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Caregiver Reports of Provider Recommended Frequency of Blood Glucose Monitoring and Actual Testing Frequency for Youth with Type 1 Diabetes

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Abstract

Aims—To identify demographic, family and clinical characteristics associated with provider recommended frequency of blood glucose monitoring (BGM), actual frequency of BGM, and concordance between these categories in youth with type 1 diabetes (T1D) as reported by child's caregiver.

Methods—Caregivers of 390 children 10–17 years were interviewed about their children's providers' recommendations for frequency of BGM and their child's frequency of performance of BGM.

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A version of these results were presented at the Society of Behavioral Medicine Meeting, in Seattle, WA on April 2010.

Results—The majority (92%) of caregivers reported being told that their child should BGM ≥4 times per day and 78% reported their child checked that frequently. Caregivers of children who were younger, non-Hispanic White, from two-parent households, higher income households, and on insulin pumps were more likely to report being told by their provider to perform BGM ≥6 times per day and more likely to report that their child performed BGM ≥6 times per day. Younger children and those with private health insurance were more likely to adhere to reported recommendations. Children whose caregivers reported that their child met/exceeded their provider recommendations had lower A1c values than those who did not.

Conclusions—These findings may help clinicians identify subgroups of youth at-risk for poor diabetes management and provide further education in order to improve outcomes.

Keywords

Blood glucose monitoring; Adherence; Type 1 Diabetes; Youth

Introduction

Given the complexity and demanding nature of modern-day treatment regimens for type 1 diabetes, it is not surprising that reported adherence to treatment recommendations among youth with diabetes is low, particularly among adolescents [1, 2]. Understanding the factors that are related to adherence is critical. Studies have clearly demonstrated that persons with higher levels of adherence to their treatment regimens have better glycemic control [3, 4]. Since sub-optimal glycemic control is associated with an increased risk for the development of diabetes-related complications [5], youth with T1D should strive to achieve and maintain good glycemic control, even at an early age. However, optimal glycemic control in youth is not often achieved, particularly by older youth [6, 7].

Based on the findings of the Diabetes Control and Complications Trial [8], frequent blood glucose monitoring (BGM) has become a cornerstone of optimal diabetes management. Adherence to frequent BGM has been found to be an integral factor in achieving optimal glycemic control [1, 9]. Greater BGM has been reported to be associated with younger age and insulin pump use [9, 10]. In most cases, a linear increase in BGM per day resulted in improvements in glycated hemoglobin (A1c) [1], but recent analyses have suggested that this effect may peak at five times per day [10].

While previous research has shown that BGM is an important contributor to glycemic control, little is known about whether BGM by children with type 1 diabetes corresponds with the frequency of BGM recommended by their health care providers. Using data from the SEARCH for Diabetes Study, these analyses explore demographic, family and clinical characteristics associated with provider recommended frequency of BGM, actual frequency of BGM, and concordance between these categories in children with T1D as reported by child's caregiver. Additionally we explore the associations between recommended and reported frequency of BGM and A1c measurements.

Materials and Methods

Study Sample

SEARCH for Diabetes in Youth is a multicenter study that conducts population-based ascertainment of youth with clinically diagnosed, non-gestational diabetes who are <20 at the time of diagnosis [11]. SEARCH has enrolled youth newly diagnosed with diabetes from 2002 through the present. Cases are ascertained from geographically defined populations in Ohio, Colorado, South Carolina and Washington, Indian Health Service beneficiaries from four American Indian populations, and enrollees in several health plans in California and Hawaii. Youth whose diabetes is not secondary to other conditions are invited to a SEARCH study visit. After obtaining informed consent and assent, physical measurements and fasting blood samples are collected from metabolically stable children, and questionnaires are administered. Youth whose diabetes was incident in 2002 through 2005 and who completed a baseline study visit were invited to return for follow-up visits.

The data included in this analysis are from children with T1D who were 10 through 17 years of age and their parent/guardian (“caregivers”) who accompanied them at their 24-month SEARCH follow-up visit where questions about their child’s provider recommendation for frequency of BGM and their child’s actual frequency of BGM were asked. The response rate for this follow-up visit was 52%. Of the 390 participants who completed a follow-up visit, 94% (n=385) completed the survey which included the questions about BGM.

