The Blood Glucose Monitoring Communication Questionnaire

An instrument to measure affect specific to blood glucose monitoring

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OBJECTIVE — The aim of this study was to present the psychometric properties of a new tool for evaluating affective response to blood glucose monitoring (BGM) in youths with type 1 diabetes and their parents.

RESEARCH DESIGN AND METHODS — Study participants included 153 youths with type 1 diabetes and their parents. Each youth and parent completed the Blood Glucose Monitoring Communication (BGMC) questionnaire, Diabetes Family Conflict Scale, and Pediatric Quality of Life Inventory. Statistical analyses evaluated the psychometric properties of the BGMC questionnaires and their association with glycemic outcomes.

RESULTS — Youth and parent BGMC questionnaires had acceptable internal consistency (youth, $\alpha = 0.77$; parent, $\alpha = 0.82$) and 1-year test–retest reliability (youth, $r = 0.60$; parent, $r = 0.80$). Higher BGMC questionnaire scores (indicating more negative affect) showed a strong association with higher levels of diabetes-specific family conflict (youth, $r = 0.33$; parent, $r = 0.44$) and poorer health-related psychosocial quality of life (youth, $r = -0.50$; parent, $r = -0.42$). Higher BGMC questionnaire scores were also associated with poorer glycemic control (youth, $r = 0.28$; parent, $r = 0.20$), even when the effects of diabetes-specific family conflict and psychosocial quality of life were controlled. Youths with BGMC questionnaire scores in the upper quartile had A1c values 1 percentage point higher (9.1%) than youths with scores in the lowest quartile (8.0%).

CONCLUSIONS — The BGMC questionnaires have strong psychometric properties and are convenient measures of affect specific to BGM. Further, BGM affect is associated with glycemic outcomes and may provide a unique contribution to factors associated with glycemic control in youths.

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During the past two decades, blood glucose monitoring (BGM) has been established as an important component of type 1 diabetes management. Findings from the Diabetes Control and Complications Trial and other studies stress the necessity of BGM for intensive treatment of diabetes, largely because of the relationship between BGM and glycemic outcomes in populations with type 1 and type 2 diabetes and the link between hyperglycemia and long-term complications (1–5). Further, in pediatric and adolescent patients with type 1 diabetes, a strong association exists between adherence to BGM and glycemic control; a higher frequency of BGM is associated with lower A1c levels (6–8). Thus, it is not surprising that the American Diabetes Association, in its clinical practice guidelines (9), stresses the importance of frequent BGM for intensive treatment of diabetes.

Despite an emphasis on intensive diabetes management, which includes frequent BGM, glycemic control remains suboptimal in pediatric and adolescent populations. Although biological and social changes in youths impact glycemic control in direct and in indirect ways (10), the demands of diabetes management can promote negative feelings in family members. Diabetes-specific family conflict is consistently identified as having a negative impact on adherence to diabetes tasks and glycemic outcomes (11–13) and may arise from either parental perception of inadequate monitoring frequency or the child's inability to achieve or maintain near-normal blood glucose levels. Thus, conflict around BGM, such as parental nagging or criticism, may serve to promote negative feelings in the youth directed at diabetes management tasks and specifically at BGM. Because optimal glycemic control is often the goal for families, failure to meet the target range of blood glucose levels may also serve to promote feelings of disappointment, guilt, or anger in the youth and subsequently modify adherence to BGM. This collection of difficulties resulting from negative feelings about diabetes management may further serve to promote poor adherence (11–13) and psychological problems (e.g., depression) (14–16).

Therefore, we developed an instrument to evaluate affect specific to BGM for both youths and their parents. This instrument is based on clinical and research findings related to the treatment of type 1 diabetes in youths and their families. In this report, we present the psychometric properties of this new instrument and provide results related to how this new

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Abbreviations: BGM, blood glucose monitoring; BGMC, Blood Glucose Monitoring Communication; PedsQL, Pediatric Quality of Life Inventory; SES, socioeconomic status.

