Personal and Family Factors Associated With Quality of Life in Adolescents With Diabetes

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OBJECTIVE — Quality of life is an important criterion for assessing outcomes of treatment in chronic illness related to psychosocial well-being. The purpose of this study was to evaluate the factors that influence quality of life in adolescents with IDDM.

RESEARCH DESIGN AND METHODS — Self-reports were obtained from 52 adolescents (age 13–20 years, mean 16.1 ± 1.9 [mean \pm SD], diabetes duration 8.2 ± 3.4 years, 49% female) using the following scales: Diabetes Quality of Life for Youths, Children's Depression Inventory, Issues in Coping with Diabetes, Diabetes Family Behavior Scale, Family Adaptability and Cohesion, Self-Efficacy for Diabetes, and the Adolescent Coping Orientation. Metabolic control was measured by HbA_{1c} .

RESULTS — Teenagers whose diabetes had the greater impact (R^2 = 0.48) and were less satisfied (R^2 = 0.45) felt that management was more difficult (r = 0.56) and that diabetes was more upsetting (r = 0.63). They also used fewer rebellion strategies for coping (r = -0.44), had lower diabetes self-efficacy (r = -0.36), and had more depressive symptoms (r = 0.61). Higher impact was also associated with higher family warmth and caring (r = -0.54) and lower family adaptability (r = -0.42). Teenagers who were more worried (R^2 = 0.37) about their diabetes felt that management was more difficult (r = 0.40) and that diabetes was more upsetting (r = 0.58), and they used less rebellion (r = -0.49) and more ventilation (r = 0.42) to cope, had lower diabetes (r = -0.40) and medical (r = -0.30) self-efficacy, were more depressed (r = 0.55), and their families were less warm and caring (r = -0.33). HbA_{1c} levels were not associated with quality of life or any other psychosocial factors except in teenagers who perceived their families as providing more guidance and control. These teenagers had lower HbA_{1c} values than those whose families were less involved.

CONCLUSIONS — Even teenagers who are successfully achieving HbA_{1c} goals of therapy may perceive diabetes as having a negative impact on their lives, be depressed, and find diabetes difficult to manage. Diabetes treatment teams need to pay equal attention to the psychosocial needs of the quiet, nonrebellious teen with well-controlled diabetes from a supportive family as they do to the rebellious adolescent with poorly controlled diabetes.

onventional goals of treatment for IDDM in children and adolescents are to minimize or eliminate symptoms of hyper- and hypoglycemia, to ensure optimal growth and development, and to use

education and counseling to reduce the adverse psychosocial consequences of coping with this difficult-to-manage condition (1). In addition, the results of the Diabetes Control and Complications Trial (DCCT)

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Abbreviations: ABCs of Diabetes, Adolescents Benefit from Control of Diabetes; ACOPE, Adolescent Coping Orientation for Problem Experiences; CDI, Children's Depression Inventory; DCCT, Diabetes Control and Complications Trial; DFB, Diabetes Family Behavior; DQOL, Diabetes Quality of Life; DQOLY, Diabetes Quality of Life for Youth; FACES, Family Adaptability and Cohesion Scale; SED, Self-Efficacy for Diabetes.

indicate that most adolescents and adults with IDDM should receive intensive therapy aimed at lowering glucose and HbA_{1c} levels as close to the nondiabetic range as possible to reduce the risks of development or progression of the microvascular and neuropathic complications of the disease (2,3). Even the DCCT investigators realized that translation of this recommendation in the treatment of large numbers of adolescents with IDDM places a particular burden on patients, families, and clinicians, since the intensively treated adolescents in that study required a disproportionate amount of staff time and effort and had HbA_{1c} levels that remained substantially higher than corresponding values in intensively treated adult patients (3).