Measures

Demographic variables included age at study visit, sex, race/ethnicity, and insurance status. Insurance was categorized as private, state-funded (Medicaid/Medicare, etc), other (which included student health clinics, military, Indian Health Services), or none. ***Family variables*** included family income which was categorized as <$25K, $25–49K, $50–74K, $75K+, don’t know/refused, and family composition which was categorized as 2-parent household, 1-parent household, or other/unknown composition.

Clinical variables included duration of diabetes since diagnosis, insulin regimen, depression, and glycemic control. Duration of diabetes was the length of time between date of diagnosis and the 24-month visit. Insulin regimen was categorized as 1) basal-bolus using the insulin pump, 2) basal-bolus with glargine plus rapid-acting insulin, 3) multiple daily injections (MDI) with ≥3 injections/day, using glargine plus more than/or other than rapid-acting insulin type, 4) MDI with ≥3 injections/day, using any insulin types excluding basal insulin, or 5) 1 to 2 injections/day, excluding glargine [6]. Detemir and glulisine were not in clinical use during the data collection period. Depression was assessed based on the child’s responses on the Center for Epidemiologic Studies Depression scale (CES-D) [12]. This 20-item scale is a commonly used measure of depressive symptomatology in children age 10 years and older [13, 14]. For these analyses, we categorized the scores as minimally (0–15), mildly (16–23), and moderately/severely (24–60) depressed mood [15, 16].

Glycemic control was assessed using blood samples shipped to a central laboratory (Northwest Lipid Research Laboratories, Seattle, WA) for analysis. An ion exchange unit (Variant II; Bio-Rad Diagnostics, Hercules, CA) quantified the glycated hemoglobin (A1c)

levels. Optimal age-specific goals for A1c in children are <8.0% for 10–12 year olds, and <7.5% for 13–18 year olds [17].

BGM Recommendations, Behaviors, and Adherence—Caregivers of children with T1D were asked to report the frequency of BGM recommended by their child's health care provider and the number of times per day their child conducted BGM over the last 3 months. Response options for both questions were 6 or more times daily, 4–5 times daily, 2–3 times daily, at least once daily, or don't know. Adherence to recommendations was determined by comparing their responses to questions about recommended and actual BGM frequency, and categorized as exceeded (child monitored more than recommended by provider), met (child monitored exactly as the provider recommended), or did not meet (child monitored less than what the provider recommended) their child's provider recommendation for daily BGM.

Statistical Analysis

Analyses were conducted using SAS version 9.2 (SAS Institute, Cary, North Carolina). Descriptive statistics (means, standard deviations, frequencies, and percents) were used to summarize demographic, family, and clinical variables. Chi-square tests were used to assess the associations between categorical variables. Unadjusted associations between demographic, clinical, and family characteristics and age, receipt of BGM recommendations, adherence to provider BGM recommendations, and A1c values measured at the study visit were assessed using chi-square tests, analysis of variance (ANOVA), or Kruskal-Wallis tests. Multivariable linear regression was used to assess the association between A1c levels with BGM recommendations and reported behaviors, adjusted for age and insulin regimen. Logistic regression was used to determine which variables were independently predictive of meeting or exceeding provider recommendations. Variables used in the logistic model included site, age (10–12, 13–15, 16+), gender, race (non-Hispanic White [NHW] versus other), insurance (private versus other), income, family composition (2 parent household versus other), diabetes duration (≤ 3 years, > 3 years), insulin regimen, and depressive symptoms. Results were considered significant if $p < 0.05$.

Results

Table 1 shows the demographic, family and clinical composition of the 390 eligible children with T1D. They ranged from ages 10–17 (mean ± SD = 14.0±2.3 years) with a mean diabetes duration of just over 3 years (37.4 months). About half were female (48%) and 74% were NHW. Youth 13–15 years had the highest mean A1c values (9.2±1.9 for 13–15 year olds, 8.4±1.5 for 10–12 year olds, and 8.7±1.8 for 16–17 year olds; p=.003) and were least likely to be in adequate control based on their A1c value (15% of 13–15 year olds, 41% of 10–12 year olds, and 27% 16+ met the goal; $p < .001$). Other demographic, clinical, and family characteristics did not differ significantly by age (data not shown).