A table elsewhere in this issue shows conventional and Système International (SI) units and conversion factors for many substances.

Table 1—*BGMC questionnaires*

	Almost never	Sometimes	Almost always
Youth BGMC questionnaire			
During the past week			
When my blood sugar is high, I get upset thinking that I will be blamed for something I ate.	1	2	3
When my blood sugar is high, I feel scared.	1	2	3
When my blood sugar is high, I feel frustrated.	1	2	3
I am upset when I have a high blood sugar.	1	2	3
I feel angry when my blood sugar is high.	1	2	3
I feel frustrated when I have a low blood sugar.	1	2	3
When my blood sugar is high, I feel guilty.	1	2	3
When my blood sugar is low, I feel scared.	1	2	3
Parent BGMC questionnaire			
During the past week			
When my child's blood sugar is high, I get upset thinking that my child ate sweets (candy bar, ice cream, etc).	1	2	3
When my child's blood sugar is high, I feel scared.	1	2	3
When my child's blood sugar is high, I feel frustrated.	1	2	3
I am upset when my child has a high blood sugar.	1	2	3
I feel angry when my child's blood sugar is high.	1	2	3
I feel frustrated when my child has a low blood sugar.	1	2	3
When my child's blood sugar is high, I feel guilty.	1	2	3
When my child's blood sugar is low, I feel scared.	1	2	3

instrument correlates with individual, family, and diabetes-specific variables related to glycemic outcomes in youth.

RESEARCH DESIGN AND METHODS

Study participants were 153 youths and their parents who were receiving care at a tertiary pediatric diabetes center from a multidisciplinary team. Eligibility criteria included type 1 diabetes diagnosed according to American Diabetes Association practice guidelines (9), age 8–16 years, duration of type 1 diabetes of ≥9 months, at least three outpatient visits in the past 2 years (or at least two visits if the patient had type 1 diabetes <1 year), residence in the northeastern U.S., and fluency in English. Exclusion criteria included major psychiatric or neurocognitive disorder (e.g., bipolar disorder, severe eating disorder, or mental retardation), significant medical disease other than type 1 diabetes or treated thyroid disorders or celiac disease, and unstable living environment (e.g., Department of Social Services or Department of Youth Services involvement).

Over a 4-month period, 174 families fulfilling these criteria were sequentially approached, and 154 (89%) agreed to participate. One patient was subsequently removed after further chart review indicated failure to meet all inclusion criteria. Of the 20 families who declined participation, 16 reported no time or interest in study participation, 2 reported family problems, 1 reported privacy concerns, and 1 family was in the process of moving. The Joslin Diabetes Center Committee on Human Studies approved the protocol. A research assistant obtained written informed consent from participating parents/guardians and assent from the youths and then administered the questionnaires in the waiting room of the pediatric and adolescent clinic.

Blood Glucose Monitoring Communication Questionnaire

The Blood Glucose Monitoring Communication (BGMC) questionnaires were designed to evaluate affective responses to BGM results experienced by youths and their parents (questionnaires displayed in Table 1). Development of the BGMC questionnaires was driven by research and clinical reports of family experiences around BGM (17,18). In addition, informal focus group sessions were conducted to identify specific feelings related to BGM. Some of the focus groups were composed of youths and parents together; others included only parents or only youths. Further, members of a multidisciplinary diabetes team reviewed initial drafts of the BGMC questionnaires, and their recommendations were used to refine the final versions. When completing the BGMC questionnaire, youths are asked to report their emotional responses to high and low blood glucose levels. Likewise, parents are asked to report their level of affect in these situations. The BGMC questionnaires have eight items with corresponding responses on a three-point Likert scale (1 = almost never, 2 = sometimes, 3 = almost always). Total scores can range from a minimum of 8 (indicating no negative affect) to 24 (indicating a high level of negative affect). According to readability statistics (Flesch-Kincaid), the BGMC questionnaires read at a grade level of 4.2. Length of time to complete the BGMC questionnaires is <5 min.

