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Momentary Assessment of Social Context and Glucose Monitoring Adherence in Adolescents with Type 1 Diabetes

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Abstract

Purpose—To investigate the associations between momentary social context and glucose monitoring adherence in adolescents with type 1 diabetes (T1D).

Methods—For 14 days, patients (14–18 years old, T1D duration >1 year) of a pediatric diabetes clinic carried handheld computers that prompted them to report their location, companionship, and attitudes toward companions at the times they usually checked their glucose, and again 30 minutes later to report whether they checked their glucose and, if not, why. Associations between social context factors and checking glucose (adherence) were analyzed using logistic generalized estimating equations and adjusted for age, sex, duration of T1D, and pump use.

Results—Thirty-six participants (mean age 16.6±1.5 years, mean duration of T1D 8.7 years ±4.4 years) completed 971 context and 1210 adherence reports, resulting in 805 paired reports. Median signal response rate was 63%. The odds of checking glucose was higher when participants expressed very strong desire to blend in (adjusted odds ratio (AOR)=2.30, 95% CI 1.07–4.94, p=0.03). Strong desire to impress others was associated with decreased likelihood of checking glucose (AOR=0.52, 95% CI 0.28–0.97, p=0.04.) Location, solitude, type of companion, and attitudes toward companions were not significantly associated with checking glucose.

Conclusions—Desire to blend in may support glucose monitoring adherence and desire to impress others may impede this behavior in adolescents with T1D. Other dimensions of social context were not linked to checking glucose in this study.

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Keywords

Type 1 Diabetes; Momentary sampling; Adolescents Adherence; Social Context

INTRODUCTION

Type 1 diabetes (T1D) is among the most common chronic illnesses in adolescents [1, 2]. Effective treatments exist, but non-adherence remains a major source of preventable medical expenditure and suffering [3, 4]. Despite advances in technology that facilitate insulin delivery, adherence to diabetes regimens continues to be most difficult during adolescence [5]. Mounting concerns about fitting in with peers [6] and social context (companions, physical environment) [7] converge with physiologic changes [8] and transitions to more autonomy [9], leading to adolescents' tendency to suboptimal glycemic control.

Studies examining how social context affects adherence have primarily investigated the role of friends and families in supporting adolescents with diabetes [4], with inconsistent findings. While some studies demonstrate no impact or a negative impact on adherence by friends and family members [10, 11], other literature supports increased adherence behaviors such as increased blood glucose monitoring [12] and dietary adherence [13]. Many adolescents mistakenly believed that friends would have negative reactions to their diabetes, leading to poorer adherence in hypothetical situations [7], even though empirical data suggests friends tend to provide encouragement [14]. Data from Australia demonstrate a link between anxiety in social situations and poor adherence in boys, but not in girls [15]. Thomas et al [16] looked at the differences in children and adolescents with regard to diabetes problem solving and adherence in social situations. They found that adolescents were less adherent owing to concerns about fitting in despite their increasing knowledge about T1D management and consequences. These studies are limited by their use of hypothetical situations or survey instruments that asked participants to answer questions based on assessment of previous behavior, condensing weeks of self-care information into a summary of an adolescent's perceived adherence long after the fact.

These issues can be addressed by using momentary sampling techniques [17], in which participants answer queries about behavior and context as they go about their regular activities. Momentary sampling has been used to study various behaviors in adolescents [18, 19] and provides a means to further our understanding of diabetes self-management. Limitations of previous work can be addressed by asking about context, motivations, and factors associated with adherence at a specific moment in real time, ameliorating concerns about recall bias. The method does place burden on participants who need to agree to disruptions in their day and feel comfortable answering questions in a variety of settings. In patients with diabetes, this is further complicated as the demands of participation overlay the substantial demands of disease management and previous work has suggested that adolescents display difficulty sustaining interest in longer but less intense interventions [20]. However, there have been recent studies in adolescents with T1D who have used momentary sampling methods successfully [21, 22] over short study periods.

In this study, we used momentary sampling techniques to investigate the associations of location type, companionship, and attitudes toward companions with adolescents' decisions to check their glucose levels according to their routine monitoring schedules. We hypothesized that adolescents would be less likely to check their glucose when in locations that felt public compared to private. We also hypothesized that adolescents would be less likely to check glucose levels when they wanted to blend in or impress those around them. Finally, we thought that adolescents would be more likely to check glucose levels when they felt their companions were supportive of their diabetes care. We explored the associations between these sociocontextual factors and glucose monitoring while adjusting for age, sex, duration of diabetes, and insulin regimen (pump treatment versus injected insulin). Finally, we evaluated the adolescents' interest in and compliance with the potentially intrusive momentary sampling procedures. By gaining a richer understanding of the role of social context in glucose monitoring adherence, we hoped to learn how to better support adolescents as they face the simultaneous challenges of increasing social demands, assuming increased responsibility for their self-care and combating the regimen-fatigue that comes with managing chronic illness.