Reported recommendation for BGM frequency

Of the caregivers surveyed, 22% reported that they were told by their health care provider their child should conduct BGM at least 6 times/day, 69% reported 4–5 times/day, and 8% reported 2–3 times/day (Table 2, n=5 with missing data). There was a significant difference

in recommended frequency by study centers (p=.04, data not shown). Caregivers report of recommended frequency of BGM varied significantly by their child's age, race/ethnicity, household composition and family income as well as insulin regimen and glycemic control (Table 2). Younger, NHW participants, those from two parent households, those from families with higher incomes, and those on an insulin pump were significantly more likely to report being told to conduct BGM at least 6 times/day (Table 2). Additionally, caregivers of children who met their A1c goal were more likely to report being told to check more frequently than those who did not meet their goal. The child's gender, health insurance status, duration of diabetes and depression scores were not associated with caregivers' report of providers' recommendations.

Reported BGM behavior

Of the caregivers surveyed, 26% reported that their child conducted BGM at least 6 times/day, 52% 4–5 times/day, 16% 2–3 times/day, and 6% reported fewer than 2 times/day (Table 2, n=2 with missing data). There was no significant difference between participant responses by study center (data not shown). Caregivers of younger children, those from two parent households, those with higher incomes, those who were NHW, and those on an insulin pump were more likely to report that their child conducted BGM at least 6 times/day (Table 2). Additionally, those children who met their A1c goal were more likely to have caregivers who reported that they conduct BGM more frequently than those who did not meet their goal. There was no association between frequency of BGM and child's gender, health insurance status, duration of diabetes, or depressive symptoms.

Associations of reported BGM recommendations and behaviors with A1c

A1c was significantly lower for children whose caregivers reported that providers recommended BGM at least 6 times per day compared to those who reported that their providers recommended BGM 4–5 times per day, or fewer. A1c values were also significantly lower for children who reported that providers recommended BGM 4–5 times per day compared to those who reported that their providers recommended BGM less than 4 times per day. Adjustment for age and insulin regimen did not change these results (Table 3, top).

A1c also varied significantly by the number of times caregivers reported that BGM was conducted (Table 3, bottom, p<.001). Youth with caregivers who reported their child conducted BGM at least 6 times a day had significantly lower A1c values than those who reported BGM fewer than 6 times a day; those who performed BGM 4–5 times a day had significantly lower A1c values than those who conducted BGM fewer than 4 times a day. Adjustment for age and insulin regimen did not change these results (Table 3).

Associations with adherence to provider BGM recommendations

We then compared caregivers' report of provider recommendations for BGM to their report of their child's frequency of BGM. While most of the caregivers (92%) reported being told by their children's providers to conduct BGM at least 4 times /day (4–5 times or 6+ times/day), only 78% reported checking that frequently. Table 4 shows that adherence to recommended monitoring frequency was reported by 62% of the caregivers, with 24%

reporting they test less frequently than recommended and 14% reporting they test more frequently. Of 10–12 year olds, 92% met or exceeded provider recommendations versus 72% of 13–15 year olds and 61% of ≥16 year olds (p<.001). Those with private insurance reported meeting or exceeding provider recommendations more than those without (79% versus 65%, p=.01), and those who met A1c goal reported meeting or exceeding provider recommendations more than those who did not (91% versus 68%, p=.001).

In the adjusted analysis using multivariable logistic models, age (odds ratio [OR] = 8.6, 95% confidence interval [CI]=3.8 – 19.6 for 10–12 year olds and OR=1.4 (CI=0.8 – 2.5) for 13–15 year olds, relative to ≥16 year olds), private insurance (OR = 2.8, CI: 1.3 – 6.2), and A1c (Exceeded = 8.6±1.4, Met = 8.5±1.6, Did not meet = 9.7±1.9; p < .001) predicted meeting or exceeding provider recommendations. Gender, family income, household composition, duration of diabetes, insulin regimen or depression scores were not significantly associated with reported adherence to recommended monitoring frequency.