A number of methods have been employed to assess psychosocial outcomes in the treatment of IDDM in adolescents, including overall psychosocial well-being (4), adjustment, and coping with the illness (5,6), and the development of psychological symptoms such as anxiety and depression (7). Quality of life is increasingly being recognized as another useful criterion for assessing the impact of treatment of diabetes and other chronic illnesses. Consequently, Jacobson and colleagues developed the Diabetes Quality of Life (DQOL) scale for use in the DCCT to determine whether the extra burden of intensive therapy as compared with conventional therapy had adverse effects on quality of life. No differences were observed in quality of life in the two treatment groups (8). However, the DCCT included only a relatively small number of highly selected patients between 13 and 17 years of age (<10% of patients recruited after the feasibility phase of the study), and Ingersoll and Marrero (9) have questioned the relevance for children and adolescents of many of the items in the DQOL scale used in the DCCT. They modified the DQOL scale for youth (DQOLY) to elicit more data on school life and relationships with peers. Neither this scale or the original DQOL scale has been used to examine in detail how personal and family factors influence quality of life in adolescents with IDDM.

Table 1—Clinical characteristics of the study subjects (n = 52)

Demographic characteristics					
Age (years)	16.1 ± 1.9 (12–20)				
Duration of	$8.0 \pm 3.7 (1.5 - 14.8)$				
diabetes (years)					
Female (%)	49				
Insulin regimens					
Total daily dose	$1.6 \pm 0.8 (0.7 - 3.5)$				
(U · kg ⁻¹ · day ⁻¹)					
Injections 2 times/day	(%) 44.7				
Injections ≥3 times/d	ay (%) 55.3				
HbA _{lc} (%)	$9.8 \pm 1.7 (6.2 - 14.0)$				
Data are means ± SD (range) or %.					

The ABCs of Diabetes Study (Adolescents Benefit from Control of Diabetes) is a prospective, randomized controlled trial that has been undertaken to examine whether a behavioral program of coping skills training (10) will lead to improved metabolic and psychosocial outcomes in a large, representative group of adolescents with IDDM at our center. Patients who are eligible for the study complete a comprehensive battery of self-report questionnaires relating to diabetes self-efficacy, coping behaviors, symptoms of depression, family functioning, and the modified DQOLY scale. A stress-adaptation model provides a framework for our study of adjustment to chronic illness, and this model has been described fully in a previous paper (11). In this framework, adaptation may be viewed as an active process whereby the individual adjusts to the environment. The model suggests that the level of adjustment to illness (quality of life, metabolic control) is associated with the psychological response to the situation (depression), individual differences (coping responses, self-efficacy, family behaviors) that may influence the response and adaptation, and preexisting characteristics, such as age and sex (12). The baseline assessments performed in the larger study have provided the opportunity to examine personal and family factors in this model that may be associated with quality of life in adolescents with diabetes.

RESEARCH DESIGN AND METHODS

Setting and sample

All youth attending the Yale Children's Diabetes Program were eligible for inclusion in

the ABCs of Diabetes Study if they met the following criteria: 1) were between the ages of 12 and 20 years; 2) had no other health problem except for treated hypothyroidism; 3) had been treated with insulin for at least 1 year; 4) had a recent HbA1c between 7.0 and 14% (normal, 4.2-6.2%); 5) had no severe hypoglycemic events within the past 6 months; and 6) were in the school grade appropriate to age within 1 year. Between 1 November 1995 and 1 March 1997, 78 patients who met the criteria were invited to participate and 52 (27 boys and 25 girls) agreed to do so. The patients and their parents gave written, informed consent for inclusion in the study, which was approved by the Yale School of Nursing Human Subjects Research Review Committee. Clinical characteristics of the patient sample are shown in Table 1. A total of 47 were white, 3 were Hispanic, and 2 were African-American. Annual family incomes were <\$40,000 in 42%, between \$40,000 and \$80,000 in 41%, and >\$80,000 in 17%. Only 26 potential subjects refused participation, and the refusers were not significantly different in sex (χ^2 = 1.28, df = 1, P = 0.22), ethnicity ($\chi^2 = 2.07$, df = 1, P = 0.22), age (t = -0.42, P = .68), and metabolic control (t = 0.43, P = 0.70) than those who enrolled.

Procedures

Baseline psychosocial data were obtained by trained research assistants on all subjects on admission to the Yale Children's Clinical Research Center before the initiation of the intervention phase of the ABCs of Diabetes Study. Established self-report questionnaires (described below) were used to assess personal and family factors. All instruments have been reported to have excellent validity and reliability. The DQOLY scale was used to measure diabetes quality of life (9).