METHODS

Participants

A convenience sample of patients 14-18 years old with T1D were recruited during their routine visits at a pediatric diabetes clinic in a large northeastern city. To participate, patients had to have been diagnosed with T1D for at least one year, be checking their blood glucose at least four times a day, and be able to communicate in English. Fifty-six patients were approached over a 6-month period, with 40 (71%) agreeing to participate. Thirty-seven of 40 participants (92.5%) provided data. In addition, data from one of the participants were irretrievable owing to a hardware malfunction, yielding data from 36 participants for analysis.

Procedure

The study protocol was approved by the clinic institutional review board. Adolescents 14-17 years old provided assent and a parent provided informed consent; those 18 years old provided informed consent.

Participants were asked to identify times when they were likely to check their glucose levels each day during the next two weeks both in and out of school. Research staff programmed a handheld computer (Palm Tungsten E2 personal digital assistant (PDA); CERTAS software, PICS, Inc., Reston, VA) to signal at times that were personalized to fit the participant's expected glucose checking schedule. Participants could have different report times each day of the week to accommodate their schedules.

For 14 days, the computer signaled participants to complete reports for each of four scheduled daily glucose checks, including while at school. For three of the four daily checks, a social context report was signaled at the time of the scheduled glucose check. For all four

daily checks, an adherence behavior report was signaled 30 minutes after the scheduled glucose check.

The signal prompting a report about social context was omitted from one of the four scheduled glucose checking times each day with the omitted signal rotating each day to assess the effect of signaling on glucose checking behavior (did signaling at a scheduled checking time change actual checking behavior) and to account for reactivity (did signaling at a scheduled checking time change response to other signals). Thus, there were three context and four glucose monitoring adherence signals daily, for a total of 56 glucose monitoring adherence and 42 social context reports per participant over the 14 days (42 context-adherence pairs of reports per participant x 36 participants = total of 1512 possible pairs of reports). Reports took 2-3 minutes to complete.

After the study visit, data regarding diabetes management (i.e., insulin regimen, frequency of daily blood glucose monitoring, HbA1c at enrollment visit) were obtained from the medical record. After two weeks, adolescents were asked to complete a paper-and-pencil survey about study burden and return the survey and handheld computer by mail.

Remuneration was based on signal response rate with completion of > 70% of reports required for full compensation of \$100.

Measures

The social context questionnaire was informed by previous research [23] but developed for this study. The report assessed, at the time of a scheduled glucose check, the participant's location (school, house, transportation, recreational space, public space/other), companionship (friend, romantic partner, an acquaintance, in a crowd, family), and sense of privacy (5-point scale, from *very public* to *very private*). If companions were present, participants were asked whether companions knew about the participant's diabetes (*yes, no*) and if the companions were supportive of their diabetes management (*yes, no*) (see Table 2). In addition, participants were asked to rate on 5-point scales how close they felt to their favorite and least favorite companion (*strong dislike/distrust* to *strong like/trust*), as well as their desire to impress (*not at all* to *very much*), romantic interest in (*not interested* to *very interested*), and desire to blend in with their companions (*blend in* to *stand out*).

Each social context report at the time of a scheduled glucose check was paired with the glucose monitoring adherence report made 30 minutes later. Context data collected on a 5-point scale were dichotomized based on the distribution of response. For desire to blend in, romantic interest in companions, feeling of privacy and closeness to favorite companion, we compared the highest response ("very strong") to the other responses (5 vs. 1-4). For dislike of least favorite companion and desire to impress companion, we compared the two highest responses ("strong") with the other responses (4-5 vs. 1-3). Contexts when participants were alone were compared to those in which companions were identified.

The glucose monitoring adherence questionnaire assessed whether the participant had checked his/her glucose level since the last time that they received a glucose query (*yes, no*). If they reported that they had checked their glucose level, they were asked why they checked it (part of my plan, felt sugars out of range, felt sick, not sure why, other). If they reported

that they had not checked their glucose level, they were asked why they did not check it (forgot, remembered but didn't feel like it, situation, not supposed to check, other). They were also asked if their behavior (checking or not checking) had been what their medical team would have recommended (*yes, no*) and if their schedule was typical (very typical, somewhat typical, not at all typical).