Discussion

These findings demonstrate that, among a large diverse sample of children with T1D, most caregivers (92%) reported being told by their child's health care provider to conduct BGM at least 4 times per day. However, only 78% reported that their child monitored that often. Children whose caregivers reported that they monitored more frequently had lower A1c values. Although causality cannot be determined from these cross-sectional data, previous reports have shown the detrimental effect of poor adherence to BGM monitoring recommendations on A1c [3]. Specifically, increased adherence has been associated with lower A1c [1, 9]. Thus, our results reinforce the notion that BGM is strongly associated with glycemic control in children with T1D.

One previous study reported that increasing BGM frequency to greater than 5 times a day did not result in further improvement of A1c [10]. In contrast, our findings suggest that those who reported checking at least 6 times per day did better than those who checked 4–5 times per day or less. Given this finding, it is interesting that only 22% of caregivers reported their provider recommended to check BGM 6 or more times per day. While frequency of provider recommendations did vary across study sites, no site differences were found in reported behaviors. In fact, compared to the percentage of caregivers reporting their provider recommended BGM ≥6 times per day, a slightly larger percentage of caregivers (26%) reported their child actually monitored that often. More attention to the accuracy of the "topping out" factor cited by Ziegler et al.'s study and factors that may be involved in checking more than prescribed would be valuable, and may also have insurance policy coverage implications for BGM supplies [10].

Age, race/ethnicity, and family variables including income and household structure emerged as important factors associated with reported recommendations for BGM, frequency of BGM, and adherence to provider recommendations. Differences in age were particularly noteworthy as there was a significant difference in reported adherence to provider recommendations between the youngest and oldest children: only 60% of 16–17 year olds met or exceeded provider recommendations for BGM, compared with 93% of 10–12 year

olds. These results are consistent with other studies which have demonstrated that older children with diabetes have poorer adherence to diabetes treatment than younger children [18, 19].

We also found that NHW participants reported being told to BGM more frequently than other race categories. While this study is not able to determine whether this is based on caregivers' perceptions or actual provider behavior, this finding may support growing literature showing racial disparities in diabetes outcomes [20], and specifically corroborates reports indicating a disparity in regimen intensity for minority youth with type 1 diabetes [21]. In addition, those on an insulin pump were more likely to report more frequent monitoring. This supports the findings of Cortina et al. [22], who also found that insulin pump users reported higher BGM than those on multiple daily injection regimens. Clearly there is a need to better understand the clinical implications, potential selection bias, and disparities that may exist surrounding intensity of the BGM recommendations children receive as well as their adherence behaviors.

There were several limitations to this study. Causality cannot be established from cross-sectional analyses. Participation in the follow-up visit was sub-optimal, which may compromise the generalizability of these findings; for example, previous findings from the SEARCH study found that older children were less likely to participate in SEARCH study visits than younger children [23]. However, of the participants, response rate to the survey was high (94%). Further, the provider recommendations assessed and the actual frequency of BGM were both based on the report from the children's caregiver which was the parent or guardian who accompanied them to the study visit. We do not have their health care providers' report of their actual recommendations nor a confirmation of the actual frequency of BGM from either the children with diabetes or from downloading their meter as these measures were not collected as part of the study protocol. We therefore cannot be sure whether these reports, particularly those for the frequency of BGM, may accurately reflect their actual frequency of BGM, particularly among older teens who are more likely to be responsible for their own care. However, caregivers' recall or understanding of these recommendations, in particular, may be as important as what was actually recommended. It is reassuring to know that most caregivers report that health care providers recommended BGM at least 4 times per day. It is acknowledged that the caregiver report of actual BGM frequency may be overestimated. However, given the discordance reported between the provider recommendations and actual BGM frequency and the significant associations found with A1c, we can be somewhat confident that these results, if inaccurate, may actually be conservative. Strengths of the study include sample size and the ethnic and geographic diversity of the children in the SEARCH study. In addition, measurement of A1c was consistent across centers and over time through the use of a single laboratory.

The need for age-specific interventions which focus on improving diabetes self-management is well-established [24, 25]. Understanding the demographic and clinical characteristics of children associated with adherence to BGM may elucidate the groups most at-risk for poor management and subsequent poor outcomes later in life. Targeting interventions to groups identified in this study who reported not knowing, or not following, these recommendations may be useful for clinicians aiming at improving glycemic outcomes in children with T1D.

