitioners (22,23), with the more severe cases (i.e., higher HbA_{1c} levels) more frequently referred to specialists (24). Yet, the more aggressive nature of youth-onset type 2 diabetes relative to adult onset (25) may warrant specialty care for most individuals. Further research into the key factors limiting specialty care for both types of youth-onset diabetes would be beneficial to improve access. Given projected increases in incidence, it is equally important to equip general practitioners to successfully manage these individuals (26).

Diabetes treatment was also a strong correlate of HbA_{1c} testing for both types of diabetes. Individuals with type 1

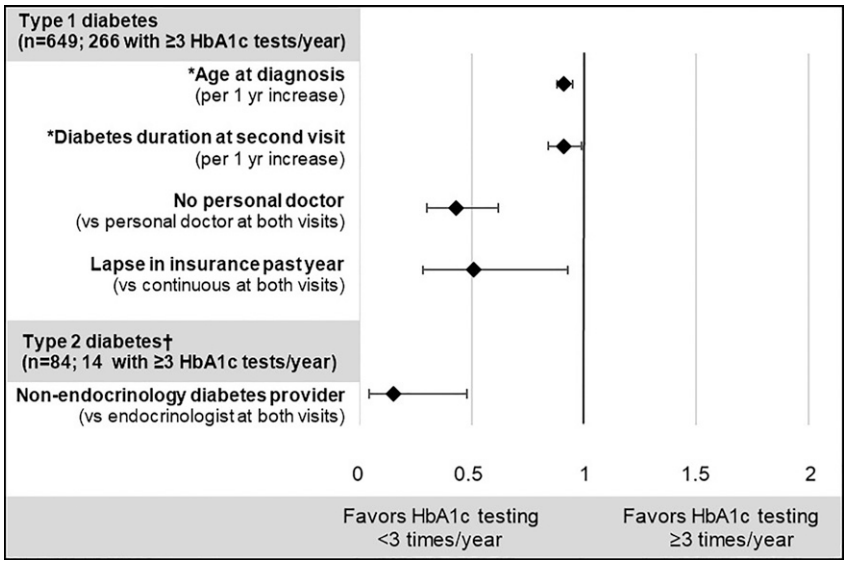

Figure 2—Sociodemographic and clinical correlates of HbA_{1c} testing longitudinally at the first and second SEARCH follow-up visits for type 1 diabetes (top) and type 2 diabetes (bottom). Data are OR (95% CI) for reporting ≥3 tests/year at both visits relative to those reporting <3 tests/year at either visit. *Core variables of age at diagnosis, diabetes duration, sex, race/ethnicity, and clinical site were not subject to stepwise selection. Candidate variables included parental education at baseline, household income at baseline, diabetes treatment, diabetes care provider, having a personal doctor, having problems with the cost of care in the prior 12 months, type of health insurance, and having continuous health insurance in the prior year. Nonsignificant core variables and nonselected candidate variables are not shown. †All variables were allowed to compete in the type 2 model because of the small sample size; only diabetes provider was retained.

diabetes not using an insulin pump were 31% less likely to have ≥3 tests/year than their peers who use a pump, with pump use likely indicating access to higher quality of care and resources to cover costs. This disparity is even more pronounced in type 2 diabetes, where individuals not using insulin were 64–93% less likely to report ≥3 tests/year than their peers who use insulin. This may be explained by the increased number of clinic visits and, therefore, more opportunities for HbA_{1c} testing among individuals who are using insulin compared with those successfully managing type 2 diabetes with noninsulin medications or diet/exercise alone. However, this likely applies to few of our participants with type 2 diabetes given that ≥60% warranted quarterly testing based on HbA_{1c} levels and/or age. While we interpret the absolute ORs with caution given the wide CIs, the pattern of results suggests that individuals who receive more intensive diabetes treatment also receive increased glycemic monitoring, with both factors likely facilitating better outcomes.

