

Assessment of Diabetes-Related Distress

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OBJECTIVE — To describe a new measure of psychosocial adjustment specific to diabetes, the Problem Areas in Diabetes Survey (PAID), and to present initial information on its reliability and validity.

RESEARCH DESIGN AND METHODS — Before their routine clinic appointments, 451 female patients with type I and type II diabetes, all of whom required insulin, completed a self-report survey. Included in the survey was the PAID, a 20-item questionnaire in which each item represents a unique area of diabetes-related psychosocial distress. Each item is rated on a six-point Likert scale, reflecting the degree to which the item is perceived as currently problematic. A total scale score, hypothesized to reflect the overall level of diabetes-related emotional distress, is computed by summing the total item responses. To examine the concurrent validity of the PAID, the survey also included a series of standardized questionnaires assessing psychosocial functioning (general emotional distress, fear of hypoglycemia, and disordered eating), attitudes toward diabetes, and self-care behaviors. All subjects were assessed for HbA_{1c} within 30 days of survey completion and again ~1–2 years later. Finally, long-term diabetic complications were determined through chart review.

RESULTS — Internal reliability of the PAID was high, with good item-to-total correlations. Approximately 60% of the subject sample reported at least one serious diabetes-related concern. As expected, the PAID was positively associated with relevant psychosocial measures of distress, including general emotional distress, disordered eating, and fear of hypoglycemia, short- and long-term diabetic complications, and HbA_{1c}, and negatively associated with reported self-care behaviors. The PAID accounted for ~9% of the variance in HbA_{1c}. Diabetes-related emotional distress, as measured by the PAID, was found to be a unique contributor to adherence to self-care behaviors after adjustment for age, diabetes duration, and general emotional distress. In addition, the PAID was associated with HbA_{1c} even after adjustment for age, diabetes duration, general emotional distress, and adherence to self-care behaviors.

CONCLUSIONS — These findings suggest that the PAID, a brief, easy-to-administer instrument, may be valuable in assessing psychosocial adjustment to diabetes. In addition to high internal reliability, the consistent pattern of correlational findings indicates that the PAID is tapping into relevant aspects of emotional distress and that its particular feature, the measurement of diabetes-related emotional distress, is uniquely associated with diabetes-relevant outcomes. These data are also consistent with the hypothesis that diabetes-related emotional distress, separate from general emotional distress, is an independent and major contributor to poor adherence. Given that the study was limited to female patients using insulin, further examination of the clinical usefulness of the PAID will need to focus on more heterogeneous samples.

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BULIT-R, Bulimia Test-Revised; GSI, Global Severity Index; HFS-W, Hypoglycemia Fear Survey, worry scale; PAID, Problem Areas in Diabetes Survey; SCI, Self-Care Inventory.

For those living with diabetes, illness-related emotional distress may not be uncommon. In the face of unending and often burdensome self-care demands, many patients may become overwhelmed or burned out by the frustrations of the regimen and illness. Given the threat or impact of severe long-term complications and the potential influence of diabetes on life expectancy, many patients may become unduly preoccupied or worried by the fear of such complications. Furthermore, in the complex adjustment to life with diabetes, many patients may feel defeated, becoming unmotivated to adhere to the diabetes regimen. A range of other emotional responses to diabetes have also been observed, including anger, guilt, frustration, denial, fear of hypoglycemia, and loneliness (1–3).

While recent reports have described many of the issues surrounding psychosocial adjustment to diabetes, including cognitive, behavioral, and emotional aspects (4–8), formal measurement is still at a relatively early stage of development. A range of standardized psychosocial measures, developed for the general population and various psychiatric groups, have been applied in diabetes (9–12). In addition, diabetes-specific measures of psychosocial adjustment have been developed, focusing primarily on the assessment of cognitive aspects (13,14) or behavioral aspects (15–17). There are, however, few measures available that focus primarily on the emotional aspects of psychosocial adjustment to diabetes.

Recent evidence suggests that emotional distress, as represented by the presence of affective disorders (7,9,18) and/or poor coping skills (19), may be linked to poor adherence with the self-care regimen, especially among adolescents with insulin-dependent diabetes mellitus (IDDM) (6,20). Apart from such examples of nonspecific emotional distress, it is presumed that diabetes-related emotional distress (e.g., feeling over-

whelmed by the diabetes regimen) may be independently linked to poor adherence. Because of the lack of appropriate instruments, however, this has rarely been examined.