Diabetes Family Conflict Scale

Each child and a parent completed an updated version of the Diabetes Family Conflict Scale (19) to evaluate the degree of family conflict in 19 management tasks. This questionnaire has excellent reliability and internal validity for both child and parent responses (19,20). Level of family conflict related to diabetes-specific tasks is rated on a three-point scale (1 = never argue, 2 = sometimes argue, 3 = always argue). We chose, however, to sum the number of items in which any level of conflict was acknowledged (2 or 3), because the impact of social desirability (from self-report in a clinic setting) on responses makes it difficult to distinguish a meaningful difference between families reporting responses of 2 and 3. In addition, there were no differences in outcomes between the two scoring methods. This questionnaire is completed in <5 min.

Pediatric Quality of Life Inventory

The Pediatric Quality of Life Inventory (PedsQL) evaluates youth and parent perceptions of the child's health-related quality of life. The PedsQL has demonstrated good reliability and validity (21). The PedsQL consists of 23 items scored on a five-point Likert scale (0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a prob-

Table 2—*Participant characteristics*

	Youth
n	153
Age (years)	12.9 ± 2.3
Sex (% female)	56
Ethnicity	
White/non-Hispanic white	138 (90)
Black/African American	4 (3)
Hispanic American	4 (3)
Native American	2 (1)
Asian American	1 (<1)
Other	4 (3)
SES*	3.23 ± 1.56
Family status	
Two-parent family	123 (81)
One-parent family	29 (19)
Type 1 diabetes duration (years)	6.4 ± 3.6
HbA_{1c} (%)	8.4 ± 1.4
Insulin (units · kg^{-1} · day^{-1})	1.0 ± 0.3
BGM	
One time per day	4 (3)
Two times per day	13 (9)
Three times per day	26 (17)
Four times per day	83 (54)
Five or more times per day	27 (18)
Insulin injections	
Two per day	23 (15)
Three per day	78 (51)
Four or more per day	16 (10)
Pump	36 (24)

Data are means ±SD or *n* (%). *Hollingshead index. Scores range from 1 to 6: 1 = major professional (e.g., physician, lawyer); 2 = minor professional (e.g., nurse); 3 = skilled worker (e.g., administrative personnel); 4 = semi-skilled worker (e.g., data entry personnel); 5 = unskilled worker (e.g., truck driver); and 6 = unemployed/retired/student.

lem, 4 = almost always a problem). Responses were scored as follows: 0 scored as 100, 1 as 75, 2 as 50, 3 as 25, and 4 as 0. Total quality-of-life score and subscale scores result from averaging all items. The psychosocial subscale (15 items), which encompasses emotional, school, and social quality of life, was used in this study. Time to complete the entire questionnaire is <5 min.

Glycemic control

On the day that families completed questionnaires in the clinic, each patient provided blood for A1c, measured by high-performance liquid chromatography (reference range 4.0–6.0%; Tosoh 2.2; Tosoh Bioscience, South San Francisco, CA).

Statistical analysis

Statistical analysis was performed with SAS version 8.02 for Windows (SAS Institute, Cary, NC). Means ± SD are presented unless otherwise indicated. The psychometric properties of the BGMC questionnaires were examined by Pearson bivariate correlations and Cronbach α. Independent *t* tests compared total score differences on the BGMC questionnaires across dichotomous variables (e.g., sex). Pearson bivariate correlations were used to examine the associations between the BGMC questionnaires and continuous variables (e.g., age, duration of type 1 diabetes, and A1c values).

RESULTS

Participant characteristics

Table 2 presents demographic and diabetes-related characteristics of the sample. The youths were 56% female and had an age of 12.9 ± 2.3 years (means ± SD). This sample was mostly white (90%), had a duration of type 1 diabetes of 6.4 ± 3.6 years, and had A1c values of 8.4 ± 1.4%. The parents/guardians who completed the parent BGMC questionnaire were mothers (79%), fathers (20%), and "others" (1%).