For type 1 diabetes, not having a personal doctor had the greatest negative impact on HbA_{1c} testing, suggesting that individuals who do not believe that any single provider knows them best may be less motivated to pursue clinic visits. Alternatively, this finding may simply reflect that individuals who are not receiving regular care (and thereby HbA_{1c} testing) do not have the opportunity to identify a provider who knows them best. This may be particularly relevant during the transition from pediatric to adult care, wherein a reduction in clinic visits often occurs, but structured transition programs may increase visits and improve HbA_{1c} (27). Participants reporting lapses in health insurance coverage or problems with the cost of care were also less likely to report ≥3 tests/year, affirming reports that individuals with diabetes receive less care during insurance gaps or financial hardship (24,28–30). Interestingly, neither parental education nor household income had clear relationships with HbA_{1c} testing, indicating that affordable health care and/or health insurance have greater implications for regular diabetes care than more general indicators of socioeconomic status. Given evidence that affordable health care and insurance can become more accessible to low-income individuals (31), our study identifies potential intermediate targets that may facilitate access to regular diabetes care. While these "cost-of-care" factors are likely interrelated, they each exhibited independent effects on HbA_{1c} testing frequency in our analysis, highlighting the substantial barriers faced by low-resourced individuals with type 1 diabetes. We note that race/ethnicity itself was not related to HbA_{1c} testing, but there are known racial/ethnic disparities in the health care–related factors that were related to testing frequency disparities (32–34). Taken together, these findings suggest that eliminating disparities in such health care factors may be a potential strategy for addressing racial/ethnic disparities in diabetes outcomes.

HbA_{1c} testing ≥3 times/year, in turn, was associated with a 0.16–0.36% decrease in HbA_{1c} levels and a 36–49% reduced odds of microvascular complications. A similarly sized shift in HbA_{1c} levels was observed with more frequent HbA_{1c} testing over 1–2 years in German and Austrian young adults with type 1 diabetes (35). However, in our study, these associations were attenuated after adjustment for the socioeconomic and clinical factors found to be related to HbA_{1c} testing frequency. We interpret these sequential results as indicating that HbA_{1c} testing ≥3 times/year is a proxy for receipt of frequent high-quality care, which, in turn, depends on access. When access to

HbA_{1c} testing is threatened, such as by a lapse in health insurance or problems with the cost of care, diabetes management is impaired, with potentially long-term consequences.

In contrast, limited HbA_{1c} testing was not observed to be associated with HbA_{1c} levels or microvascular complications in type 2 diabetes. As a prior study of nearly 200,000 older adults (mean age >60 years) reported improved HbA_{1c} levels following quarterly testing (36), we note that our analysis was likely underpowered with <250 participants. Alternatively, it may have been confounded by more severe (uncontrolled) cases of diabetes having poorer outcomes, even with more intensive clinical monitoring, while less severe cases could achieve better outcomes with more intensive clinical monitoring. Nonetheless, it remains concerning that nearly 60% of participants reported <3 HbA_{1c} tests/year over time despite average HbA_{1c} levels >9%. We observed increases in mean HbA_{1c} over time, as has been reported previously (37), which may be the result of treatment failure in highly aggressive youth-onset type 2 diabetes (38). Diabetes provider type and treatment type, but not sex, age, race/ethnicity, and socioeconomic factors, were related to HbA_{1c} testing frequency, suggesting that interventions targeting providers rather than patients may be needed to increase testing and, ultimately, quality of care. Specifically, general practitioners who more frequently treat adult-onset type 2 diabetes may need education on the aggressive nature of youth-onset type 2 dia-betes and support for adjusting care processes appropriately for younger indi-viduals.