We have developed a new measure of psychosocial adjustment specific to diabetes, the Problem Areas in Diabetes Survey (PAID). The primary aim of the PAID is to tap the breadth of emotional responses to diabetes; it is intended to be a screening measure for clinical and research use in diabetes; it is also designed to help clinicians identify patients experiencing high levels of diabetes-related distress and formulate treatment interventions around specific problem areas.

This study presents initial information on the reliability and validity of the PAID.

RESEARCH DESIGN AND METHODS

— Before the routinely scheduled medical appointments of female patients at the Joslin Diabetes Center in Boston, their case records were reviewed, and those who met the following criteria were deemed eligible for the study: diagnosis of diabetes, insulin-requiring for at least 1 year before the study, age between 13 and 60 years, not currently pregnant, and no severe visual limitations. These data were drawn from a larger study that was investigating disordered eating behaviors in women with diabetes (21).

Eligible patients ($n = 531$) were approached at the time of their medical visit and asked to complete a series of self-report measures, requiring ~40 min to complete, which included the PAID as well as instruments assessing psychological functioning, self-care behaviors, and clinical variables. Twenty patients refused, 21 patients agreed but did not return the survey, and 39 patients returned incomplete surveys in which the PAID could not be used. In total, 451 completed surveys (85%) were returned.

Initial test construction

Items for the PAID were solicited from 10 health care providers at the Joslin Diabetes Clinic (including diabetes nurse specialists, dietitians, and diabetologists) and from patient comments elicited during routine patient interviews carried out by the senior author that focused on the range of difficulties encountered by patients living with diabetes. To clarify the meaning and relevance of items, early drafts of the item pool were piloted using 25 insulin-requiring patients. As a result of this process, specific items were modified or eliminated, and new items were added. The final measure comprised 20 items (Table 3), each representing a unique area of diabetes-related distress. These range from anger (“feeling angry when you think about having diabetes and living with diabetes”) and interpersonal distress (“feeling that your friends and family are not supportive of your diabetes efforts”) to frustration with aspects of the diabetes regimen (“not having clear and concrete goals for your diabetes care”).

On a 6-point Likert scale, patients rate the degree to which each item is currently problematic for them, from 1 (“no problem”) to 6 (“serious problem”). A total scale score is computed by summing the total item responses, which can range from 24 to 144.

Psychological and clinical measures

In addition to the PAID, the survey included the following measures:

1. The Brief Symptom Inventory (22), designed to assess emotional distress, lists 53 psychological symptoms that respondents may or may not have experienced during the previous week. Each symptom is rated on a five-point scale of distress, from 0 (“not at all”) to 4 (“extremely”). While nine primary symptom dimensions and three global indexes can be derived, the present study focused on the Global Severity Index (GSI), the most sensitive of the global indexes, reflecting recent level of overall distress. Henceforth, we will refer to this as “general emotional distress” (i.e., emotional distress not specifically related to diabetes). Internal reliability of the inventory, as derived from this sample, was high ($\alpha = 0.97$).
2. The Bulimia Test-Revised (BULIT-R) (23) comprises 36 statements focusing on attitudes and behaviors central to bulimia nervosa (binge eating, purging behaviors, and weight preoccupation). This measure was included since eating-related distress was found to be a common concern during PAID development. Each item is rated by respondents on a five-point scale, with higher summed scores indicating greater pathology. Internal reliability, as derived from this sample, was high ($\alpha = 0.95$). There is recent evidence to support the use of the BULIT-R as a sound screening instrument for bulimia nervosa (23,24).
3. The Hypoglycemia Fear Survey (1) focuses on worries about hypoglycemia (17 items) and behaviors designed to avoid hypoglycemia (10 items). Each item is rated on a five-point scale, from 1 (“never”) to 5 (“very often”), with higher scores signifying greater fear. In the current study, only the worry subscale was administered (HFS-W). Internal reliability, as derived from this sample, was high ($\alpha = 0.94$).
4. The Self-Care Inventory (SCI) (25), designed to assess regimen adherence behaviors, lists 14 diabetes self-care tasks (e.g., blood glucose testing). Each task item is rated on a five-point scale, indicating how well the subject feels that she has followed her physician’s recommendations for this task during the past month, from 1 (“never do it”) to 5 (“always do this as recommended without fail”). Selected items were combined into the following subscales: 1) blood glucose testing (“glucose recording” plus “glucose testing”), 2) use of insulin (“administering correct insulin dose,” “ad-