BGMC questionnaire scores

The average youth score on the BGMC questionnaire was 12.17 ± 3.08 (range 8–22), with higher scores reflecting the experience of more negative affect. The average parent BGMC questionnaire score was 13.68 ± 3.32 (range 8–23). Total scores on the BGMC questionnaires for youths and parents were not significantly correlated with youth's age, duration of type 1 diabetes, or reported socioeconomic status (SES). However, there was a significant difference between males and females on the youth BGMC questionnaire [$t(151) = 2.11$, $P < 0.04$]. The group means ± SD for female participants (12.63 ± 3.20) was higher than the that for male participants (11.58 ± 2.83). In addition, youths of lower SES (i.e., Hollingshead categories of semiskilled, unskilled, and unemployed workers) had higher BGMC questionnaire scores than youths of higher SES [$t(151) = -2.19$, $P < 0.03$]. Youths of lower SES obtained a BGMC questionnaire score of 13.18 ± 3.37, compared with a score of 11.88 ± 2.94 for youths of higher SES. Finally, parents of lower SES had higher BGMC questionnaire scores than parents of higher SES [$t(151) = -3.32$, $P < 0.002$]. Parents of lower SES obtained a BGMC questionnaire score of 15.3 ± 3.70, compared with a score of 13.22 ± 3.06 for parents of higher SES.

Youth and parent agreement

The youth and parent BGMC questionnaire scores were correlated ($r = 0.32$, $P < 0.0001$), indicating similar response patterns for youth and their parents. However, parent BGMC questionnaire scores were significantly higher than youth scores [$t(152) = 5.00$, $P < 0.0001$], indicating that parents perceived a slightly higher level of negative BGM affect than did their children.

Internal consistency

Rates of internal consistency (Cronbach α) for the BGMC questionnaires were calculated: youth BGMC questionnaire, α = 0.77; parent BGMC questionnaire, α = 0.82. These rates demonstrated acceptable internal reliability for both youths

and parents because each of the eight items consistently contributed to the total BGMC questionnaire score.

Test-retest reliability

A subsample of 52 families was reevaluated ~1 year later (13.3 ± 1.89 months), during which time the families continued to receive routine multidisciplinary diabetes care at the same clinic. Pearson bivariate correlations for youth and parent BGMC questionnaire scores demonstrated stability across the period of 1 year: for youth BGMC, $r = 0.60$, $P < 0.0001$; for parent BGMC, $r = 0.80$, $P < 0.0001$.

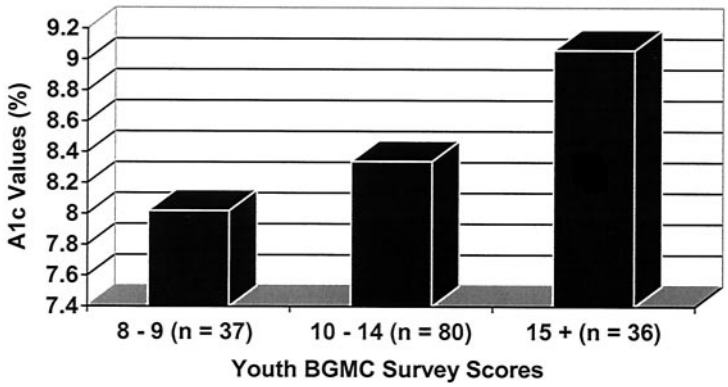

Figure 1—*Youths with BGMC questionnaire scores in the upper quartile had A1c values 1 percentage point higher (9.1%) than youths with scores in the lowest quartile (8.0%), whereas youths with scores in the interquartile range had intermediate A1c values (8.3%).*

Concurrent validity

Concurrent validity was evaluated by comparing responses on the BGMC questionnaires to the Diabetes Family Conflict Scale and the PedsQL psychosocial subscale. The amount of negative affect around BGM was hypothesized to be associated with diabetes-specific family conflict, because BGM is a fundamental aspect of type 1 diabetes management involving diabetes-specific family interactions. Further, the inherent wide fluctuations of blood glucose levels in youths with type 1 diabetes may be fertile ground for family conflict and "blame and shame" (22). Youth and parent scores on the BGMC questionnaires were positively correlated with scores on the Diabetes Family Conflict Scale: youth, $r = 0.33$, $P < 0.0001$; parent, $r = 0.44$, $P < 0.0001$. More negative affect was associated with more diabetes-specific family conflict reported by both youths and parents.