Personal factors

The Self-Efficacy for Diabetes (SED) scale, developed by Grossman, Brink, and Hauser (13), measures the self-perceptions or expectations of adolescents regarding their personal competence, power, and resource-fulness for successfully managing their diabetes. The scale focuses on youngsters' estimates of their own ability to cope with their illness and is based on Bandura's conception of self-efficacy (14). The scale consists of 35 items in three subscales: diabetes-specific self-efficacy (24 items); medical situation self-efficacy (5 items); and

general situations (6 items). Subjects are asked to rate their degree of confidence for all items on a five-point scale ("very sure I can't" to "very sure I can"). Kuder-Richardson reliability coefficient α ranged from 0.90 to 0.92 for the total scale and the diabetes-specific subscale to 0.60 for the general situations subscale.

The Children's Depression Inventory (CDI) was developed by Kovacs (15) to measure self-reported depressive behavior in children and adolescents. The inventory assesses a variety of depressive symptoms including disturbance in mood and hedonic capacity, self-evaluation, vegetative functions, and interpersonal behaviors. It contains 27 multiple choice items that yield total scores from 0 to 54. Higher scores reflect greater symptomatology. Internal consistency reliability has ranged between 0.71 and 0.87, and test-retest reliability at 0.80 and 0.87. The score of \geq 13 is a criterion for identifying clinical depression (16). Because depression is not normally distributed, CDI scores are treated with a logarithmic transformation before analysis.

The Issues in Coping with IDDM (ICD) scale was developed by Kovacs and colleagues to assess what IDDM-related issues children and adolescents with IDDM find hard or difficult to handle or experience as upsetting (17,18). The How Hard subscale consists of 15 diabetes tasks to which the respondent indicates how difficult that task is to do on a 0- to 4-point Likert scale. There are 13 items in the Upset scale, to which the respondent indicates how upsetting the activities or thoughts about diabetes are. Higher scores indicate that the tasks are harder or more upsetting. The scale has been used in previous studies of adaptation to diabetes over time, and reliability (α) has ranged from 0.78 to 0.90 depending on the sample.

The Adolescent Coping Orientation for Problem Experiences (ACOPE) scale is an inventory designed to identify behaviors that are helpful in managing problems or in difficult situations (19). The scale consists of 54 items in ten categories of behaviors. The respondent rates each as to how often the behavior is used during a difficult time, with higher scores indicating more coping skills. The categories of behaviors are as follows: ventilating feelings, seeking diversions, developing self-reliance, developing social support, solving family problems, avoiding problems, seeking spiritual support, investing in close friends, seeking professional support, engaging in demanding activity, being humorous, and relaxing. The internal consistency for the scale is high at 0.86, and the subscale reliabilities range from 0.67 to 0.78.

Family factors

Developed by McKelvey and colleagues, the Diabetes Family Behavior (DFB) scale was designed to measure diabetes-specific family behaviors thought to be important in helping or hindering a child or adolescent in following a diabetes treatment regimen (20). The scale includes 47 items yielding a total score, and two subscales measuring specific areas of family support, guidance, and control (15 items) and warmth and caring (15 items). Subjects are asked to rate the frequency with which certain behaviors occur within their family ("all the time" to "never"). Cronbach's α coefficients were 0.86 for the total score, 0.81 for the guidance and control subscale, and 0.79 for the warmth and caring subscale.

The Family Adaptability and Cohesion Scale (FACES II), developed by Olsen and colleagues, focuses on the adaptability and cohesion dimensions of family function (21). Cohesion describes the emotional bonding within a family and has four levels: disengaged (very low), separated (low to moderate), connected (moderate to high), and enmeshed (very high). Adaptability refers to the ability of a family to alter its role relationships, power structure, and relationship roles in response to situational and developmental stress. This dimension also has four levels: rigid (very low), structured (low to moderate), flexible (moderate to high), and chaotic (very high). The most functional levels for both of these concepts fall into the middle ranges. The instrument consists of 30 items, including a 16-item scale for cohesion and a 14-item scale for adaptability in which the subject rates how frequently each item applies to one's own family. The α reliabilities are high (0.87 for cohesion, 0.78 for adaptability, 0.90 for the total scale) (22). These scales were completed by the adolescents and reflect their perception of their families.