The follow-up written questionnaire focused on assessing study burden and feasibility [19]. Questions assessed on a 1 to 5 scale how willing adolescents would be to participate again (*very willing to not at all willing*), if participation interfered with usual activities (*interfered very little to interfered very much*), and how much of a pleasure or burden it was to participate (*great pleasure to great burden*.) Participants also rated whether insulin use and blood glucose monitoring increased, decreased or stayed the same during the study and indicated the reasons they did not respond to a signal.

Data Analysis

Sixteen participants completed reports spontaneously before being signaled, but close to a time of interest. These self-initiated reports were included in the analyses if they occurred within a timeframe mirroring the grace period allowed by the device to enter a response. As reports within each participant were correlated, logistic generalized estimating equations (GEE)[24] were used to assess the odds of checking glucose in different social contexts. First, unadjusted models for each context predictor were fit, then models adjusting for age, sex, duration of diabetes, and pump use were fit.

We first compared events in which participants checked glucose levels against those in which participants did not check, regardless of reason (Model 1). However, we noted that the frequency of responses in which participants answered that they did not check glucose but were “not supposed to” was high (52.9%). The heterogeneity of possible reasons for this response pattern—e.g., planned signal times did not match actual schedule, social desirability of responses, earlier glucose check initiated by the adolescent, etc.—led us to test a second model to improve specificity in our assessment of non-adherence behavior. We therefore compared reports in which participants checked glucose to those in which participants did not check glucose but felt they should have checked (Model 2). All analyses were performed using SAS version 9.2 (SAS Institute, Cary, NC).

Feasibility questions were analyzed by grouping responses into either positive (two lowest), neutral (middle) or negative (two highest) categories. Reactivity was assessed by examining whether participants were more or less likely to respond to a signal after an intentionally omitted signal or an unanswered signal. The effect on glucose monitoring was also evaluated by examining whether participants were more or less likely to check glucose after an intentionally omitted signal or an unanswered signal.

RESULTS

Descriptive

Approximately one-half of participants (53%) were female (Table 1) and the sample represented all eligible ages (mean 16.6 ± 1.5 years) and had a mean duration of T1D of 8.7 ± 4.4 years. Mean HbA1c was $8.7 \pm 1.4\%$; almost two-thirds (63%) used an insulin pump.

Median signal response rate was 63% (range 0%-97%) with 27 participants (75%) completing more than 50% of possible reports. Response rate was not associated with age, sex, T1D duration, baseline glucose monitoring frequency, HbA1c, or pump use. Participants completed a total of 971 context and 1210 adherence reports, yielding 805 pairs of completed context and glucose monitoring adherence questionnaires bracketing a scheduled glucose check (58% of scheduled glucose check times). The mean number of reports per participant did not differ significantly among the four scheduled glucose check times over the two weeks (10.0 for time 1 vs. 9.4 for time 2 vs. 9.6 for time 3 vs. 10.6 for time 4, $p=0.06$). There was no significant difference in reporting rates on weekends vs. weekdays (2.98 reports/day on weekends vs. 3.02 reports/day on weekdays, $p=0.83$).

Participants responded they had checked glucose on 387 (32.1%) of glucose monitoring adherence reports, had not checked glucose but were not supposed to on 639 (52.9%), and had not checked glucose but were supposed to on 181 (15.0%).

Contextual predictors of checking blood glucose (Model 1)

In unadjusted analyses, participants were more likely to report checking glucose when they had a very strong desire to blend in compared to when they did not. After adjusting for age, sex, duration of T1D, and pump use, this association remained significant, with odds of checking glucose 2.30 times higher (95% confidence interval [CI] 1.07-4.94, $p=0.03$) when participants had a very strong desire to blend in than when their desire to blend in was not as strong (Table 4). Adjusting for the co-variables, strong desire to impress those around them was significantly associated with being less likely to check glucose (OR=0.52, 95% CI 0.28-0.97, $p=0.04$). Other contextual variables were not associated with glucose checking behavior.

Contextual predictors of blood glucose checking vs. not checking but supposed to check (Model 2)

After excluding times when participants felt they were not supposed to check, contexts in which participants felt a very strong desire to blend in were associated with an increased likelihood of checking glucose (OR=9.13, 95% CI=2.53-32.9, $p=0.0007$) in adjusted models. Adjusted models also showed significantly decreased likelihood of checking glucose in contexts in which participants had a strong desire to impress those around them (OR= 0.23, 95% CI= 0.08-0.62, $p=0.004$), compared to contexts in which they did not.

