Assessing Psychosocial Distress in Diabetes

Development of the Diabetes Distress Scale

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OBJECTIVE — The purpose of this study was to describe the development of the Diabetes Distress Scale (DDS), a new instrument for the assessment of diabetes-related emotional distress, based on four independent patient samples.

RESEARCH DESIGN AND METHODS — In consultation with patients and professionals from multiple disciplines, a preliminary scale of 28 items was developed, based a priori on four distress-related domains: emotional burden subscale, physician-related distress subscale, regimen-related distress subscale, and diabetes-related interpersonal distress. The new instrument was included in a larger battery of questionnaires used in diabetes studies at four diverse sites: waiting room at a primary care clinic ($n = 200$), waiting room at a diabetes specialty clinic ($n = 179$), a diabetes management study program ($n = 167$), and an ongoing diabetes management program ($n = 158$).

RESULTS — Exploratory factor analyses revealed four factors consistent across sites (involving 17 of the 28 items) that matched the critical content domains identified earlier. The correlation between the 28-item and 17-item scales was very high ($r = 0.99$). The mean correlation between the 17-item total score (DDS) and the four subscales was high ($r = 0.82$), but the pattern of interscale correlations suggested that the subscales, although not totally independent, tapped into relatively different areas of diabetes-related distress. Internal reliability of the DDS and the four subscales was adequate ($\alpha > 0.87$), and validity coefficients yielded significant linkages with the Center for Epidemiological Studies Depression Scale, meal planning, exercise, and total cholesterol. Insulin users evidenced the highest mean DDS total scores, whereas diet-controlled subjects displayed the lowest scores ($P < 0.001$).

CONCLUSIONS — The DDS has a consistent, generalizable factor structure and good internal reliability and validity across four different clinical sites. The new instrument may serve as a valuable measure of diabetes-related emotional distress for use in research and clinical practice.

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Abbreviations: CESD, Center for Epidemiological Studies Depression Scale; DDS, Diabetes Distress Scale; EB, emotional burden subscale; ID, diabetes-related interpersonal distress subscale; JOS, Joslin Diabetes Center's Diabetes Outpatient Intensive Treatment program; KP, Kaiser Permanente Diabetes Clinic; NMC, Naval Medical Center Internal Medicine Clinic; PAID, Problem Areas in Diabetes scale; PD, physician-related distress subscale; QSD-R, Questionnaire on Stress in Patients with Diabetes-Revised; RD, regimen-related distress subscale; SDSCA, Summary of Diabetes Self-Care Activities; SMBG, self-monitoring of blood glucose; TAMC, Tripler Army Medical Center.

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

Living with diabetes can be tough. In the face of a complex, demanding, and often confusing set of self-care directives, patients may become frustrated, angry, overwhelmed, and/or discouraged. Diabetes-related conflict with loved ones may develop, and relationships with health care providers may become strained. The risk of depression is elevated (1,2). As a result, motivation for self-care may be impaired. To investigate the nature and breadth of such distress, a number of self-report instruments have been developed, including the ATT39 (3), Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R) (4), and Problem Areas in Diabetes scale (PAID) (5). These measures aim to tap the range of emotional responses to diabetes and to serve as screening measures for clinical and research use. The PAID has been the most widely used of the measures and has been recently translated into several other languages (6–8). PAID scores have been linked to diabetes self-care behaviors (5,6) and glycemic control (2,5–9) and are associated with general emotional distress (5), perceived burden of diabetes (8), diabetes-related health beliefs (10), diabetes coping (10), and marital adjustment (11,12). The instrument is responsive to change (13) and is a useful measure of several aspects of diabetes-related quality of life (14,15).

All of these measures, including the PAID, have some limitations. Some critical areas of interest are covered either too briefly or not at all (e.g., in the PAID, only one item addresses patients' feelings about their health care provider). Anecdotal reports suggest that patients may be confused over the exact meaning of some items (e.g., in the PAID, "not having clear and concrete goals for your diabetes care," and in the QSD-R, "I suffer from irritability"). Finally, there is growing interest in a brief instrument that can, for both clinical and research purposes, assess (and perhaps distinguish among) different types of diabetes-related emotional distress. Although the ATT39 and QSD-R have es-

tablished subscales, they are not brief (45 and 39 items, respectively). In contrast, the PAID is brief (20 items), but subscales have not been developed. Given these concerns, we decided to develop a new measure, the Diabetes Distress Scale (DDS), which builds on the strengths of previously developed instruments and addresses at least some of their limitations. This study presents initial data on the factor structure of the DDS based on four independent patient samples and on its reliability and validity.

