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What do Youth with Type 1 Diabetes Know about the HbA1c Test?

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Abstract

The purpose of this study was to examine youths' knowledge of the hemoglobin A1c (HbA1c) test and glycemic control. Seventy youths (11-16 year olds) with type 1 diabetes were interviewed concerning their knowledge of the HbA1c test, health risks associated with particular HbA1c values, and their own glycemic goals. Results revealed that only 13% of youths accurately described the HbA1c test. Fewer correctly identified the HbA1c ranges for good, fair, and poor glycemic control. The majority of youths did not know the blood glucose values corresponding to specific HbA1c results. Only a small number of youth correctly estimated the short-term and long-term risks associated with maintenance of HbA1c of 7% and 12%. In this sample of mostly lower-income, minority youths with type 1 diabetes, there was a significant lack of knowledge concerning the meaning and implications of the HbA1c test. Findings suggest that interventions for this patient population should use the HbA1c test results to help young patients to better understand and set goals for their glycemic control.

Keywords

Youth; Type 1 Diabetes; HbA1c; Knowledge

The hemoglobin A1c (HbA1c) test is an index of a patient's average blood glucose level over the past 2-3 months and is the most widely accepted outcome measure for evaluating glycemic control in individuals with diabetes (Ziel & Davidson, 1987). The HbA1c test provides the most objective and reliable information about long-term metabolic control (Singer, Coley, Samet, & Nathan, 1989) and test results offer important feedback to health care professionals as well as patients. The Diabetes Control and Complications Trial (DCCT, 1993) has established specific recommendations for HbA1c levels, such that maintaining levels as close as possible to the normal range (80-120mg/dL; 4.44mmol/L – 6.66 mmol/L) results in considerable reductions in long-term health complications. Data published by the American Diabetes Association (ADA, 2005) on goals for children and adolescents (6-19 years of age) with type 1 diabetes indicates that appropriate plasma blood glucose goals are lower limits of 90-100mg/dL (4.44mmol/L – 5.55mmol/L) and upper limits between 130 and 180mg/dL (7.22 mmol/L – 9.99 mmol/L).

The relationship between diabetes knowledge and metabolic control has been well studied, such that the ADA Standard of Medical Care in Diabetes (American Diabetes Association [ADA], 2005b) now stresses the application of ongoing educational programs in the management of diabetes. Thus, improving young patients' understanding of the HbA1c measurement and its implications for long-term sequelae seems to be an important aspect of diabetes education. However, few studies have examined patients' knowledge and

understanding of HbA1c testing, with samples including only adults with diabetes. Findings from a previous study (Cagliero, Levina, & Nathan, 1999) reveal the majority of adult patients with type 1 diabetes know what a satisfactory HbA1c value is, although a considerable number (25%) were unaware of the meaning of other HbA1c values (e.g., 10% or 12%). Studies comparing the impact of receiving immediate feedback compared to delayed feedback of HbA1c levels on subsequent levels HbA1c values have found that immediate HbA1c feedback helped improve subsequent glycemic control in adults with type 1 and type 2 diabetes (Cagliero et al., 1999; Miller et al., 2003).

Little is known about youth's understanding of this important test and the factors that may be related to their understanding. To date, no published study has examined children and adolescents' interpretation of the HbA1c test. The established relationship between HbA1c measurements and long-term complications (DCCT, 1993), as well as the association between regular HbA1c testing and improved metabolic control (Larsen, Horder, & Mogensen, 1990) underscores the importance of determining the extent of youths' understanding of this very important test. Therefore, the objectives of this descriptive study were (1) to examine youth's knowledge of the HbA1c test and their individual HbA1c goals, (2) investigate youth's ability to estimate health risks based on HbA1c values, and (3) analyze the relationship between knowledge of HbA1c values and patient demographics (age, gender, socioeconomic status, ethnic/racial group) and disease-related characteristics (duration of diabetes, glycemic control).