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Table 1

Demographic, family, and clinical characteristics of 390 SEARCH Study Youth with Type 1 Diabetes.

	N (%)
Total	390 (100)
Demographic Variables	
Age at Study Visit (years)	
10–12	136 (35)
13–15	161 (41)
16–17	93 (24)
Gender	
Female	189 (48)
Male	201 (52)
Race/Ethnicity	
Black	40 (10)
Hispanic	45 (12)
Non-Hispanic White	289 (74)
Other	16 (4)
Health Insurance	
Private	307 (79)
Medicaid/Medicare	70 (18)
Other	8 (2)
None	5 (1)
Family Variables	
Family Income	
<25K	56 (14)
25–49K	61 (16)
50–74K	81 (21)
75K+	171 (44)
Don't know or Refused	21 (5)
Family Composition	
2 parent household	273 (70)
1 parent household	102 (26)
other/unknown	15 (4)
Clinical Variables	
Duration of Diabetes (months) – Mean ± SD	37.4±7.5
≤3 years	195 (50)
>3 years	195 (50)
Insulin Regimen[a]	
1	153 (40)
2	133 (34)
3	42 (11)
4	33 (9)

	N (%)
5	25 (6)
HbA1c (%) – Mean (SD)	8.8±1.8
HbA1c Goal[b]	
Met	93 (27)
Not Met	253 (73)
CES-D[c] Score Category	
Minimally (<16)	317 (83)
Mildly (16–23)	49 (13)
Moderately/Severely (≥ 24)	17 (4)

[a] Insulin regimen categories: 1) insulin pump, 2) long + short/rapid insulin, 3) 3X+/day long + any other combination, 4) 2X+/day any insulin combination excluding long, 5) 3X+/day any insulin(s) taken 1x/day, or any insulin combination excluding long 2x/day.

[b] Met = <8.0% for 10–12 year olds and <7.5% for 13–17 year olds

[c] CES-D= Center for Epidemiologic Studies of Depression

Table 2

Association of significant demographic, family, and clinical characteristics with caregivers' reports of provider recommended frequency for BGM and youths' actual frequency of BGM

		Times/day BGM recommended					Times/day BGM conducted				
Characteristic	**N**	**≥ 6**	**4–5**	**<4**	**p-value**	**N**	**≥ 6**	**4–5**	**2–3**	**<2**	**p-value**
		N (%)	**N (%)**	**N (%)**			**N (%)**	**N (%)**	**N (%)**	**N (%)**	
Total	385	86 (22)	267 (69)	32 (8)		388	102 (26)	200 (52)	64 (16)	22 (6)	
Age Group, (years)					.002						<.001
10–12	135	43 (32)	86 (64)	6 (4)		136	60 (44)	70 (51)	5 (4)	1 (1)	
13–15	159	33 (21)	111 (70)	15 (9)		160	34 (21)	84 (53)	31 (19)	11 (7)	
≥ 16	91	10 (11)	70 (77)	11 (12)		92	8 (9)	46 (50)	28 (30)	10 (11)	
Race/Ethnicity					.013						<.001
Black	39	6 (15)	30 (77)	3 (8)		39	5 (13)	28 (72)	6 (15)	0 (0)	
Hispanic	44	8 (18)	30 (68)	6 (14)		45	9 (20)	22 (49)	13 (29)	1 (2)	
Non-Hispanic White	286	70 (24)	198 (69)	18 (6)		288	86 (30)	145 (50)	41 (14)	16 (6)	
Other/Unknown	16	2 (13)	9 (56)	5 (31)		16	2 (13)	5 (31)	4 (25)	5 (31)	
Family Income					.002						.018
<25K	56	10 (18)	39 (70)	7 (13)		56	8 (14)	34 (61)	11 (20)	3 (5)	
25–49K	59	7 (12)	40 (68)	12 (20)		60	9 (15)	35 (58)	12 (20)	4 (7)	
50–74K	81	16 (20)	61 (75)	4 (5)		80	18 (23)	44 (55)	10 (13)	8 (10)	
75K+	168	49 (29)	110 (65)	9 (5)		171	59 (35)	76 (44)	30 (18)	6 (4)	
Don't know or Refused[a]	21	4 (19)	17 (81)	0 (0)		21	8 (38)	11 (52)	1 (5)	1 (5)	
Household Composition					.003						.003
2 parent household	270	73 (27)	181 (67)	16 (6)		273	88 (32)	125 (46)	44 (16)	16 (6)	
1 parent household	100	12 (12)	74 (74)	14 (14)		100	12 (12)	64 (64)	18 (18)	6 (6)	
Other/Unknown	15	1 (7)	12 (80)	2 (13)		15	2 (13)	11 (73)	2 (13)	0 (0)	
Insulin Regimen[b]					<.001						<.001
1	152	48 (32)	100 (66)	4 (3)		152	62 (41)	67 (44)	15 (10)	8 (5)	
2	130	27 (21)	88 (68)	15 (12)		133	24 (18)	72 (54)	29 (22)	8 (6)	
3	42	3 (7)	32 (76)	7 (17)		42	8 (19)	22 (52)	10 (24)	2 (5)	
4	32	5 (16)	26 (81)	1 (3)		32	4 (13)	23 (72)	3 (9)	2 (6)	