Quality of life

Initially developed by the DCCT Research Group and later modified by Ingersoll and Marrero (9), the Diabetes Quality of Life: Youth (DQOLY) scale consists of three subscales: 17-item Diabetes Life Satisfaction scale; 23-item Disease Impact scale; and 11-item Disease-Related Worries scale (9). Cronbach's α for each scale in psychomet-

ric testing by the authors was as follows: Satisfaction, 0.85; Impact, 0.83; and Worries, 0.82. Each item is answered in a 5-point Likert scale, so that total scores can range from 17 to 85 in the Satisfaction scale, 23 to 115 on the Impact scale, and 11 to 55 on the Worries scale, with higher scores indicating lower quality of life on the Impact and Worries scales, and higher life satisfaction on the Satisfaction scale. The authors reported that all three scales were associated with adolescent's self-rated health status, but that DQOLY scale scores were not correlated with HbA₁ values.

HbA_{1c}

 ${\rm HbA_{1c}}$ levels were obtained on all subjects on the same day as psychosocial data were obtained (23). Analyses were performed using the Bayer DCA2000, a portable device for measuring ${\rm HbA_{1c}}$ from a fingerstick (normal range = 4.2–6.2%), by study staff who have been trained in the reliable use of the machine, and controls are performed at least twice per month.

Data analysis

All data were double-entered in a database and checked for accuracy. Analyses were performed using the SAS system (version 6.11) and SPSS (version 7.5). Descriptive statistics were calculated on the subjects, and bivariate correlations were estimated to test for relationships between the personal and family factors and quality of life. Variables associated with the three types of quality of life were entered into the appropriate regression model using stepwise entry. The sample of 52 subjects provides a statistical power of >0.80 for a multiple regression analysis with five independent variables and an expected R² of 0.35 (24). Data are presented as mean \pm SD where appropriate.

RESULTS — Results of the teenagers' assessments of their quality of life and the personal and family factors are shown in Table 2. In general, adolescents perceived their quality of life as good, with high satisfaction with life, moderate impact of diabetes on their quality of life, and relatively low worries about diabetes. The majority were not clinically depressed (6 of the 52 had scores over 13 on the CDI). They found diabetes hard to deal with and relatively upsetting, but they felt confident in their abilities to manage diabetes. They used the coping strategies of rebellion (e.g., staying out late, deliberately not obeying rules) and ventilating (e.g., fighting, yelling) to cope

Table 2—Scores for personal and social factors and quality of life

SED	97.7 ± 9.3 (80–114)					
Depression*	$6.7 \pm 1.3 (0-29)$					
ACOPE						
Rebellious	$16.5 \pm 3.4 (5-23)$					
Ventilate	$14.9 \pm 2.5 (7-20)$					
ICD						
Hard	18.9 ± 3.1 (12–26)					
Upset	$17.6 \pm 3.5 (12-24)$					
DFB						
Warmth and caring	$55.5 \pm 6.7 (33-67)$					
Guidance and	$38.5 \pm 5.9 (23-53)$					
control						
FACES						
Adaptability	$46.1 \pm 7.3 (19-58)$					
Cohesion	$57.7 \pm 8.5 (31-71)$					
DQOLY						
Impact	49.5 ± 10.5 (30–78)					
Satisfaction	$65.2 \pm 12.4 (29-83)$					
Worry	$21.2 \pm 6.8 (11-38)$					

Data are means ± SD (range). ICD, Issues in Coping with Diabetes. *Scores normalized with a square root transformation.

with problems in their lives, as opposed to more constructive behaviors (e.g, learning more about the problem bothering them). They found their families to be relatively warm and caring, but providing less guidance and control than average adolescents. They also reported their families to be relatively flexible and connected.

The correlation matrix is shown in Table 3. Adolescents who reported that diabetes had a larger impact on their quality of life were more likely to believe that management was harder and more upsetting, were less likely to use rebellious coping strategies, had lower diabetes self-efficacy, and had more symptoms of depression. Those who reported more worry about diabetes were more depressed, had lower diabetes self-efficacy, and found coping with diabetes both harder and more upsetting. On the other hand, those adolescents who were more satisfied with their quality of life reported fewer symptoms of depression, found coping with diabetes less hard and less upsetting, had higher diabetes self-efficacy, and had families whom they perceived as being more warm and caring. Quality of life was associated with subjects' sex. Although the impact of diabetes and satisfaction with life were similar between boys and girls, the girls worried more about their diabetes than did boys $(23.1 \pm 7.6 \text{ vs.})$