Method

Participants

Seventy-nine youths (39 girls and 40 boys) with type 1 diabetes and disease duration of at least 6 months ($M = 4.7$ years, $SD = 3.2$) and a mean HbA1c of 10.5% ($SD = 2.9$) were recruited from a university-based outpatient diabetes specialty clinic. Participating adolescents (77% of those approached) did not differ from those who refused participation with respect to demographic characteristics (i.e., ethnicity, gender, and socioeconomic status).

Participants were between the ages of 11-16 years ($M = 13.7$ years, $SD = 1.7$). The youth were primarily of minority ethnic backgrounds (62% Hispanic and 31% Black; 7% White Non-Hispanic) and lower income status (mean SES = 31; 38% living in single parent households), as indicated by the Hollingshead Index of Social Position (Hollingshead, 1975). All youth participants spoke English. Due to incomplete data from nine youths, the final sample consisted of seventy adolescents. See Table 1 for details regarding participant's metabolic control.

Measures

Diabetes Related Health Problems (DRHP)—The DRHP was developed as part of a larger study and designed to examine children's and adolescents' knowledge (i.e., the definition) of the HbA1c and the significance of its values, as well as the perceived risks of short-term and long-term consequences of diabetes that could occur to self or to someone else. The present study focused on examining youth's knowledge of the HbA1c test, blood glucose values corresponding to specific HbA1c values, perception of the likelihood of specific long-term and short-term health risks associated with particular HbA1c values (7% and 12%), and their own daily glycemic goals (i.e., upper and lower limits for blood sugar). Data on youth's risk perception to self and other has been previously published (Patino, Sanchez, Eidson, & Delamater, 2005). The DRHP is administered in the form of an interview. For the current study, twenty close-ended questions were analyzed along with seven open-ended questions (see Table 2). Adequate internal consistency was demonstrated ($\alpha = 0.71$). The items, with high face and content validity, were generated by senior investigators who are experienced in the clinical care of and research with youth who have type 1 diabetes. Each of the close-ended questions

was rated on a 5-point Likert scale ranging from (1) “not at all likely/0-19% chance” to (5) “very likely/ 80-99% chance.” Responses were then scored based on their accuracy. For example, on the close-ended questions a correct response included “pretty likely” or “very likely” that an HbA1c of 12% would lead to consequences consistent with high blood sugar, and “not at all likely” or “not too likely” that it would lead to symptoms of low blood sugar.

For the purposes of this study, we considered good control to be an HbA1c < 8%, fair control to be an HbA1c ≥ 8% and < 9%, and poor control to be an HbA1c ≥ 9%. Published data from the Diabetes Control and Complications Trial (Rohlfing, Wiedmeyer, Little, England, Tennil, & Goldstein, 2002) was also used to equate HbA1c values with average blood glucose (mg/dl). With regard to specific complications for elevated HbA1c, acceptable responses included: having high blood sugar, feeling symptoms of high blood sugar, ketoacidosis, kidney disease, eye disease, amputation/loss of a limb, and sexual dysfunction. In terms of acceptable responses for an HbA1c of 7%, the following were considered: feeling symptoms of low blood sugar, going to the hospital for low blood sugar, and having low blood sugar leading to loss of consciousness. Answers were scored based on the above mentioned guidelines.

Hemoglobin A1c (HbA1c)—The level of HbA1c reflects glycemic control. HbA1c is the mean blood glucose concentration during the 3 months preceding measurement. Higher values indicate higher blood glucose levels, and therefore, more poorly controlled diabetes. Laboratory results for blood samples for HbA1c assays are conducted as part of the patients’ regular outpatient visit. All laboratory analyses were conducted at the Clinical Chemistry Laboratories at the Diabetes Research Institute; the normal range on this assay is 4.0-6.1%.

Procedure

Adolescents were recruited during their regularly scheduled clinic visits. Written informed consent was obtained from the parents and assent from the youth prior to their participation. Only adolescents who received parental permission and gave assent participated in the study. All study procedures were approved by the Institutional Review Board of the University of Miami. Parents provided information regarding their ethnicity, gender, highest grade completed, and occupations. Trained graduate students administered the interviews. HbA1c values obtained from the time of the interview were obtained from the medical chart.