	Times/day BGM recommended					Times/day BGM conducted					
Characteristic	**N**	**≥ 6**	**4–5**	**<4**	**p-value**	**N**	**≥ 6**	**4–5**	**2–3**	**<2**	**p-value**
		N (%)	**N (%)**	**N (%)**			**N (%)**	**N (%)**	**N (%)**	**N (%)**	
5	25	2 (8)	18 (72)	5 (20)		25	3 (12)	14 (56)	7 (28)	1 (4)	
A1c Goal					.002						<.001
Met [c]	91	29 (32)	61 (67)	1 (1)		93	40 (43)	46 (49)	4 (4)	3 (3)	
Not Met	250	49 (20)	174 (70)	27 (11)		251	51 (20)	126 (50)	56 (22)	18 (7)	

[a] Where noted, chi-squared tests excluded “Don’t Know/Refused” category

[b] Insulin regimen categories: 1) insulin pump, 2) long + short/rapid insulin, 3) 3X+/day long + any other combination, 4) 2X+/day any insulin combination excluding long, 5) 3X+/day any insulin(s) taken 1x/day, or any insulin combination excluding long 2x/day.

[c] Met = <8.0% for 10–12 year olds and <7.5% for 13–17 year olds

Table 3

Associations between reported frequency of blood glucose monitoring per day and A1c values.

How many blood glucose checks/day provider suggested	Unadjusted		Adjusted for Age and Insulin Regimen	
	N	Mean A1c ± SE	N	Mean A1c ± SE
≥6/day	78	8.34 ± 0.18 [a]	77	8.42 ± 0.20 [a]
4–5/day	235	8.87 ± 0.11	234	8.85 ± 0.11
<4/day	28	9.98 ± 0.35	28	9.76 ± 0.32
p-value for trend		<.001		.002
How many blood glucose checks/day reported	N	Mean A1c ± SE	N	Mean A1c ± SE
≥6/day	91	8.04 ± 0.14[b,c,d]	90	8.07 ± 0.19[b,c,d]
4–5/day	172	8.76 ± 0.12[c]	172	8.71 ± 0.12[c]
2–3/day	60	9.88 ± 0.25	60	9.80 ± 0.21
<2/day	21	9.53 ± 0.45	20	9.51 ± 0.36
p-value for trend		<.001		<.001

[a] all groups significantly different from one another

[b] significantly different from 4–5/day

[c] significantly different from 2–3/day

[d] significantly different from <2/day

Table 4

Caregivers report of blood glucose monitoring frequency relative to their report of providers' recommendations for blood glucose monitoring[a]

Provider Recommendation for BGM		BGM Frequency in Relation to Provider Recommendation – n (%)[a]		
Frequency of BGM	**N (%)[b]**	**Exceeded**	**Met**	**Did Not Meet**
≥ 6 times/day	86 (22)	---	60 (70)	26 (30)
4–5 times/day	267 (70)	41 (15)	167 (63)	59 (22)
<4 times/day	31 (8)	14 (45)	11 (35)	6 (19)
Total[c]	384 (100)	55 (14)	238 (62)	91 (24)

[a] row percent

[b] column percent

[c] One participant was missing and was excluded from this analysis.