Reactivity

Participants were less likely to complete an adherence report (85% vs 98%, OR=0.14, 95% CI=0.07-0.25, $p<0.0001$) and less likely to report that they checked their glucose level (23%

vs 60%, OR=0.21, 95% CI=0.13-0.34, $p<0.0001$) following receipt of a context signal compared to those scheduled glucose check times for which the context signal was intentionally omitted. In addition, when participants completed a context report, they were significantly less likely to report checking their glucose level (16% vs 58%, OR=0.15, 95% CI=0.08-0.27, $p<0.0001$) than when they did not complete a context report after being prompted to do so.

Feasibility

Thirty-two participants (80%) returned completed feasibility surveys. 59% reported willingness to participate again and 56% reported little interference of the signals with their activities. Over the 14 day study period, rate of report completion declined from the first week of signal responses to the second week (58% vs. 50%, $p=0.007$). The two most common reasons participants reported failing to respond were “did not hear alarm” (72%) and it “occurred at an inconvenient time” (56%).

DISCUSSION

This study supports the idea that social context may affect glucose monitoring behaviors in adolescents with T1D. In the sample, adolescents with T1D were *more* likely to check glucose levels when reporting a strong desire to blend in, contrary to our hypothesis. As hypothesized, they were *less* likely to check glucose when around people they wanted to impress. However, other social context variables were not associated with glucose checking, contrary to the hypotheses that adolescents would adjust behavior owing to concerns about privacy or support by companions.

Overcoming the adolescent's concerns about feeling different is one of the major challenges experienced by adolescents with a chronic disease. Clinicians often address this concern by devising a management plan that offers treatment options that make it easier for the adolescent to normalize life and remain an active part of his/her peer group. Indeed, experienced diabetes clinicians encourage patients to check their glucose levels frequently as a means to provide the adolescents with confidence they will not be surprised by symptoms of high or low glucose levels, which could necessitate an interruption in the adolescent's activities. Thus, while acknowledging the burden of glucose monitoring to adolescents, it remains important to focus on how monitoring provides a safety net for adolescents to fit-in with their social group and avoid embarrassing situations.. This framing may be particularly important when the adolescent faces a charged, ‘hot cognitive’ situation in which social concerns and/or emotional arousal impairs decision making, particularly in adolescents[25]. If the adolescent's goal is to blend in, typically a passive, low stress, “cold cognitive” situation, it may be better to manage diabetes with the minor social discomfort of a discrete fingerstick and treatment as needed than risk embarrassment resulting from feeling ill or passing out as a result of out-of-range glucose levels. Indeed, the data suggest that this message may resonate with adolescents as participants were more likely to check glucose levels when they wanted to fit in. However, this message may be overwhelmed when the social stakes are higher and adolescents want to impress those around them, switching from a “cold cognitive” state to a “hot cognitive” one. At such times, the decision-making may

shift as the adolescent prefers to risk a major social embarrassment to avoid the perceived social awkwardness of the glucose check.

The data included a significant proportion of responses in which participants indicated they had not checked glucose levels, but reported they were not supposed to check. This option had been intended to capture the few situations when the participant might stray from the monitoring schedule they had self-identified at study start, perhaps due to a sick day or event which prompted an irregularly timed glucose check. Indeed, excluding these responses lead to the dramatic changes in confidence intervals and p-value of the statistically significant variables between model 1 and model 2. This may reflect the clarity gained by removing instances where the participant did not think they were supposed to check their blood glucose. Therefore their reason for not checking was that they did not think they were supposed to check rather than the social context. However, the large number of these responses coupled with the participants' self-selected times makes it challenging to untangle the meaning of this response. There may have been a tendency toward socially desirable responses, although participants could have stated they had checked glucose if social desirability was paramount. There may have been greater inconsistency in the adolescent's schedule than anticipated, although this seems unlikely as most participants were in school 10 of the study's 14 days with regimented schedules and predictable glucose checking times.

While using momentary sampling techniques minimized recall bias, there were limitations to the study. As occurs frequently in behavioral research, we were reliant on self-report of behaviors and contextual factors that were not confirmed objectively. There were several checking times where either the context or adherence report was not answered yielding a lower than expected number of report pairs around blood glucose checking times. Since paired reports were required for the models (context affecting adherence), a smaller number of observations were available. In addition, small participant sample size limited the ability to look at modification of associations by individual characteristics. Participants may have been less likely to answer queries in certain situations where they felt less comfortable, creating a selection bias against events in which they were less likely to check glucose levels. There may have been important social contexts that we did not assess or combinations of contextual factors that the study was not powered to uncover such as adolescents with romantic interest in someone around them whom they wanted to impress. Finally, it is possible that the skewed distribution of some variables led to an outlier effect which distorted relationships.