Typical Clinic Procedures—The majority of patients who attend our clinic begin their diabetes education in the hospital during the time of their diagnosis. At that time they meet with a certified diabetes educator (CDE) and then have continued follow-up with the CDE in clinic during regularly scheduled outpatient diabetes appointments, approximately every 3-4 months. The CDE may meet with the patient and family to discuss various diabetes management issues, including insulin injection teaching and techniques, blood glucose monitoring, etc. Patients are instructed on goals for blood glucose and HbA1c levels, according to the American Diabetes Association recommendations for age.

Patients and their parents come to their regular outpatient visit without having the HbA1c test. At the time of the visit, therefore, only previous HbA1c tests are available. The family is instructed to get the youths’ HbA1c test conducted after their outpatient appointment; after receiving the results, the physician calls the parent to discuss the results by phone. The physician reports both the child’s HbA1c and the target or goal value. The physician also explains the blood glucose ranges that correspond to the child’s HbA1c. During the subsequent clinic visit, this information is reviewed again with the patient and family. Patients may be shown a chart illustrating HbA1c levels, corresponding blood glucose values, and risk of complications (low, medium, or high) to facilitate understanding.

Results

Knowledge of HbA1c and Glycemic Goals

Only 13% of youths were able to accurately describe the HbA1c test correctly, as an index of a patient's average blood glucose level during the past 2-3 months. Just 11%, 7.8%, and 7.8% correctly identified the HbA1c value ranges for good (i.e., < 8%), fair ($\geq 8\%$ and < 9%), and poor ($\geq 9\%$) glycemic control, respectively. In addition, very few youths (4 - 8%) knew the actual blood glucose values that correspond to specific HbA1c results (e.g., an HbA1c of 8% is equivalent to average blood glucose of 205mg/dl [11.38mmol/L]). With regard to personal glycemic goals, 30% reported an inappropriate lower limit for their daily glycemic goal (<80 mg/dl or >100 mg/dl). In addition, 30% reported an inappropriate upper limit for their daily glycemic goal (<120mg/dl or >180mg/dl).

Estimating Health Risks based on HbA1c

The majority of the sample (63% and 61%, respectively) reported they did not know the likelihood of feeling symptoms of low blood sugar with an HbA1c less than 7% or the chance of feeling symptoms of high blood sugar with an HbA1c of 12%. Only 4% of the sample correctly reported that it was "pretty likely" or "very likely" that someone with an HbA1c of <7% would feel symptoms of low blood sugar. Approximately seven percent of youths correctly estimated any of the risks of serious hypoglycemia (i.e., loss of consciousness) with maintenance of an HbA1c of < 7%. Although approximately 30% of youths recognized that maintenance of an HbA1c of 12% was indicative of having high blood sugar that could possibly lead to diabetic ketoacidosis, relatively few youths correctly estimated the association of this HbA1c value with the risk of kidney disease (21.9%), eye disease (23%), amputation (21%), or sexual dysfunction in males (11%).

HbA1c Knowledge and Patient Characteristics

We were interested in determining whether demographic characteristics, such as age, gender, child ethnicity, and socioeconomic background, and disease variables, such as duration of diabetes and mean HbA1c, were related to knowledge of HbA1c. Biserial correlations revealed that age was associated with knowledge of what the HbA1c test measures, with older children more likely to answer correctly ($r_{bi} = .31, p = .01$). In addition, higher socioeconomic status was related to children more likely knowing what blood glucose values correspond to HbA1c values for fair ($r_{bi} = .32, p = .008$) and poor control ($r_{bi} = .26, p = .03$). Due to the small number of youth in each ethnic group who correctly demonstrated knowledge, comparisons were not statistically possible (i.e., chi square cells had expected counts less than 5). Similarly, comparisons between males and females were not possible, because so few demonstrated knowledge.