Negative affect around BGM was also hypothesized to be associated with health-related quality of life. Specifically, we expected to find that youths who experienced negative feelings about diabetes tasks would perceive themselves as having poorer health-related psychosocial quality of life. For youths, scores on the BGMC questionnaire were negatively correlated with scores on the psychosocial subscale of the PedsQL ($r = -0.50$, $P < 0.0001$). More negative youth affect was significantly associated with lower psychosocial health-related quality of life. Likewise, parent scores on the BGMC questionnaire were negatively correlated with the parent proxy report of the youth's psychosocial quality of life ($r = -0.42$, $P < 0.0001$).

Relationship between BGM affect and glycemic control

To examine the association between scores on the BGMC questionnaires and glycemic control (A1c values), Pearson bivariate correlations were calculated. For youths, scores on the BGMC questionnaire were significantly correlated with A1c ($r = 0.28$, $P = 0.0005$). More negative BGM affect was associated with higher A1c values. Youth with BGMC survey scores in the upper quartile had A1c values >1 percentage point higher (9.1%) than youths with scores in the lowest quartile (8.0%), whereas youths with scores in the interquartile range had intermediate A1c values (Fig. 1). For parents, more reported negative BGM affect was also associated with higher youth A1c values ($r = 0.20$, $P < 0.013$). Scores on the BGMC questionnaires were not correlated with frequency of BGM.

Next, partial correlations were performed to better understand the association between youth-reported BGM affect and glycemic control by controlling for the effects of youth-reported diabetes-specific family conflict and youth-reported psychosocial quality of life. As reported previously, the correlation between youth-reported BGM affect and glycemic control was significant ($r = 0.28$, $P = 0.0005$). Diabetes-specific family conflict provided a partial explanation for the association between youth-reported BGM affect and glycemic control (partial $r = 0.20$, $P = 0.016$). The same was true for youth-reported psychosocial quality of life (partial $r = 0.23$, $P = 0.004$). In both cases, although r decreased slightly when the effect of the third variable (i.e., family conflict or quality of life) was controlled, the relationship between A1c and BGM affect remained significant.

CONCLUSIONS — Our initial investigations reveal that the BGMC questionnaires are reliable, valid, and stable indicators of affective response to BGM. Both the youth and parent BGMC questionnaires show strong internal consistency and remain stable indicators of BGM affect across a period of 1 year. Further, the construct of BGM affect is associated with diabetes-specific family conflict, health-related quality of life, and glycemic outcomes, for both youths and parents. Finally, among youths, BGM affect is significantly associated with glycemic outcomes and appears to provide a unique contribution to the collection of factors related to glycemic control in youth.

Management of type 1 diabetes in youths is a family process. Many aspects of family functioning impact type 1 diabetes management and, vice versa, type 1 diabetes management impacts family functioning. It appears that higher levels of youth-reported and parent-reported BGM affects are associated with poorer glycemic outcomes. However, because of the correlative nature of our data, it is not possible to establish a causal association between these two variables. In fact, it is possible that the direction of this association may go either way: negative affect leading to poorer glycemic outcomes or out-of-range blood glucose meter readings and elevated A1c values caused by suboptimal glycemic control, leading to increased negative affect. For the former case, we propose two potential

pathways from BGM affect to poorer glycemic control.