ministering insulin at right time," plus "adjusting insulin intake based on blood glucose values"), 3) use of food ("eating the proper foods; sticking to a meal plan" plus "eating meals on time"), and 4) use of exercise ("exercising regularly" plus "exercising strenuously"). For each subscale, lower summed scores indicate poorer adherence in that particular area. As derived from this sample, internal reliability for each subscale was acceptable (blood glucose testing, $\alpha = 0.81$; insulin, $\alpha = 0.53$; food, $\alpha = 0.71$; exercise, $\alpha = 0.65$).

5. To examine differences in targeted ranges for blood glucose values, subjects were asked to estimate the blood glucose levels at which they felt that they should begin treatment of hyperglycemia (maximally acceptable value) and of hypoglycemia (minimally acceptable value). It was emphasized that subjects should indicate their actual targeted range, not their physician's recommendation. This was designed to serve as a second measure of regimen adherence, with elevated ranges believed to be associated with poorer adherence (26).
6. The following clinical variables were measured. Total HbA_{1c} was measured by an agar gel electrophoretic method (27); the normal range in our laboratory is 5.4–7.4%. The coefficient of variation is 4.42%. Only HbA_{1c} results from blood samples drawn on the day of survey completion or within 30 days of survey completion were included in the initial analyses ($n = 395$). In addition, long-term microvascular complications (neuropathy and retinopathy) were assessed. Medical records were examined by a research assistant who was blinded to the survey responses of subjects. Where a diagnosis of retinopathy was documented in the patient's chart, the type and presence of retinopathy were recorded. When a diagnosis of neuropathy was indicated and/or symptoms of neuropathy were documented (e.g.,

Table 1—Clinical characteristics of the subject sample

	Value
Demographic factors	
Age	36.3 ± 13.4
Percentage who completed college	39.3
Duration of diabetes (years)	15.9 ± 10.7
Diabetes type	
Type I (%)	82.4
Type II (%)	17.6
Medical factors	
HbA _{1c} (%)	10.7 ± 2.1
Percentage with neuropathy	26.8
Percentage with retinopathy	54.3
Percentage with ≥1 severe hypoglycemic episode during past month	15.3
Psychosocial factors	
Fear of hypoglycemia (HFS-W)	36.6 ± 13.7
Generalized distress (GSI)	56.8 ± 11.4
Disordered eating (BULIT-R)	53.7 ± 22.3
Adherence to self-care behaviors (SCI)	
Use of blood glucose testing	3.3 ± 1.3
Use of insulin	4.2 ± 0.9
Use of food	3.4 ± 1.0
Use of exercise	2.5 ± 1.2

Data are means ± SD. $n = 451$ for the study sample; $n = 395$ for HbA_{1c}; $n = 372$ for percentages with neuropathy and retinopathy.

chronic numbness or tingling in the extremities) in the patient's chart, neuropathy was assumed to be present. Of the 451 subjects, 372 records were located, examined, and included in these analyses.

Approximately 2 years after survey completion, medical records were examined for the most recent HbA_{1c} results for all available subjects. To determine the PAID's ability to predict long-term glycemic control, all subjects were included whose most recent HbA_{1c} measurement was performed at least 1 year after survey completion and the baseline HbA_{1c} ($n = 221$). The average time elapsed between baseline and follow-up HbA_{1c} results (\pm SD) was 533 ± 86 days.

Statistical analysis

Internal reliability of the PAID was measured by Cronbach's α . If the PAID items are homogeneous and measuring a simi-

lar construct, internal consistency should typically be >0.80 (28).

