Metabolic Control and Quality-of-Life Self-Assessment in Adolescents With IDDM

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OBJECTIVE — To examine the relation between metabolic control and self-assessed quality of life in adolescents with IDDM.

RESEARCH DESIGN AND METHODS — The Diabetes Quality of Life (DQOL) questionnaire for youths was given to 69 subjects with IDDM aged 10–20 years at the time of their outpatient visit. Subjects with IDDM of <1 year's duration or with documented psychotic disorder or mental retardation were excluded. Metabolic control was assessed by the mean HbA_{1c} during the preceding year (long-term), by a single HbA_{1c} at the time of the visit (short-term), and by the number of acute events related to IDDM in the preceding year.

RESULTS — The DQOL score correlated with mean HbA_{1c} ($\beta = 6.13$, $R^2 = 0.22$, $P = 0.0122$) and single HbA_{1c} ($\beta = 3.94$, $R^2 = 0.18$, $P = 0.05$). Self-health assessment was the best predictor of DQOL score ($\beta = -44.42$, $R^2 = 0.45$, $P < 0.0001$). The Worries subscale score on DQOL correlated with the occurrence of acute events ($\beta = 6.97$, $R^2 = 0.2$, $P = 0.006$), but did not correlate with either HbA_{1c} level. Correlations of mean HbA_{1c} with the predictors were stronger than the correlations of single HbA_{1c} with the same predictors.

CONCLUSIONS — Metabolic control and quality of life are two important outcomes of IDDM care. In our study, adolescents in better metabolic control report better quality of life. Both components need to be addressed in developing successful diabetes treatment strategies for adolescents with IDDM.

IDDM is a chronic condition whose daily management presents numerous challenges to achieve satisfactory metabolic control: multiple daily insulin injections, frequent blood glucose monitoring, frequent contact with medical professionals, and careful regulation of exercise and meal schedules. Patients diagnosed with IDDM face increased stress when dealing with major lifestyle changes and the possibility of experiencing debilitating and life-threatening complications if they cannot achieve optimal metabolic control. Moreover, patients with IDDM are at increased risk for depression, anxiety syndromes, and eating disorders (1).

The Diabetes Control and Complications Trial (DCCT) demonstrated that intensive diabetes management can improve metabolic control and decrease the risk of complications associated with the disease (2). However, the significant drawback of intensive management may be its possible effects on quality of life, especially in young people with diabetes. Historically, studies of clinical diabetes treatment have focused on metabolic control as a primary indicator of quality of care. Current thought, however, supports the idea that patient self-perceived quality of life is a valuable measure as well (3).

During the DCCT, investigators developed the Diabetes Quality of Life questionnaire (DQOL) to address their subjects' self-perceived burden of the trial. The DQOL is a multiple-choice tool designed for ease of administration and for use with both adolescents and adults. It has four primary scales (Satisfaction, Impact, Diabetes Worry, Social/Vocational Worry) with 46 core items for use in all patients. The questions are posed from three perspectives: the impact generated by diabetes, patient satisfaction with him/herself, and worry about anticipated effects of diabetes (4).

More recently, Ingersoll and Marrero (5) refined the questionnaire for specific use in youths with diabetes. This tool is identical to the DCCT DQOL, except that age-inappropriate questions were omitted. Their questionnaire is similarly composed of three intercorrelated scales: a Diabetes Life Satisfaction scale, a Disease Impact scale, and a Disease-Related Worries scale. When this instrument was administered to 74 patients aged 10.8–20.8 years, Ingersoll and Marrero (5) found that self-perceived quality of life did not correlate with metabolic control, defined as a single HbA_{1c} value obtained at the time of assessment.

We follow a large and diverse population of children and adolescents with IDDM. The treatment plan for each patient is individualized, with the aim to achieve blood glucose levels as near normal as possible. As others have noted, this requires an intensive regimen (1–5). Most of our population receives three or more insulin injections and three or more blood glucose measurements per day. For a variety of reasons, primarily psychosocial, glycemic control is attempted with a less-intensive regimen in the remainder. Patient visits are scheduled every 3 months at minimum and include team evaluation by a physician, nurse educator, nutritionist, and social worker during most visits.

In contrast to the findings of the study by Ingersoll and Marrero (5), it was our belief that adolescents in better metabolic control seemed to have a better quality of life. The present study examines the correlation between indexes of metabolic control (HbA_{1c} and number of acute events related to IDDM in the year preceding the study) and self-perceived quality of life in a sample of our patients. We also correlated self-

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Abbreviations: DCCT, Diabetes Control and Complications Trial; DQOL, Diabetes Quality of Life.