Our study has limitations and strengths. Our analysis was limited by the small sample size for type 2 diabetes, as noted above. We were also unable to examine microvascular complications individually because of relatively low prevalence. We estimated the number of participants warranting quarterly testing based on research study visit HbA_{1c} ≥7% and/or age <18 years (just for type 2 diabetes) but focused our analysis on HbA_{1c} testing ≥3 times/year because we did not have data on clinical HbA_{1c} or medication changes in the full year prior to the SEARCH visit (which also informs testing frequency [4,5]). Less frequent testing may have been appropriate for participants meeting treatment goals. We also did not have information on number of clinic visits in the prior year and, thus, cannot draw conclusions on whether HbA_{1c} testing was low because clinic visits overall were low or whether testing was not done at clinic visits. Misclassification of testing frequency may have been a result of reliance on participant report, although patient recall of HbA_{1c} testing correlates well with medical record data (39,40). We included self-monitoring of blood glucose as a covariate, with testing ≥4 times/day (including continuously) serving as a proxy for a higher level of engagement with diabetes self-management. Further study of how continuous glucose monitoring specifically (vs. more or fewer tests per day) is related to HbA_{1c} levels and complications would be warranted in a future study. Key strengths of this analysis include the large sample size for type 1 diabetes, the racial/ethnic and socioeconomic diversity for both types, clinical assessments of microvascular complications, consideration of socioeconomic and clinical factors, and the longitudinal design.

In conclusion, our study affirms the recommendations for frequent HbA_{1c} testing in type 1 diabetes to facilitate reaching glycemic goals and potentially to reduce microvascular complications as the disease progresses. No consistent association was observed between HbA_{1c} testing and glycemic control or microvascular complications in type 2 diabetes as of 13 years diabetes duration. Nonendocrinology providers appear to monitor HbA_{1c} less frequently, particularly in type 2 diabetes, highlighting a target population for interventions to increase testing and, in turn, potentially improving glycemic control. Our results also suggest that youth and young adults may forgo HbA_{1c} testing during health insurance lapses or financial instability, while those having a personal doctor report more frequent testing. Thus, continued access to quality health care appears critical to successful management of diabetes, especially during the transition from pediatric to adult care.

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and D.D. designed the present research question. J.M.S. and R.B.D. analyzed the data. J.M.L., A.K.M., C.P., and D.D. supervised data collection. S.S. contributed to the study design and data interpretation. All authors interpreted the results and reviewed, critically revised, and approved the manuscript. K.A.S. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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References