RESEARCH DESIGN AND METHODS

— Patients, diabetes nurse specialists, dietitians, diabetologists, and diabetes-knowledgeable psychologists from around the country were asked to review the items previously developed for the PAID, QSD-R, and ATT39 and to suggest new or similar items for a new instrument. From this pool of items, an early draft of the new scale containing 50 items was developed and pilot tested with several small groups of patients. Feedback from these groups led to deletion of items that were vague, difficult for patients to comprehend, or merely duplicative, resulting in a scale of 28 items. These included seven items from each of four domains central to diabetes-related emotional distress, created a priori based on focus group discussions: emotional burden subscale (EB) (e.g., "feeling overwhelmed by the demands of living with diabetes"), physician-related distress subscale (PD) (e.g., "feeling that my doctor doesn't take my concerns seriously enough"), regimen-related distress subscale (RD) (e.g., "feeling that I am not sticking closely enough to a good meal plan"), and diabetes-related interpersonal distress subscale (ID) (e.g., "feeling that my friends/family don't appreciate how difficult living with diabetes can be"). Following a format similar to those developed for the PAID and QSD-R, patients rated the degree to which each item was currently problematic for them on a 6-point Likert scale, from 1 (no problem) to 6 (serious problem).

The new instrument was included as part of larger studies of patients with diabetes at four clinical sites. Human subject approval was received for each of these studies at their respective institutions, and all patients provided informed consent. At all sites, patients were deemed eligible if they met broad inclusion criteria: ≥18 years old, a diagnosis of type 1 or 2 diabetes, and no severe visual or cognitive limitations.

San Diego

Patients at two San Diego sites, the Kaiser Permanente Diabetes Clinic (KP) and the Naval Medical Center Internal Medicine Clinic (NMC), were approached immediately before their medical visit and asked to complete a battery of self-report measures, requiring ~15–20 min, which included instruments assessing psychological functioning, self-care behaviors, and clinical variables. The study was designed to ascertain the prevalence and severity of diabetes-related emotional and behavioral dysfunction at these two sites, as a prelude to the development of a comprehensive plan for intervention. Of 233 eligible patients approached at KP, 41 refused, 2 did not return the survey, and 11 returned incomplete surveys, resulting in 179 completed surveys (76% of the sample). At NMC, of 275 eligible patients approached, 67 refused and 8 returned incomplete surveys, resulting in 200 completed surveys (72% of the sample).

Honolulu

Patients at Tripler Army Medical Center (TAMC) were invited to join an intervention study examining an intensive group education and skills training experience combined with medical management (16). In addition to the eligibility criteria listed above, patients were also required to be in poor glycemic control (most recent HbA_{1c} ≥8.5%). Patients in the TAMC database who met eligibility criteria were sent a letter describing the study, followed several days later by a phone call from the project's nurse recruiter. Patients were also recruited through mailings to TAMC physicians. Of the 224 patients contacted who met eligibility requirements, 196 (88%) agreed to join the study and to complete a baseline questionnaire requiring ~30 min, assessing psychological functioning, self-care behaviors, and clinical variables. Completed surveys were obtained from 167 patients (75% of patients approached).

Boston

Eligible patients enrolled at Joslin Diabetes Center's Diabetes Outpatient Intensive Treatment program (JOS), a 3.5-day group education course integrated with intensive medical management, were approached at the start of the program and asked to complete a brief questionnaire battery that assessed psychological functioning and selected clinical variables. Of 158 patients approached, 137 completed the survey (87% of patients approached).

No information was available regarding those who refused participation at the four sites, so differences between those who did and did not complete survey forms could not be ascertained.

Psychological and clinical measures

In addition to the DDS, questionnaire batteries at all sites included the Center for Epidemiological Studies Depression Scale (CESD), a widely used, 20-item questionnaire designed to assess the major symptoms of depression (17). A reliable and well-validated instrument, the CESD's targeted symptoms include depressed mood, changes in appetite and sleep, low energy, feelings of hopelessness, low self-esteem, and loneliness. Respondents are asked to consider the presence and duration of each item/symptom over the past week and to rate each along a 4-point scale from 0 (rarely or never) to 3 (most or all of the time). Possible scores range from 0 to 60. A score ≥16 is the most common cutoff point, indicating a "likely depression" (17). However, this cannot be equated to a clinical diagnosis of depression.