Although no absolute criterion or gold standard exists for emotional adjustment to diabetes, the construct validity of the PAID can be determined from a convergence of evidence from a number of different sources. These include concurrent validity (to establish that PAID scores correlate strongly with meaningful external criteria thought to measure the same attribute or property) and predictive validity (to determine whether PAID scores predict some future event or behavior). For this reason, this study examined the associations between the PAID and the psychological and clinical measures described above. Pearson correlations and, when appropriate, analyses of variance were used (in all cases, adjusted for age and diabetes duration). Hierarchical multiple regression was used to determine the unique contribution of PAID scores to

Table 2—Correlations between PAID and demographic factors, psychosocial factors, regimen adherence, and long-term glycemic control (adjusted for age and disease duration)

	PAID scores
Age	-0.11*
Disease duration	-0.12*
General emotional distress (GSI)	0.63†
Fear of hypoglycemia (HFS-W)	0.57†
Disordered eating (BULIT-R)	0.61†
Adherence to self-care behaviors (SCI)	
Use of blood glucose testing	-0.19†
Use of insulin	-0.31†
Use of food	-0.49†
Use of exercise	-0.09
Lowest acceptable blood glucose	0.27†
Highest acceptable blood glucose	0.23†
HbA _{1c}	0.30†

n = 451, except n = 395 for HbA_{1c}. *P < 0.05; †P < 0.0005.

self-care, initial HbA_{1c}, and HbA_{1c} results at follow-up. Given the pilot nature of this investigation, the type I error rate was not adjusted to account for the number of analyses.

RESULTS— Table 1 displays the clinical and demographic characteristics of the recruited sample. The majority (82.4%) had type I diabetes, with a mean duration of 15.9 years and a mean HbA_{1c} of 10.7%. Mean age was 36.2 years, and patients in the sample were well-educated, with 39.3% having completed college. Of the sample, 27% were found to have neuropathy, 54% had retinopathy, and 15% had one or more severe hypoglycemic episodes in the previous month.

For the PAID, Cronbach's α was 0.95, indicating a high level of internal reliability. Item-to-total correlations were good, ranging from 0.32 to 0.84, with a mean of 0.68. The mean PAID score (\pm SD) was 54.5 \pm 23.1, ranging from 20 to

115. Few demographic differences were apparent. PAID scores were not significantly different between subjects with type I versus type II diabetes. As displayed in Table 2, PAID scores were only weakly correlated with age and disease duration.

Feelings of distress about diabetes were not uncommon. Of the 451 subjects, 271 (60.2%) reported at least one serious diabetes-related problem (scoring ≥ 5 on at least one PAID item). When those who reported at least one serious problem were compared with those who did not, there were no significant differences in type of diabetes or disease duration. However, those who reported no serious diabetes-related problems were significantly older than those who reported problems [$t(448) = -2.38, P < 0.05$]. Examination of individual PAID items points to important differences in feelings about diabetes (Table 3). While some issues in diabetes were commonly

Table 3—Distribution of PAID item scores, indicating the percentage of subjects who reported each item as a "serious problem" (scoring ≥ 5) and as "no problem" (scoring ≤ 2)

	No problem (% scoring ≤ 2)	Serious problem (% scoring ≥ 5)
Worrying about the future and the possibility of serious complications	20.9	42.0
Feeling guilty or anxious when you get off track with your diabetes management	31.3	30.3
Feeling scared when you think about having/living with diabetes	45.3	25.7
Feeling discouraged with your diabetes regimen	39.1	24.3
Feeling depressed when you think about having/living with diabetes	48.2	24.0
Feeling constantly concerned about food and eating	44.9	22.4
Feeling "burned out" by the constant effort to manage diabetes	50.2	22.2
Feeling angry when you think about having/living with diabetes	53.6	22.2
Coping with complications of diabetes	48.7	20.0
Feeling that diabetes is taking up too much mental and physical energy	57.6	18.2
Worrying about reactions	56.0	17.4
Not knowing if the mood or feelings you are experiencing are related to your blood glucose	45.5	17.3
Feeling overwhelmed by your diabetes regimen	53.4	16.7
Feeling alone with diabetes	58.0	15.4
Feelings of deprivation regarding food and meals	52.6	15.0
Not "accepting" diabetes	64.9	14.7
Not having clear and concrete goals for your diabetes care	60.7	10.9
Uncomfortable interactions around diabetes with family/friends	69.3	10.5
Feeling that friends/family are not supportive of diabetes management efforts	71.7	8.0
Feeling unsatisfied with your diabetes physician	85.5	4.9

n = 451. Items are listed in descending order of reported severity.

associated with significant levels of distress (e.g., worrying about the possible development of serious complications, feelings of guilt and anxiety regarding the diabetes regimen), other issues were rarely perceived as distressing (dissatisfaction with one's physician, poor social support for diabetes management efforts).