Table 3—Correlation matrix of personal and family factors associated with quality of life

								DFBS					
		DQOLY			IC	D		ACC	PE	Warmth and	Guidance and	FACES	
Variable	Impact	Worry S	ry Satisfaction CDI Hard Upset SED Rebellious V		Ventilate			Adaptability Cohe	sion HbA _{1c}				
DQOLY													
Impact	_												
Worry	0.07												
Satisfaction	-0.58‡	-0.38†	_										
CDI	0.60‡	0.55‡	-0.61‡										
ICD													
Hard	0.59‡	0.41†	-0.52‡	0.51‡	_								
Upset	0.66‡	0.61‡	-0.55	0.50‡	0.66‡								
SED scale	-0.39*	-0.42 +	0.54‡	-0.36*	-0.32	-0.53†	_						
ACOPE													
Rebellious	-0.44†	-0.49†	0.17	-0.33	-0.25	-0.27	0.14	_					
Ventilate	0.31	-0.17	0.04	0.01	-0.11	-0.03	0.12	0.07	_				
DFBS													
Warmth	0.05	-0.25	0.37*	-0.53†	-0.35*	-0.45†	0.25	0.19	0.16	_			
Guidance	-0.50 †	0.17	0.02	-0.07	-0.01	0.03	-0.14	-0.07	-0.12	0.19			
FACES													
Adaptability	-0.42†	0.29	0.18	-0.50‡	-0.32	-0.37	0.08	0.14	0.21	0.63‡	0.43†		
Cohesion	-0.33	-0.07	0.15	-0.28	-0.12	-0.16	-0.03	0.17	-0.19	0.56*	0.43*	0.65‡ —	_
HbA _{1c}	-0.21	-0.28	0.04	-0.03	0.06	0.01	0.08	0.09	-0.13	-0.02	-0.41	-0.13 $-0.$	11 —

^{*}P < 0.05; †P < 0.01; ‡P < 0.001.

 20.1 ± 5.8 , t = 4.50, P = 0.03). Family functioning as measured by the FACES of adaptability and cohesion was not associated with quality of life.

Metabolic control, as measured by ${\rm HbA_{1c}}$, was not associated with quality of life. Duration of diabetes and the adolescent's current age were also not associated with ${\rm HbA_{1c}}$ (r=-0.08 and -0.06, respectively), nor was treatment with twice-daily or multiple-daily injection regimens (P for F>0.05). ${\rm HbA_{1c}}$ levels were negatively associated with adolescents' perceptions of their families having more guidance and control. Thus, better metabolic control was associated with families who maintained involvement in the adolescents' diabetes care.

Multiple regression analyses of these independent variables on quality of life revealed that depression was the most consistent variable associated with quality of life, as shown in Table 4. The table shows the models that best fit the data as well as the regression weights for those variables that did not enter the model. Adolescents who were more depressed reported that they worried more about diabetes, diabetes had more impact on their quality of life, and they were less satisfied with life, even when other variables are controlled. Those who felt that diabetes had a greater impact also found coping with diabetes more upsetting. These two variables, depression and the degree of upset with coping with the diabetes, accounted for 48% of the variance in the impact of diabetes on quality of life (adjusted $R^2 = 0.48$, P < 0.001). In addition to less depression, those adolescents who were more satisfied with their quality of life also had higher diabetes self-efficacy (adjusted $R^2 = 0.45$, P < 0.001). Finally, those who had higher worry scores also were more likely to be depressed, to find coping with diabetes more upsetting, and to use more rebellious coping strategies (adjusted $R^2 = 0.425$, P < 0.001).

CONCLUSIONS — While the adolescents in our study reported generally positive quality of life, there was substantial variation among individual adolescents in quality of life. Thus, our data agree with others that while IDDM is a risk factor for psychological disorders in adolescents, the majority of teenagers do well (25). Adolescents, especially girls, are more prone to depression in general (26), as are female patients with diabetes (27). Adolescents in our study who were depressed were more likely to report poorer quality of life in all three areas measured. Thus, depression can be considered a marker for problems in quality of life in teenagers with diabetes. Girls worry more about their diabetes than do boys, and therefore, could be at higher risk for depression.