First, the significant correlation between BGM affect and diabetes-specific family conflict indicates that these factors are closely related. We theorize that youths with type 1 diabetes and their families struggle to meet the goals, unrealistic at times, of optimal control of blood glucose levels. Youths and families are "set up" to fail because it is unrealistic to expect youths to meet these goals consistently or perfectly. Consequently, feelings of anger, disappointment, or guilt may follow. This negative affect may then carry over into the family relationship around diabetes management, promoting more family conflict and ultimately leading to poorer glycemic control (11).

A second, more direct, path from BGM affect to glycemic control may also exist. Findings from this study indicate that youth-reported BGM affect is associated with glycemic control, even when factors such as diabetes-specific family conflict and quality of life are controlled. This may indicate a direct link between the physiological effects of increased negative affect (e.g., anger and guilt) and glycemic control, possibly mediated through the stress response. Various physiological stresses, such as anesthesia, myocardial infarction, and diabetic ketoacidosis, are known to promote counter-regulatory hormonal release, inducing a state of relative insulin resistance (23,24). Although this "physiological link" between affect, a stress response, and glycemic outcomes has yet to be clearly delineated with respect to an ambulatory pediatric population with type 1 diabetes, stress and resulting hypercortisolemia have been shown to have potential damaging effects on the immune system (25). Findings from our study suggest the need for future investigations of the potential direct and indirect paths from BGM affect to glycemic outcomes.

The opposite pathway between BGM affect and glycemic outcomes is that higher A1c values may lead to increased negative affect. Youths with poorer glycemic control are likely to experience more frequent out-of-range blood glucose values on their meters, leaving them vulnerable to parental blame and shame and their own distress and disappointment. Hence, the negative affect experienced by both youths and parents may not be the cause of less optimal glycemic control, but rather the result.

Before conducting this study, we hypothesized that BGM affect would be related to adherence to BGM (i.e., frequency of BGM). However, we found no association between BGM affect and BGM frequency. Lack of a finding in this area may be explained by the cross-sectional design of this study or by the self-reported nature of BGM frequency. A longitudinal analysis of BGM affect and how it relates to BGM adherence ascertained by downloaded meter data would probably provide a better evaluation of this hypothesized relationship. Further, it may be that BGM affect is closely tied to the results of monitoring (highs and lows), but not necessarily tied to the process or frequency of monitoring. Future studies can help clarify this relationship.

Discussion of how different groups of youth scored on the BGMC questionnaire is noteworthy. Female youths were more likely to obtain higher scores, representing more negative affect, on the BGMC questionnaire than male youths. Likewise, youths of lower SES scored higher on the BGMC questionnaire than youths of higher SES. Notably, in our sample, SES tracked with minority status in a manner similar to that seen in previous research findings (26). Despite the statistically significant differences in BGMC survey scores by SES and sex, clinically significant differences in BGMC survey scores are more apparent at the extremes of the distribution. In particular, we found a clinically significant difference of 1 percentage point in A1c between youths with BGMC scores of 15 or more and youths with scores of 8 or 9.

When the BGMC questionnaires are used, several points should be considered. First, the primary purpose of this study was to document the psychometric properties of the BGMC questionnaires. The explanations we offer about the associations among studied variables are based on cross-sectional data, and longitudinal data are necessary to empirically test the processes involved. Second, we have a small sample of youth who identified themselves as ethnic minorities (n = 15). Thus, careful interpretation and further investigation in minority samples are needed.

In sum, the BGMC questionnaires are reliable and valid indicators of BGM affect for youths and parents. These questionnaires are brief and easy to administer and can be used clinically and in research settings to provide valuable information. Further, these questionnaires contribute to the overall understanding of factors associated with glycemic control. In the future, it will be important to design studies aimed to understand the complex relationships between BGM affect, adherence, diabetes-specific family conflict, quality of life, and glycemic outcomes. To provide the best care for youths with type 1 diabetes and their families, the nature and direction of these complex relationships need to be further investigated and better understood. Future studies should be designed with this in mind. The BGMC questionnaires can play a valuable role in these investigative efforts.

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