Table 1—*Patient characteristics*

	Boys	Girls
n	25	44
Age (years)	15.1 ± 3.0	15.0 ± 2.5
Age at diagnosis (years)	8.2 ± 3.9	7.5 ± 3.5
Duration of IDDM (years)	6.9 ± 4.8	7.5 ± 4.3
Intensive regimen (%)	69	59
HbA_{1c} in past year (%)	8.9 ± 1.6	9.4 ± 1.8
Acute events	3 (12)	10 (22)
Ethnic minority	6 (24)	17 (38)

Data are *n* (%) or means ± SD.

health assessment of our patients with their metabolic control, as well as with self-perceived quality of life.

RESEARCH DESIGN AND METHODS

Subjects

The study was approved by the Mount Sinai Institutional Review Board. During the period from 1 September 1996 to 2 February 1997, 177 patients with IDDM ages 10–20 years were seen in our practice. Five patients with documented psychotic disorders or mental retardation were excluded from the study, as were 22 patients with duration of IDDM <1 year and/or not followed in our practice for the previous year. Incompletely filled questionnaires excluded an additional 20 subjects. Participation was solicited in two ways. The DQOL questionnaire was mailed to patients meeting the above-mentioned guidelines, with a request to complete and return the questionnaire at their next outpatient visit. Since the return rate was low (~10%), subjects were asked to participate when they arrived for outpatient visits. The purpose of the study was explained to the patients and/or their parents, and the informed consent was obtained at the same time by one of the investigators. A total of 69 patients agreed to participate and were included in our study. The demographic characteristics of these subjects are given in Table 1. These did not differ significantly from demographics of the adolescents who chose not to participate.

All subjects' charts were reviewed to obtain HbA_{1c} values and the number of acute events in the 12 months preceding the study participation. Acute events were defined as emergency room visits or hospital admissions because of IDDM-related medical problems. Data from the chart were also obtained to classify the intensity of the IDDM regimen in the same period. IDDM regimen was defined as intensive if it employed three or more insulin injections per day and if three or more blood glucose readings per day were documented.

HbA_{1c} was determined using the Bayer DCA 2000 analyzer on fresh capillary specimens. The nondiabetic range is 4.5–6.3%, and patients were advised that an HbA_{1c} below 8% is considered good blood glucose control. Patients were educated about the importance of aiming for blood glucose readings in the target range of <180 mg/dl. For the purposes of analysis, we used the HbA_{1c} value at the time of study visit (single HbA_{1c}) as a measure of short-term control (past 2–3 months) and the mean level (mean HbA_{1c}) in the year preceding the visit as a measure of long-term control. Mean HbA_{1c} was calculated from average 3.9 ± 1.4 measurements in a year preceding participation in the study (range 2–9 measurements per year.)

Instrument

The DQOL is composed of a 17-item Diabetes Life Satisfaction scale, a 23-item Diabetes Impact scale, and an 11-item Diabetes-Related Worries scale, with the response format of a 5- or 6-point Likert scale. A general self-rating of overall health (5) is also included. Scores on each item range from 1 to 5 on Diabetes Life Satisfaction scale and Diabetes Impact scale, and 0 to 5 on Diabetes-Related Worries scale, with higher scores representing more negative ratings. Each scale was rated individually. The total score is determined by the sum of the three scale scores. The Self-Health Assessment tool is scored such that positive readings received higher scores (from poor = 1 to excellent = 4), the opposite to DQOL system.

Statistical analysis

The reliability and validity of the DQOL measurement in this study was assessed with Cronbach's α coefficients and factor analysis. After the assessment of measurement quality yielded satisfactory results, multiple linear regression analyses were used to relate mean HbA_{1c} level and DQOL scores to various predictor variables. The effects of chronological age, age at diagnosis, sex, and ethnicity were controlled in these regression analyses.

RESULTS — The analysis of the reliability of the instrument showed the following acceptable Cronbach's α coefficients of reliability: Satisfaction scale = 0.88, Impact scale = 0.88, Worries scale = 0.82. The scale scores are highly intercorrelated. It is of interest, however, that while dissatisfaction and worries are highly correlated, r = 0.56, the correlation was not as strong as between the other two pairs (Satisfaction vs. Impact, r = 0.76, Impact vs. Worries r = 0.73). However, each of these correlations is highly statistically significant ($P <$ 0.001).

We examined relations between the DQOL score and *1*) measures of metabolic control (e.g., mean HbA_{1c}, single HbA_{1c}, and acute events), and 2) the self-reported measures (e.g., self-health assessment). Age, sex, age at diagnosis, and ethnicity were used as covariates in all the analyses. Few subjects belonged to any one individual minority group, (14 Hispanic, 8 African-Americans, 1 Asian-American); therefore these subjects were grouped together under the category "minority."