1. Divers J, Mayer-Davis EJ, Lawrence JM, et al. Trends in incidence of type 1 and type 2 diabetes among youths - selected counties and Indian reservations, United States, 2002-2015. MMWR Morb Mortal Wkly Rep 2020;69:161–165
2. Kahkoska AR, Shay CM, Crandell J, et al. Association of race and ethnicity with glycemic control and hemoglobin A_{1c} levels in youth with type 1 diabetes. JAMA Netw Open 2018;1: e181851
3. Dabelea D, Stafford JM, Mayer-Davis EJ, et al.; SEARCH for Diabetes in Youth Research Group. Association of type 1 diabetes vs type 2 diabetes diagnosed during childhood and adolescence with complications during teenage years and young adulthood. JAMA 2017;317:825–835
4. American Diabetes Association. 6. Glycemic targets: standards of medical care in diabetes-2021. Diabetes Care 2021;44(Suppl. 1):S73–S84
5. American Diabetes Association. 13. Children and adolescents: standards of medical care in diabetes-2021. Diabetes Care 2021;44(Suppl. 1): S180–S199
6. Malik FS, Stafford JM, Reboussin BA, et al.; SEARCH for Diabetes in Youth Study. Receipt of recommended complications and comorbidities screening in youth and young adults with type 1 diabetes: associations with metabolic status and satisfaction with care. Pediatr Diabetes 2020; 21:349–357
7. Waitzfelder B, Pihoker C, Klingensmith G, et al.; SEARCH for Diabetes in Youth Study Group. Adherence to guidelines for youths with diabetes mellitus. Pediatrics 2011;128:531–538
8. Miller KM, Foster NC, Beck RW, et al.; T1D Exchange Clinic Network. Current state of type 1 diabetes treatment in the U.S.: updated data from the T1D Exchange clinic registry. Diabetes Care 2015;38:971–978
9. Phan TL, Hossain J, Lawless S, Werk LN. Quarterly visits with glycated hemoglobin monitoring: the sweet spot for glycemic control in youth with type 1 diabetes. Diabetes Care 2014; 37:341–345
10. Parcero AF, Yaeger T, Bienkowski RS. Frequency of monitoring hemoglobin A1C and achieving diabetes control. J Prim Care Community Health 2011;2:205–208
11. Diabetes Control and Complications Trial Research Group. Effect of intensive diabetes treatment on the development and progression of long-term complications in adolescents with insulin-dependent diabetes mellitus: Diabetes Control and Complications Trial. J Pediatr 1994; 125:177–188
12. Hamman RF, Bell RA, Dabelea D, et al.; SEARCH for Diabetes in Youth Study Group. The SEARCH for Diabetes in Youth study: rationale, findings, and future directions. Diabetes Care 2014;37:3336–3344
13. Bjornstad P, Cherney DZ, Maahs DM. Update on estimation of kidney function in diabetic kidney disease. Curr Diab Rep 2015;15:57
14. Klein R, Klein BE, Magli YL, et al. An alternative method of grading diabetic retinopathy. Ophthalmology 1986;93:1183–1187
15. Feldman EL, Stevens MJ, Thomas PK, Brown MB, Canal N, Greene DA. A practical two-step quantitative clinical and electrophysiological assessment for the diagnosis and staging of diabetic neuropathy. Diabetes Care 1994;17: 1281–1289
16. Jaiswal M, Lauer A, Martin CL, et al.; SEARCH for Diabetes in Youth Study Group. Peripheral neuropathy in adolescents and young adults with type 1 and type 2 diabetes from the SEARCH for Diabetes in Youth follow-up cohort: a pilot study. Diabetes Care 2013;36:3903–3908
17. Garvey KC, Markowitz JT, Laffel LM. Transition to adult care for youth with type 1 diabetes. Curr Diab Rep 2012;12:533–541
18. Ali MK, Bullard KM, Saaddine JB, Cowie CC, Imperatore G, Gregg EW. Achievement of goals in U.S. diabetes care, 1999-2010. N Engl J Med 2013;368:1613–1624
19. Pihoker C, Forsander G, Fantahun B, et al. ISPAD clinical practice consensus guidelines 2018: the delivery of ambulatory diabetes care to children and adolescents with diabetes. Pediatr Diabetes 2018;19(Suppl. 27):84–104
20. Pettus JH, Zhou FL, Shepherd L, et al. Incidences of severe hypoglycemia and diabetic ketoacidosis and prevalence of microvascular complications stratified by age and glycemic control in U.S. adult patients with type 1 diabetes: a real-world study. Diabetes Care 2019;42: 2220–2227
