Out of Pocket Diabetes-Related Medical Expenses for Adolescents and Young Adults With Type 1 Diabetes: The SEARCH for Diabetes in Youth Study

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The significant increase in the complexity of diabetes care over the last two decades is associated with a high economic burden (1), with almost one-quarter of adults with diabetes burdened with significant out of pocket expenses (OOPEs) (2). Little is known about the OOPEs for families of adolescents and young adults with type 1 diabetes. We therefore report the diabetes-related OOPEs for these families from the SEARCH for Diabetes in Youth (SEARCH) study and their association with demographic, socioeconomic, clinical, and health care characteristics.

A detailed description of the SEARCH study methods has previously been published (3). Participants had a baseline visit shortly after diabetes diagnosis and one or more follow-up visits; this report includes data from a follow-up visit between November 2011 and July 2015, at which time participants' diabetes duration was >5 years. Participants ≥18 years old or a parent/guardian of participants <18 years old completed surveys, including questions about sociodemographics, diabetes treatment, health insurance, and OOPEs. The primary outcome was OOPEs in a typical month. Monthly OOPEs were captured in intervals of unequal lengths expressed in 2013 U.S. dollars as $0, $1–19, $20–49, $50–99, $100–199, and ≥$200.

Descriptive analyses were based on the midpoint of each interval. The midpoint of the last interval (≥$200) was estimated at $278, based on MarketScan data (4). Interval-censored regression models were fit assuming a Weibull distribution to evaluate the association between categories of OOPEs and covariates. The relationship between OOPEs and each covariate was assessed after adjustment for nonmodifiable characteristics (model 1), modifiable clinical factors (model 2), and health insurance categories (model 3). SAS 9.4 was used for analyses. An a priori $\alpha = 0.05$ was used to assess statistical significance.

After exclusion of 221 participants with missing OOPEs data from the 2,384 participants with type 1 diabetes who completed a follow-up visit, 2,163 participants were included in these analyses. At the visit, mean ± SD age was 17.0 ± 4.7 years and mean diabetes duration was 7.9 ± 1.9 years. The median monthly diabetes-related OOPE was estimated at $64.60. Approximately 60% of participants had OOPEs of at least $50 per month, and 40% at least $100 per month.

Table 1 shows the adjusted association of OOPEs presented as an OOPE rate relative to the reference group and 95% CIs. Participants whose parents had not completed high school had lower OOPEs compared with participants whose parents had at least a high school education (model 3: OOPE rate 0.55 [95% CI 0.34, 0.88]). OOPEs were lower for families with household income of <$25,000 compared with families with household income of $50,000–74,000 (model 3: OOPE rate 0.66 [95% CI 0.49, 0.88]). OOPEs were higher for families who received diabetes care from an adult endocrinologist or family practitioner versus a pediatric endocrinologist (model 3: OOPE rate 1.47 [95% CI 1.14, 1.9] and 1.69 [95% CI 1.07, 2.67], respectively). Insulin injections were associated with lower OOPEs than insulin pumps (model 3: OOPE rate 0.82 [95% CI 0.69, 0.98] for

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Table 1—Adjusted monthly diabetes-related OOPE rates for the associations with demographic and treatment variables among participants with type 1 diabetes, using interval-censored regression models