The PAID was positively associated with general emotional distress, fear of hypoglycemia, and disordered eating attitudes and behaviors and negatively associated with adherence to physicians' recommendations for blood glucose testing, insulin usage, and meal planning (Table 2). The PAID was positively associated with subjects' targeted ranges of blood glucose levels. Greater diabetes-related distress was linked to positively skewed ranges (i.e., higher targets for minimal and maximal values). Under-scoring the potential importance of diabetes-related distress (in comparison with general emotional distress), hierarchical multiple regression analysis revealed that the PAID was associated with adherence to the three main types of regimen behaviors (blood glucose testing, insulin usage, and meal planning) even after adjustment for age, diabetes duration, and general emotional distress (Table 4).

The PAID was positively correlated with glycemic control (HbA_{1c}), with greater distress associated with poorer glycemic control. Interestingly, while glycemic control was correlated with adherence to the three types of regimen behaviors (*r* values ranging from -0.25 to -0.28, *P* < 0.0005), glycemic control was just as strongly linked to diabetes-related distress (*r* = 0.30, *P* < 0.0005). Again highlighting the potential value of assessing diabetes-related distress, hierarchical multiple regression analysis indicated that diabetes-related distress was linked to glycemic control even after adjustments for age, diabetes duration, general emotional distress, and adherence to the three regimen behaviors (Table 5).

Short- and long-term complications were associated with PAID scores. Subjects with recent severe hypoglycemia

Table 4—Hierarchical multiple regression to predict adherence to self-care behaviors (SCI) from age, disease duration, general emotional distress (GSI), and diabetes-related distress (PAID)

Models	β	R ²	R ² change	Model F
Use of blood glucose testing				
Model 1		0.02		3.32*
Disease duration	-0.01			
Age	0.02*			
General emotional distress (GSI)	-0.01			
Model 2		0.08	0.06‡	9.16‡
Disease duration	-0.01			
Age	0.01*			
General emotional distress (GSI)	0.02†			
Diabetes-related distress (PAID)	-0.02‡			
Use of insulin				
Model 1		0.04		5.95†
Disease duration	0.01*			
Age	0.00			
General emotional distress (GSI)	-0.01†			
Model 2		0.09	0.05‡	10.39‡
Disease duration	0.01			
Age	-0.00			
General emotional distress (GSI)	0.00			
Diabetes-related distress (PAID)	-0.01‡			
Use of food				
Model 1		0.13		20.82‡
Disease duration	0.01*			
Age	0.01*			
General emotional distress (GSI)	-0.03‡			
Model 2		0.23	0.10‡	32.79‡
Disease duration	0.01			
Age	0.00			
General emotional distress (GSI)	-0.01			
Diabetes-related distress (PAID)	-0.02‡			

Data for β are standardized. *n* = 437. **P* < 0.05; †*P* < 0.005; ‡*P* < 0.0005.

scored significantly higher on the PAID (61.6 ± 23.5) than subjects free from severe hypoglycemia (53.3 ± 22.4) (*F*(1/428) = 7.63, *P* < 0.007). Subjects with neuropathy displayed significantly higher PAID scores (62.6 ± 24.3) than subjects without neuropathy (51.6 ± 21.9) (*F*(1/364) = 26.73, *P* < 0.0001). An identical pattern was seen when subjects with retinopathy (57.0 ± 23.4) versus those without retinopathy (51.8 ± 22.2) were compared (*F*(1/367) = 10.65, *P* < 0.002).

Diabetes-related distress was also linked to future glycemic control. Ad-

justed for baseline HbA_{1c}, age, and diabetes duration, the PAID was predictive of glycemic control at ≥1 year after the survey (*F*(1/216) = 4.75, *P* < 0.05). However, baseline HbA_{1c} accounted for the majority of variance in follow-up HbA_{1c} (*r*² = 0.45), while the unique amount of variance shared by the PAID and the follow-up HbA_{1c} was very small (*r*² = 0.01).