There was a significant correlation between the total score on the DQOL and mean HbA_{1c} (β = 6.13, R^2 = 0.22, P = 0.0122, Fig. 1), as well as between total score and acute events (β = 21.54, R^2 = 0.20, P = 0.0273) and between total score and self-health assessment ($\beta = -44.42$, R^2 = 0.45, $P < 0.0001$). Thus, subjects in better overall metabolic control reported better quality of life and better general health. Self-health assessment was the best predictor of self-reported quality of life across all the scales. This might be because the constructs were similar: how healthy one perceives oneself to be should relate to how much one worries about one's diabetes, the perceived impact of diabetes on one's life, and one's level of overall life satisfaction.

Analysis of the DQOL subscales showed the following: mean HbA_{1c} over the past year was also strongly related to

reported level of satisfaction at the end of that year ($\beta = 2.8$, $R^2 = 0.26$, $P = 0.0021$). Acute events were not significantly related to satisfaction ($\beta = 4.66$, $R^2 = 0.16$, $P = 0.2101$). Both mean level of HbA_{1c} over the past year ($\beta = 2.32$, $R^2 = 0.17$, $P = 0.0470$) and acute events ($\beta = 9.9$, $R^2 = 0.18$, $P = 0.0323$) appeared related to the perceived impact of diabetes on quality of life, although less significantly than with the Satisfaction scale. Acute events was the only clinical measure that was related to reported worries about diabetes ($\beta = 6.97$, $R^2 = 0.27$, $P = 0.0060$). Mean HbA_{1c} level was not significant in predicting reported worries ($\beta = 1.0$, $R^2 = 0.21$, $P = 0.1241$).

When a single HbA_{1c} level at the time of the visit was taken as a variable reflecting short-term metabolic control, it remained a statistically significant predictor of a total score on DQOL ($\beta = 3.94$, $R^2 = 0.18$, $P = 0.05$). Single HbA_{1c} levels predicted satisfaction scores equally well as the mean HbA_{1c} ($\beta = 2.35$, $R^2 = 0.26$, $P = 0.0017$) but was not significantly related to the scores on Impact or Worries scales of DQOL.

Both age at diagnosis and minority status were significant predictors of mean HbA_{1c} level. The mean HbA_{1c} of the minority-group subjects was 1.7% higher than the Caucasian group (10.3 ± 1.9 vs. 8.6 ± 1.2; $P < 0.001$). As the age of diagnosis increased, the mean HbA_{1c} decreased ($P < 0.03$).

We also found a statistically significant relation between our two indexes of metabolic control: mean HbA_{1c} and acute events related to IDDM. Patients who had any acute events ($n = 13$, 19%) had a mean HbA_{1c} 1.7% higher than those who did not have any acute events (10.5 ± 2.1 vs. 8.8 ± 1.3; $P < 0.001$). When a single HbA_{1c} value was used as a variable, with the same covariates employed, only minority status was associated with significantly higher HbA_{1c} ($\beta = 1.55$, $R^2 = 0.17$, $P = 0.0014$). Correlation between two metabolic control variables, single HbA_{1c} level and acute events, was weaker but still statistically significant ($\beta = 1.19$, $R^2 = 0.22$, $P = 0.04$).

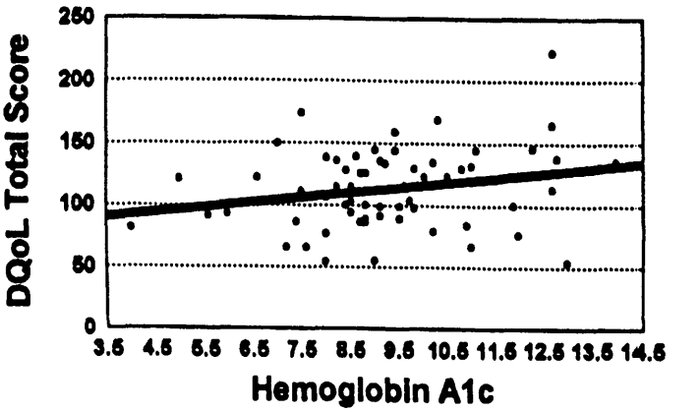

Figure 1—*A scatter plot of the DQOL total score against the mean HbA_{1c} for the preceding year. Linear regression analysis revealed a significant correlation, $R^2 = 0.22$, $P = 0.0122$. The solid line represents the regression line between the two variables.*

CONCLUSIONS — Our results indicate that an association does exist between the self-perceived quality of life and metabolic control in our adolescent patient population.

Unlike Ingersoll and Marrero's study (5), we found a correlation between DQOL scores and indexes of metabolic control, even though our groups were similarly sized and our reliability estimates (Cronbach's α coefficients) were similar to those reported by Ingersoll and Marrero. Since our study subjects were volunteers and thus self-selected, there is a true possibility of selection bias in this result. Thus it is unclear the extent to which our findings are generalizable to other populations of adolescents with diabetes.