With regard to estimating health risk, biserial correlations indicated that age was associated with knowing the consequences of maintaining an elevated HbA1c, with older children more accurately identifying the likelihood of long-term complications when someone maintains an HbA1c of 12%. Older youth, compared to younger youth, were more likely to correctly identify the likelihood of eye disease ($r_{bi} = .28, p = .02$), amputation ($r_{bi} = .31, p = .009$), and sexual dysfunction ($r_{bi} = .35, p = .003$). Chi-square analyses revealed no gender differences in youth's ability to estimate health risks. Overall, it was observed that participants were more likely to know the negative consequences of maintaining an HbA1c of 12% than the positive consequences of maintaining an HbA1c of 7%. Due to the small number of youth in each ethnic group who correctly demonstrated knowledge, comparisons were not statistically possible (i.e., chi square cells had expected counts less than 5).

Participants' mean HbA1c was unrelated to knowledge of HbA1c and accuracy in estimating health risks. In contrast, duration of diabetes was associated with accuracy in estimating health risks of maintaining an elevated HbA1c, such that youth who have had diabetes for a longer duration were more likely to make errors in their estimations (*rbi* ranging from -.24 - -.29).

Discussion

This is the first study to address the issue of youth knowledge of the most commonly used test to assess glycemic control in diabetes. In this sample of mostly lower-income, minority youths with type 1 diabetes, there was a significant lack of knowledge concerning the meaning and implications of the HbA1c test: only 13% of youths could define the test, less than 10% understood its health risk implications, and just 4-8% could correctly identify the corresponding blood glucose levels in mg/dl for various HbA1c levels. Despite their initial diabetes education at diagnosis and the ongoing discussions in clinic with the physician about HbA1c test results, it is clear that the majority of youths in our setting do not understand the meaning and implications of this important test.

Although most (70%) youth demonstrated awareness of their target blood sugar range (i.e., daily glycemic goals), very few were able to generalize this knowledge to understanding the HbA1c test and grasp the sequelae of specific HbA1c values. In the current study, knowledge of HbA1c was not related to the patients' actual HbA1c. However, analyses did reveal an association between age and knowledge, such that older children were more likely to know what the HbA1c test measures and to accurately identify complications of maintaining an elevated HbA1c. It is likely that younger children's conceptualization of the HbA1c test and diabetes knowledge differs from that of older children, due to developmental differences, including differences in cognitive processes, maturity, and illness beliefs, as well as expectations for self care, etc... Compared to younger children, older children may be more able to grasp the association between feeling symptoms (i.e., dizziness) and certain blood glucose values, as well as understand the concept of long-term consequences associated with poor blood glucose control (i.e., amputation). Our finding is consistent with previous findings of older children displaying higher levels of general diabetes knowledge than younger children (Auslander, Haire-Joshu, Rogge, & Santiago, 1991). Findings from this study indicating that longer disease duration was associated with poorer ability to estimate health consequences based on HbA1c, suggests that the youth's age or perhaps cognitive maturity is a more important factor in determining the youth's ability to anticipate the negative sequelae of poor blood glucose control.

Our unique sample of primarily low-income minority youth may limit the generalizability of these findings, as we did not have the sufficient number of participants in each racial or ethnic group to test for group differences. Because there was limited variability of youths' knowledge, analyses of gender and ethnic or racial group effects were constrained. However, we did find that participants with higher socioeconomic status had increased knowledge of HbA1c. Further research assessing a broader range of patients in terms of knowledge, HbA1c levels, and ethnic, racial, and socioeconomic status is needed.

Previous research with adult patients with type 1 and type 2 diabetes has shown not only a relationship between regular HbA1c testing and improved metabolic control (Larsen, Horder, & Mogensen, 1990), but also that immediate feedback, point of care (POC) A1c, and discussion of values (including use of graphs) resulted in decreased HbA1c values and increased understanding of what the values mean (Cagliero et al., 1999; Miller et al., 2003; Chapin, Williams, & Adair, 2003; Peterson et al., 2007). This metabolic improvement has demonstrated short-term effects (six and twelve months) post-study (Cagliero et al., 1999), as well as long-term impacts (3.5 years) on metabolic control (Peterson et al., 2007). Although it is unclear

whether the above findings would be generalizable to children with diabetes or their parents, it is possible that POC A1c, education of HbA1c test and values, and increased knowledge will lead to positive results. For example, a recent study revealed that children of caregivers with higher diabetes knowledge scores tended to have lower HbA1c levels (Stallwood, 2006). The rapid and accurate results provided by the POC A1c not only allow health care professionals to provide immediate feedback to patients, but also the opportunity to conduct face-to-face counseling.