As has been reported previously, quality of life is not associated with metabolic control (8,9). Further, quality of life is not associated with treatment regimen, so that more injections per day as may be recommended in intensified treatment regimens may not be associated with poorer (or better) quality of life in this age-group. Our data suggest that metabolic control as measured by HbA1c is not a sufficient indicator of treatment success in adolescents. Quality of life must be considered separately from the metabolic treatment goals of diabetes care. Interestingly, neither age nor duration of diabetes was associated with higher HbA_{1c}. This finding may be due to the more limited age range of the subjects in this study as compared with other studies of youth with diabetes.

Several other researchers have also shown that adolescents whose parents maintain some guidance and control in the management of diabetes have better metabolic control (28–30). Thus, continuing to involve parents appropriately, with shared management, is associated with improved control. The challenge is to find the degree of parental involvement that is comfortable for all involved, without risking poorer control from overinvolvement or underinvolvement.

In contrast to previous studies (20,30,31), our data did not demonstrate

Table 4—Multiple regression of personal and social factors on diabetes quality of life

Variable	В	SE B	β	t	P value				
Impact ($R^2 = 0.502$, adjusted $R^2 = 0.48$, $F = 22.2$, df = 2.49, $P \le 0.001$)									
Coping: upset	1.28	0.40	0.41	3.19	0.003				
CDI	0.66	0.22	0.39	3.08	0.004				
Coping: hard	_		0.14	0.94	0.35				
DFBS: warmth			-0.18	-1.34	0.18				
FACES: adaptation		_	-0.09	-0.68	0.50				
Rebellious coping			-0.21	-1.90	0.06				
SED scale	_	_	0.06	0.44	0.66				
Satisfaction ($R^2 = 0.473$	Satisfaction ($R^2 = 0.473$, adjusted $R^2 = 0.45$, $F = 19.8$, df = 2.49, $P \le 0.001$)								
CDI	-0.91	0.24	-0.46	-3.86	0.001				
SED scale	0.48	0.16	0.35	2.91	0.006				
Coping: hard		_	-0.22	-1.74	0.09				
Coping: upset	_	_	-0.17	-1.13	0.26				
DFBS: warmth		_	0.05	-0.34	0.73				
Worry ($R^2 = 0.450$, adjusted $R^2 = 0.43$, $F = 18.0$, df = 2.49, $P \le 0.001$)									
Coping: upset	0.95	0.23	0.48	4.07	0.001				
ACOPE: rebellious	-0.66	0.23	-0.34	-2.90	0.006				
CDI	0.41	0.12	0.26	1.94	0.059				
Coping: hard	_		-0.02	-0.15	0.88				
DFBS: warmth		_	-0.02	-0.15	0.88				
SED scale			-0.12	-0.88	0.39				

that family warmth and caring behaviors, adaptability or cohesion were associated with quality of life. It may be that these adolescents have already negotiated a degree of involvement that is comfortable for them, and thus, family involvement does not interfere with their quality of life. These data were collected as baseline data for a larger study involving intensifying their diabetes treatment regimen. Those teenagers who did not consent to participate may not have negotiated a comfortable degree of family involvement.

Further, rebellious coping strategies and feeling that coping with diabetes is harder and more upsetting were associated with poorer quality of life. These findings confirm earlier studies that certain coping behaviors used by children and adolescents are associated with poorer psychosocial adjustment (5,6,32). It is not possible to determine whether poorer quality of life preceded the use of these coping behaviors or vice-versa, but given the consistency with which such behaviors are associated with poorer outcomes in youth with diabetes, the use of such behaviors may be considered a marker for adolescents having potential for poorer quality of life

The findings of the study suggest that clinicians working with adolescents need to be aware of early signs of depression and refer those who are having difficulty. Further,

adolescents with diabetes can be assessed to determine how difficult and upsetting they find coping with diabetes. If they are having difficulty, they will require counseling and training to develop more constructive coping strategies and evaluated for less troublesome methods of coping. Moreover, our findings indicate that diabetes treatment teams need to pay equal attention to the psychosocial needs of the quiet, nonrebellious teenager with well-controlled diabetes from a supportive family as it does to the rebellious adolescent with poorly controlled diabetes. As more teenagers use more intensive treatment regimens, assisting them to negotiate reasonable guidance from their families may help them to maintain better metabolic control and quality of life.

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