	Model 1		Model 2		Model 3	
Variable (%)	Monthly OOPE rate (95% CI)	*P*‖	Monthly OOPE rate (95% CI)	*P*‖	Monthly OOPE rate (95% CI)	*P*‖
Age (in years)	0.99 (0.97, 1.01)	0.50	1.0 (0.98, 1.03)	0.93	1.00 (0.75, 1.33)	0.79
Diabetes duration (in years)	1.00 (0.96, 1.05)	0.99	1.0 (0.95, 1.05)	0.93	1.01 (0.99, 1.01)	0.51
Race/ethnicity						
Non-Hispanic black (11)	0.66 (0.51, 0.85)	0.006	0.76 (0.57, 1)	0.12	1.00 (0.75, 1.33)	0.60
Hispanic (12)	0.77 (0.6, 0.99)		0.79 (0.6, 1.04)		0.85 (0.65, 1.11)	
Other (2.5)	0.82 (0.51, 1.33)		1.07 (0.63, 1.84)		0.82 (0.48, 1.4)	
Non-Hispanic white (74.5)	Reference		Reference		Reference	
Sex						
Female (50.1)	0.92 (0.78, 1.07)	0.28	0.88 (0.75, 1.04)	0.14	0.88 (0.75, 1.04)	0.14
Male (49.9)	Reference		Reference		Reference	
Level of parental education						
Bachelor's degree or more (51.6)	1.45 (1.1, 1.91)	0.0001	1.3 (0.97, 1.74)	0.002	1.05 (0.82, 1.33)	0.01
Some college (33.3)	1.11 (0.85, 1.46)		1.06 (0.8, 1.41)		0.9(0.68, 1.19)	
Less than high school (3.8)	0.59 (0.37, 0.93)		0.53 (0.33, 0.87)		0.53 (0.33, 0.85)	
High school graduate (11.25)	Reference		Reference		Reference	
Median household income						
$75,000+ (38)	1.27 (1.01, 1.61)	<0.0001	1.22(0.96, 1.56)	<0.0001	1.04(0.82, 1.32)	0.004
$50,000–74,000 (16.1)	Reference		Reference		Reference	
$25,000–49,000 (16.9)	0.71 (0.54, 0.93)		0.73 (0.55, 0.97)		0.82 (0.62, 1.08)	
<$25,000 (16)	0.37 (0.28, 0.49)		0.39 (0.29, 0.52)		0.61 (0.45, 0.82)	
Did not know/refused (13.1)	0.89 (0.66, 1.2)		0.88 (0.64, 1.2)		0.89 (0.65, 1.21)	
Type of diabetes provider						
Adult endocrinologist (16.9)	1.51 (1.17, 1.94)	0.03	1.62 (1.24, 2.12)	0.005	1.44 (1.11, 1.87)	0.003
Family practice doctor (3.7)	1.32 (0.85, 2.05)		1.72 (1.07, 2.77)		1.98 (1.21, 3.22)	
None/no source of medical care (1.2)	1.01 (0.49, 2.08)		1.08 (0.48, 2.41)		0.59 (0.24, 1.49)	
Other (19.3)	1.10 (0.89, 1.35)		1.12 (0.9, 1.4)		1.05 (0.85, 1.31)	
Pediatric endocrinologist (58.9)	Reference		Reference		Reference	
HbA_{1c}, age-specific†						
Intermediate (40.7)			1.05 (0.8, 1.38)	0.72	0.96 (0.73, 1.27)	0.54
Poor (47.1)			1.11 (0.84, 1.46)		1.07 (0.8, 1.42)	
Good (12.3)			Reference		Reference	
BMI						
<85th percentile (66.6)			Reference	0.26	Reference	0.32
85th–95th percentile (20.8)			0.93 (0.76, 1.13)		0.95 (0.78, 1.16)	
>95th percentile (12.6)			0.82 (0.64, 1.05)		0.85 (0.66, 1.08)	
Insulin regimen						
Insulin injections including long acting (35.6)			0.84 (0.7, 1.01)	0.01	0.78 (0.65, 0.94)	0.004
Insulin injections excluding long acting (8.3)			0.63 (0.45, 0.87)		0.63 (0.45, 0.86)	
Pump therapy (56.1)			Reference		Reference	
Frequency of SMBG						
Did not use a glucometer (2.2)			1.06 (0.59, 1.89)	0.37	1.06 (0.59, 1.89)	0.45
Less than once a day, only when sick (12.6)			1.09 (0.84, 1.42)		1.09 (0.84, 1.42)	
1–2 times a day (10.4)			0.99 (0.75, 1.32)		0.99 (0.75, 1.32)	
3 times a day (13.6)			1.13 (0.87, 1.45)		1.13 (0.87, 1.45)	
4–6 times a day (50.4)			Reference		Reference	
≥7 times a day (10.8)			1.38 (1.03, 1.85)		1.26 (0.94, 1.69)	
CGM use						
Yes (17.4)			1.29 (1.03, 1.62)	0.03	1.35 (1.08, 1.68)	0.01
No (78.3)			Reference		Reference	
Health insurance						
None (3.3)					0.83 (0.5, 1.38)	<0.0001
Other/Medicaid/Medicare (25.7)§					0.22 (0.18, 0.27)	
Private (71)					Reference	

Model 1 examines OOPE with adjustment for nonmodifiable characteristics including age, diabetes duration, race/ethnicity, sex, highest level of parental education, household income, type of diabetes provider, and SEARCH site. Model 2 builds on model 1 with addition of modifiable clinical variables including HbA_{1c}, BMI, insulin regimen, and frequency of SMBG and CGM use. Model 3 builds upon model 2, controlling for health insurance. SMBG, self-monitoring of blood glucose. †We defined glycemic control based on the following HbA_{1c} level cutoffs. For participants <18 years old, glycemic control is good with HbA_{1c} <7.5%, intermediate with HbA_{1c} 7.5% to <9%, and poor with HbA_{1c} >9.0%. For participants ≥18 years old, glycemic control is good with HbA_{1c} <7%, intermediate with HbA_{1c} 7% to <9%, and poor with HbA_{1c} >9.0%. §Other insurance categories include school-based insurance and Tribe/Indian Health Service. ‖*P* value of the omnibus test for comparing the different subgroups with the reference.

regimens including long-acting insulin and 0.72 [95% CI 0.52, 0.98] for regimens not including long-acting insulin). Continuous glucose monitoring (CGM) use was associated with higher OOPEs (model 3: OOPE rate 1.35 [95% CI 1.08, 0.1.68]). OOPEs were lower in those who had public health insurance (OOPE rate 0.22 [95% CI 0.18, 0.27]) compared with those with private health insurance.

This study is subject to limitations. The survey was cross-sectional, and data on OOPEs and treatment measures were obtained from self-reported surveys. The data were obtained between 2011 and 2015 and might not account for higher insulin costs and newer diabetes technologies that evolved since then (5). Additionally, the OOPEs reported are only related to diabetes medications and supplies and do not account for copays or coinsurance for clinic or hospital visits and insurance premiums. We also do not report on other expenses that might be incurred, such as productivity losses due to missed work or school. Lastly, our descriptive analyses were based on the midpoint of each cost interval. Since the intervals are not equal, this could misestimate the variation in the amount paid between individuals. The midpoint for the highest interval was derived from empirical data (4) and may underestimate OOPEs given the long tail of high expenditures.

Our findings suggest that most adolescents and young adults with type 1 diabetes have some OOPEs related to diabetes medications and supplies. These OOPEs vary with different demographic and clinical factors. Future studies may explore causal pathways that drive higher OOPEs and whether OOPEs create barriers and disparities in health care utilization. This will ultimately help develop interventions to improve access to health care for underserved populations.

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