There are some limitations of the current study. The data are cross-sectional in nature; therefore, predictions of the impact knowledge has on subsequent glycemic control cannot be determined in this study. Since this study only evaluated youths' knowledge, future studies should include assessment of parents' knowledge of the HbA1c test. Additional studies should determine the effect of increasing knowledge about the HbA1c test on the child's actual HbA1c values. Also, family functioning, general diabetes knowledge, and cognitive ability should be assessed in future research as these could increase our understanding of additional variables that may be related to deficiencies in HbA1c knowledge.

Implications for Practice

Given the use of hemoglobin A1c as the “gold standard” for evaluating glycemic control in individuals with diabetes and the importance placed on maintaining HbA1c levels as close to the normal range as possible, it follows that patients and their parents would benefit from greater understanding of this test. Consistent with previous research that supports the efficacy of diabetes education for caregivers of a child to achieve better glycemic control (Stallwood, 2006) effective interventions should consist of diabetes education for both the youth and the caregiver. However, it is unlikely that education alone will be sufficient to improve diabetes self management, particularly in high-risk youth with chronically poor metabolic control. Furthermore, attention to the child's age, responsibility for self-care tasks, and ability to understand consequences is warranted, as it appears older children are better able to appreciate the effects of poor diabetes management. Further studies should determine whether POC A1c and/or specific diabetes education around HbA1c and blood glucose levels is helpful for youth with diabetes. Additionally, research examining strategies that combine education and behavioral intervention to motivate patients and their parents will contribute to our knowledge of how best to help families effectively manage their child's diabetes.

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Table 1

Metabolic Control (N = 70)

	Mean (Range)	Frequency (N)
HbA1c	10.2% (5.7 – 19.7)	
≤6%		5.7 % (4)
≥6 to <7%		4.3% (3)
≥7% to <8%		7.1% (5)
≥8% to <9%		14.3% (10)
≥9% to <10%		21.4% (15)
≥10%		47.2% (33)

Table 2

Items from the Diabetes Related Health Problems

1. What is your ideal blood sugar range?									
2. What is the glycosylated hemoglobin test?									
3 - 5. What GHb readings are considered to be in the:									
a. good range									
b. fair range									
c. poor range									
6 - 10. If someone maintains a GHb of 7% what is the likelihood of:									
(a) feeling symptoms of low blood sugar	Not at all likely	Not too likely	50/50%	Pretty likely	Very likely				
(b) having low blood sugar leading to loss of consciousness	1	2	3	4	5				
(c) having high blood sugar	1	2	3	4	5				
(d) having such high blood sugar leading to ketoacidosis	1	2	3	4	5				
(e) going to the hospital for high blood sugar	1	2	3	4	5				
(f) going to the hospital for low blood sugar	1	2	3	4	5				
(g) kidney disease	1	2	3	4	5				
(h) eye disease	1	2	3	4	5				
(i) amputation	1	2	3	4	5				
(j) sexual dysfunction	1	2	3	4	5				
11 - 20. If someone maintains a GHb of 12% what is the likelihood of									
(a) feeling symptoms of low blood sugar	Not at all likely	Not too likely	50/50%	Pretty likely	Very likely				
(b) having low blood sugar leading to loss of consciousness	1	2	3	4	5				
(c) having high blood sugar	1	2	3	4	5				
(d) having such high blood sugar leading to ketoacidosis	1	2	3	4	5				
(e) going to the hospital for high blood sugar	1	2	3	4	5				
(f) going to the hospital for low blood sugar	1	2	3	4	5				
(g) kidney disease	1	2	3	4	5				
(h) eye disease	1	2	3	4	5				
(i) amputation	1	2	3	4	5				

(j) sexual dysfunction	1	2	3	4	5
21. What blood sugar level corresponds to a GHb level of 6%?					
22. What blood sugar level corresponds to a GHb level of 8%?					
23. What blood sugar level corresponds to a GHb level of 10%?					
24. What blood sugar level corresponds to a GHb level of 13%?					