21. Lawson VL, Lyne PA, Harvey JN, Bundy CE. Understanding why people with type 1 diabetes do not attend for specialist advice: a qualitative analysis of the views of people with insulin-dependent diabetes who do not attend diabetes clinic. J Health Psychol 2005;10:409–423
22. Rao DT, Sunio LK, Lo YJ, Gossain VV. Comparison of the adherence to the American Diabetes Association guidelines of diabetes care in primary care and subspecialty clinics. J Diabetes Metab Disord 2015;14:35
23. Grant RW, Buse JB; University HealthSystem Consortium (UHC) Diabetes Benchmarking Project Team. Quality of diabetes care in U.S. academic medical centers: low rates of medical regimen change. Diabetes Care 2005;28:337–442
24. McBrien KA, Naugler C, Ivers N, et al. Barriers to care in patients with diabetes and poor glycemic control-A cross-sectional survey. PLoS One 2017;12:e0176135
25. Nadeau KJ, Anderson BJ, Berg EG, et al. Youth-onset type 2 diabetes consensus report: current status, challenges, and priorities. Diabetes Care 2016;39:1635–1642
26. Imperatore G, Boyle JP, Thompson TJ, et al.; SEARCH for Diabetes in Youth Study Group. Projections of type 1 and type 2 diabetes burden in the U.S. population aged $<$20 years through 2050: dynamic modeling of incidence, mortality, and population growth. Diabetes Care 2012; 35:2515–2520
27. Lyons SK, Becker DJ, Helgeson VS. Transfer from pediatric to adult health care: effects on diabetes outcomes. Pediatr Diabetes 2014;15: 10–17
28. Heydarabadi AB, Mehr HM, Nouhjah S. Why rural diabetic patients do not attend for scheduled appointments: results of a qualitative study. Diabetes Metab Syndr 2017;11(Suppl. 2): S989–S995
29. Nelson KM, Chapko MK, Reiber G, Boyko EJ. The association between health insurance coverage and diabetes care; data from the 2000 Behavioral Risk Factor Surveillance System. Health Serv Res 2005;40:361–372
30. TODAY Study Group. Health care coverage and glycemic control in young adults with youth-onset type 2 diabetes: results from the TODAY2 study. Diabetes Care 2020;43:2469–2477
31. Kominski GF, Nonzee NJ, Sorensen A. The Affordable Care Act's impacts on access to insurance and health care for low-income populations. Annu Rev Public Health 2017;38: 489–505
32. Willi SM, Miller KM, DiMeglio LA, et al.; T1D Exchange Clinic Network. Racial-ethnic disparities in management and outcomes among children with type 1 diabetes. Pediatrics 2015;135:424–434
33. Gallegos-Macias AR, Macias SR, Kaufman E, Skipper B, Kalishman N. Relationship between glycemic control, ethnicity and socioeconomic status in Hispanic and White non-Hispanic youths with type 1 diabetes mellitus. Pediatr Diabetes 2003;4:19–23
34. Paris CA, Imperatore G, Klingensmith G, et al. Predictors of insulin regimens and impact on outcomes in youth with type 1 diabetes: the SEARCH for Diabetes in Youth study. J Pediatr 2009;155:183–9.e1
35. Schwandt A, Best F, Biester T, et al.; Diabetes-Patienten-Verlaufsdokumentation (DPV) Initiative. Both the frequency of HbA_{1c} testing and the frequency of self-monitoring of blood glucose predict metabolic control: a multicentre analysis of 15 199 adult type 1 diabetes patients from Germany and Austria. Diabetes Metab Res Rev 2017;33:e2908
36. Driskell OJ, Holland D, Waldron JL, et al. Reduced testing frequency for glycated hemoglobin, HbA1c, is associated with deteriorating diabetes control. Diabetes Care 2014;37:2731–2737
37. Nambam B, Silverstein J, Cheng P, et al.; Pediatric Diabetes Consortium. A cross-sectional view of the current state of treatment of youth with type 2 diabetes in the USA: enrollment data from the Pediatric Diabetes Consortium Type 2 Diabetes Registry. Pediatr Diabetes 2017;18: 222–229
38. TODAY Study Group. Effects of metformin, metformin plus rosiglitazone, and metformin plus lifestyle on insulin sensitivity and β-cell function in TODAY. Diabetes Care 2013;36:1749–1757
39. Løvaas KF, Cooper JG, Sandberg S, Røraas T, Thue G. Feasibility of using self-reported patient data in a national diabetes register. BMC Health Serv Res 2015;15:553
40. Fowles JB, Rosheim K, Fowler EJ, Craft C, Arrichiello L. The validity of self-reported diabetes quality of care measures. Int J Qual Health Care 1999;11:407–412