We were concerned that the signals would lead to increased glucose monitoring, but the findings suggested that being signaled to complete a context questionnaire may have reduced rather than increased subsequent reporting and glucose checking behavior. The extra demands associated with answering the context questions may have contributed to these associations and warrant evaluation in future studies.

Most adolescents seemed to experience little burden from study participation and indicated willingness to participate again, supporting our belief that momentary sampling techniques are acceptable to adolescents with T1D.

This study highlights the importance of considering social context and its potential effect on adherence behaviors in adolescents with T1D and adds to previous studies by obtaining information in real time. It reinforces the need for providers to recognize the role that attitudes toward companions may play in diabetes management, suggesting an area where providers might help adolescents anticipate and problem-solve potential conflicts between social situations and adherence behaviors. Finally, adolescents' difficulty in adhering to medical recommendations for diabetes management likely resonates with other chronic illnesses [26]. Based upon the study's demonstration that adolescents with diabetes will participate in a demanding study design suggests that momentary sampling techniques could be used to study adherence behaviors in adolescents with other difficult-to-manage chronic illnesses.

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Implications and Contribution

Using real time assessments, this study uncovered the importance of selective social contexts upon glucose monitoring behaviors in adolescents with type 1 diabetes. Desire to blend in supported and desire to impress others impeded glucose monitoring, offering providers an avenue to encourage glucose monitoring by preparing adolescents for these environments.

Table 1

Demographic and diabetes treatment characteristics of participants (N=40)

<u>Participant Characteristics</u>	<u>Mean±SD or N (%)</u>
Age, years	16.6±1.5
Sex, female	21 (53%)
T1D duration, years	8.7±4.4
Insulin regimen, pump treated	25 (63%)
Hemoglobin A1c, % (reference range: 4%-6%)	8.7±1.4

Table 2

Characteristics of social context at the time of a scheduled blood glucose check.

Characteristic of Social Context	N (%)
<i>For all social contexts^a</i>	
Place feels very private	427 (44.3)
Companionship	
Alone	422 (43.8)
With companion(s)	541 (56.2)
<i>If with companion(s)^b</i>	
Companion was a friend	170 (31.4)
Companion was a romantic partner	28 (5.2)
Companion was an acquaintance or in a crowd	69 (12.8)
Companion was family member	274 (71.0)
Very strong romantic interest in companion(s)	33 (6.1)
Strong desire to impress companion(s)	122 (22.6)
Very strong desire to blend in	49 (9.1)
Very strongly like favorite companion	405 (74.7)
Strongly dislike least favorite companion	58 (10.7)
Companion(s) know about participant's diabetes diagnosis	497 (91.7)
<i>If companion(s) know about diabetes diagnosis^c</i>	
Companion(s) support participant's diabetes care	487 (98.0)
<i>Locations</i>	
School	152 (15.8)
House	684 (71.0)
Transport	74 (7.7)
Recreational Space	14 (1.5)
Public Space or other location	39 (4.1)

^aN = 963 reports

^bN = 539-542 reports about contexts with companion(s), depending on missing responses.

^cN = 497 reports about contexts in which companion knows about participant's diabetes diagnosis.

Table 3

Odds Ratios for Blood Glucose Monitoring by Social Context **Adjusted** for Age, Sex, Duration of Diabetes, and Pump Use

Social Context Characteristics	Model 1: Blood Glucose Checked Vs. Not Checked, Any Reason			Model 2: Blood Glucose Checked Vs. Not Checked, Supposed To		
	OR	(95% CI)	<i>p</i>	OR	(95% CI)	<i>p</i>
Place feels very private	1.14	(0.72-1.80)	0.58	1.25	(0.68-2.28)	0.47
Alone Vs. with companion(s)	0.90	(0.59-1.38)	0.64	0.72	(0.39-1.33)	0.30
Companion(s) know about T1D	0.99	(0.49-2.00)	0.99	1.32	(0.65-2.68)	0.44
Companion(s) support T1D care	1.23	(0.14-10.84)	0.85	3.41	(0.07-170.09)	0.54
Very strong romantic interest in companion(s)	0.83	(0.38-1.82)	0.64	0.18	(0.01-2.79)	0.22
Strong desire to impress companion(s)	0.52	(0.28-0.97)	0.04	0.23	(0.08-0.62)	0.004
Very strong desire to blend in	2.30	(1.07-4.94)	0.03	9.13	(2.53-32.90)	0.0007
Very strongly like favorite companion	0.89	(0.46-1.72)	0.72	1.39	(0.49-3.92)	0.54
Strongly dislike least favorite companion	0.77	(0.37-1.61)	0.49	0.66	(0.20-2.19)	0.50