When a single HbA_{1c} level was used as an index, the correlations were weaker than when the mean HbA_{1c} over the preceding year was used. Perhaps the difference in statistical correlation when using the mean HbA_{1c} versus a single HbA_{1c} is a reflection of the structure of the instrument. The questions address issues without a specified time frame (e.g., "How often do you feel bad about yourself?" or "How often do you worry about whether you will get married?"); the answers may reflect longer-standing beliefs and worries. The mean HbA_{1c}, in contrast, assesses the glycemic control over a year, giving a longer-range clinical profile of a patient's blood glucose control than a single value, which represents metabolic control over a 2- to 3-month period. The score on the Worries scale related exclusively to the experience of acute events in the preceding year, leading us to speculate that the frightening experience of acute illness makes one worry more about his underlying condition.

A statistically significant relation between the age of diagnosis and mean HbA_{1c} is reported: the older the patient at diagnosis, the better the glycemic control. This finding is not surprising, because of the known effect of residual C-peptide secretion, which is reported to be a significant predictor of metabolic control as long as 5 years after IDDM diagnosis (6). When single HbA_{1c} level was used as a variable, there was no correlation with the age at diagnosis, supporting the hypothesis that a mean HbA_{1c} level is a more reliable measure of glycemic control than a single one, even when taken at the time of study.

To our knowledge, this is the first study reporting statistically significant correlations between metabolic control and quality-of-life assessment in adolescent patients with IDDM. The DQOL measure has been employed in multiple studies (5,7–9) of both children and adults with IDDM. Factors that seem to predict quality of life in adults with diabetes are the multiple socioeconomic factors and nondiabetes-related issues (e.g., comorbidity, nondiabetic medications, marital status, social relationships, as well as long-term complications [7,8]). Two recent studies attempting to relate DQOL and metabolic control in younger patients with diabetes failed to show any association between the two (5,9). As discussed above, our results indicate that measures of long-term glycemic control (mean HbA_{1c} over 1 year) correlate more strongly with DQOL assessment than the short-term measure (single HbA_{1c}). In most of the studies mentioned (5–9), a single HbA_{1c} at the time of the visit was used, which might partially explain the fact that no correlation was found with the quality-of-life estimates, especially if there is a wide fluctuation of HbA_{1c} levels from visit to visit in a patient group studied.

Of the explored covariates, minority status was a potent predictor of HbA_{1c} levels, both single and mean, as well as of quality-of-life assessments. Minority patients had higher HbA_{1c} levels and reported a less sat-

isfactory quality of life than the Caucasians. However, this finding should be interpreted with caution, as only one-third of the subjects in our study belonged to a minority group. An impact of other factors, such as socioeconomic status, environmental factors, or intensity of the regimen, rather than minority status could not be excluded in the interpretation of the results. Of the minority patients, 84% were receiving public assistance as compared with 5% of Caucasians; 16% of minority subjects employed intensive IDDM regimen, as opposed to 91% of the Caucasians, suggesting that more than one particular variable accounts for poorer metabolic control and poorer reported quality of life in minority subjects. Because of the small sample size and this strong link between ethnicity and intensity of regimen, neither one of these variables could be analyzed independently.

The impact of various psychosocial variables on both metabolic control and quality of life has been studied extensively in young patients with IDDM (11–15). These studies have demonstrated additional psychosocial factors that influence metabolic control and DQOL. Therefore, the evidence supports assessment of these factors when developing treatment strategies for individual patients.

Even though it was long believed that long-term complications of IDDM do not depend on the level of glycemic control before the cessation of puberty, recent findings (10) indicate that poor metabolic control during puberty and adolescence leads to significantly increased incidence of retinopathy in young adults with IDDM. Thus it appears that good metabolic control has a significant role in complications even in pubertal children and deserves to be a goal in all such patients.

In conclusion, this research was undertaken because our experience and observation from our clinical practice suggested to us that metabolic control and quality of life were connected. Our study's findings, which vary significantly from previous investigation, suggest that these two outcomes are interrelated. These conclusions are compelling because they bring a new focus to an old issue: "Why do all of this work?" Children with diabetes want to know why they need to endure difficult regimens and painful procedures. Perhaps reframing diabetes control as a quality-of-life issue would be more tolerable and constructive for teenagers. Therefore, in developing successful therapeutic strategies for adolescents with IDDM, future research might consider the following questions: *1*) Is good glycemic control the cause or the effect of improved quality of life; 2) are diabetes-related consequences more effectively postponed or prevented if teenagers are encouraged to maintain good glycemic control because of its impact on their immediate and long-term quality of life; and 3) can quality of life be redefined and new instruments implemented to more specifically reflect and address these important outcomes?

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