CONCLUSIONS— These data suggest that the PAID may be a clinically valuable instrument in assessing psychosocial adjustment to diabetes. Its reliability is supported by the finding of strong

Table 5—Hierarchical multiple regression to predict HbA_{1c} from age, disease duration, generalized distress (GSI), adherence to self-care behaviors (SCI), and diabetes-related distress (PAID)

Models	β	r^2	r^2 change	Model F
Model 1		0.01		1.54
Disease duration	0.01			
Age	-0.01			
General emotional distress (GSI)	0.01			
Model 2		0.10	0.09†	7.06†
Disease duration	0.01			
Age	-0.00			
General emotional distress (GSI)	0.00			
Adherence to self-care behaviors (SCI)				
Use of blood glucose testing	-0.19*			
Use of insulin	-0.31*			
Use of food	-0.30*			
Model 3		0.15	0.05†	9.36†
Disease duration	0.02			
Age	0.00			
General emotional distress (GSI)	-0.03*			
Adherence to self-care behaviors (SCI)				
Use of blood glucose testing	-0.14			
Use of insulin	-0.31*			
Use of food	-0.14			
Diabetes-related distress (PAID)	0.03†			

Data for β are standardized. $n = 395$. * $P < 0.05$; † $P < 0.0005$.

internal consistency for the scale. Tests of concurrent validity indicated that the PAID was significantly associated with relevant psychosocial measures of distress (including general emotional distress, disordered eating, and fear of hypoglycemia), regimen adherence, short- and long-term diabetic complications, and glycemic control. In total, the PAID accounted for ~9% of the variance in glycemic control. An important fact was that the PAID was found to contribute uniquely to regimen adherence and to glycemic control, based on a series of multiple regression analyses that controlled for age, duration of diabetes, and general emotional distress. These data support the fact that the PAID is tapping into relevant aspects of emotional distress and that its particular focus, the measurement of diabetes-related emotional distress, is uniquely associated with several key clinical outcomes. In addition, these findings are consistent with the hypothesis that diabetes-related emotional dis-

stress, separate from general emotional distress, is an independent and major contributor to poor adherence (29).

Diabetes-related emotional distress appears to be common, with serious concerns being reported for at least one PAID item in 60% of the study sample. Worries about the possible development of long-term complications and feelings of guilt and anxiety regarding poor adherence to the diabetes regimen were the most prominent of these concerns. Of interest, serious dissatisfaction with one's physician was found to be rare. Note, though, that these surveys were completed in a clinic setting, albeit anonymously, immediately before the patients' visits with their physicians. It would be interesting to examine whether more patients might report strong concerns about their physicians if these data were collected in other settings.

While the PAID was linked to long-term glycemic control at >1 year after the survey, the amount of shared vari-

ance was small. Thus, while statistically significant, diabetes-related emotional distress appears to be of little clinical importance in the determination of future glycemic control, at least at 1 year. Indeed, given the large n in this sample, it seems likely that the observed association is merely a statistical artifact. The strong association between baseline and follow-up HbA_{1c}, however, points to the general lack of change in HbA_{1c} in this sample over the long term (and, therefore, little variance remaining for which the PAID could account). If valuable as a predictor, diabetes-related distress seems more likely to be important in patients in whom a clinically significant glycemic change has occurred (e.g., in a behavioral change program designed to promote improved glycemic control).

It must be emphasized that these results are preliminary. Study subjects were limited to those taking insulin and women, thus restricting the generalizability of our conclusions. Replication with larger and more heterogeneous samples is essential. These initial data suggest that the PAID, a brief, easy-to-administer instrument, may serve as a useful clinical tool in the identification of patients who are experiencing high levels of diabetes-related distress. In our clinical experience, we have also found that the PAID may serve as a useful catalyst in initiating dialogues with patients about the specific details of their diabetes-related concerns.

As investigations concerning the utility of the PAID continue, it will be valuable to examine whether 1) PAID scores are generally stable over time, 2) the PAID is sensitive to clinically important changes in patient status (e.g., in response to appropriate educational and/or psychosocial interventions believed to promote significant reductions in diabetes-related emotional distress), and 3) a cutoff PAID score may be determined that would signify a pathological level of distress. If clinicians are to be successful in the promotion of greater adherence to diabetes self-care behaviors, it is essential that the subtleties and dynamics of psy-

chosocial adjustment to diabetes be more closely examined in all patients. Use in clinical practice of such self-report instruments as the PAID may be a useful step in this direction.

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