All sites (except for JOS) included the Summary of Diabetes Self-Care Activities (SDSCA), a 12-item, self-report scale that assesses the frequency of blood glucose monitoring, exercise and dietary behaviors, and medication usage over the previous 7 days (18). Adequate reliability and validity have been demonstrated (19). Attention was focused on a subset of the items targeting self-monitoring of blood glucose (SMBG) ("how often you checked glucose levels"), exercise ("how often you participated in at least 20 min of physical exercise"), and dietary behavior ("how often you followed your recommended meal plan"). SMBG response alternatives were "every day," "most days," "some days," and "none of the days." Exercise response alternatives were 0–7 days. Dietary response alternatives were "always," "usually," "sometimes," "rarely," and "never." Responses to the exercise item were reverse scored, so that higher scores on all items reflect better self-management.

Table 1—*Baseline characteristics*

	NMC	KP	TAMC	JOS	Total	*P*
n	200	179	167	137	683	
Male (%)	44.5	57.5	53.9	54.7	52.3	
Age (years)	62.0	59.3	50.9	50.6	56.3	<0.001
Ethnic background (%)*						<0.001
Non-Hispanic white	54.5	68.2	34.1		52.7	
African American	13.0	9.5	17.4		13.2	
Hispanic	5.0	11.2	4.8		7.0	
Asian/Pacific Islander	22.0	5.6	31.7		19.6	
High school graduate (%)	85.6	88.7	92.2		88.7	
Diabetes duration (years)	12.5	15.3	10.5		12.8	<0.001
Medication use (%)						<0.05
Insulin	47.5	58.7	44.9		50.4	
Oral hypoglycemic agents only	42.5	35.8	49.7		42.5	
Diet controlled (%)	10.0	5.6	5.4		7.1	
HbA_{1c} (%)	8.7	7.6	10.4	8.2	8.8	<0.001
CESD	15.4	13.9	14.3	20.2	15.7	<0.001
DDS (total score)	31.7	36.1	39.3	50.6	38.5	<0.001
Self-care						
Meal planning†	67.7	64.4	36.7	—	56.9	<0.001
Exercise‡	2.6	2.8	3.0	—	2.8	
SMBG§	70.7	77.7	69.9	—	72.7	

*Percentages do not sum to 100% because smaller ethnic groups (Hispanics and African Americans) were excluded from these analyses; †those following recommendations "always" or "usually" during the past 7 days; ‡number of days of exercise (20 min or more) during the past 7 days; §those reporting monitoring "every day" or "most days."

Metabolic variables

At NMC, TAMC, and JOS, HbA_{1c} was measured by high-performance liquid chromatography; the consensus normal range was 4.0–6.0%. At the KP site, HbA_{1c} was measured by the Roche/BMC method; the normal range was 4.2–6.7%. At TAMC, all subjects completed HbA_{1c} testing within 90 days before survey completion. At JOS, all subjects completed HbA_{1c} testing on the day of survey administration. To make analyses comparable across sites, only HbA_{1c} results from blood drawn within 90 days of survey completion at NMC ($n = 136$) and KP ($n = 125$) were examined. To compare values directly across sites, HbA_{1c} results were standardized such that they reflected the percentage above (or below) the Diabetes Control and Complications Trial upper limit of the normal range (6.0%).

At TAMC and KP, the most recent lipid profiles were obtained from clinical records. Values were included only if they had been collected within the past 12 months. Lipid profiles were available for 139 subjects at TAMC and 131 subjects at KP. Analyses focused on total cholesterol only.

Statistical analyses

An exploratory factor analysis was performed on the 28-item scale for each site separately using principal factor analysis with Promax rotation. Cronbach's α was used to assess the internal consistency of the total scale and the subscales, and Pearson correlations compared the DDS total scale and each subscale with the CESD, SDSCA, and metabolic variables, which were used as validity coefficients.

RESULTS — The clinical and demographic characteristics of the four samples are presented in Table 1. Mean age was 56.3 years, and males comprised 52.3% of the total sample. The majority (83.3%) had type 2 diabetes, and the mean HbA_{1c} was 8.8%. In the three samples for which further demographic data were available, the majority of patients (50.4%) were using insulin: 42.5% were receiving oral hypoglycemic agents only, and 7.1% were managed by diet only. Non-Hispanic whites predominated (52.7%), followed by Asian Americans and Pacific Islanders (19.6%), African Americans (13.2%), and Hispanics (7.0%). Most subjects (87.7%) had graduated from high school.

NMC and KP subjects were recruited from general care settings where their diabetes was managed. In contrast, TAMC and JOS subjects came from more highly specialized programs, which suggested that these individuals may have been more ill and/or were having more trouble managing their diabetes. Therefore, it is noteworthy that significant site differences occurred (Table 1). Patients from TAMC and JOS were significantly younger than patients from NMC and KP ($P < 0.001$). JOS patients reported higher depression scores than patients from the other three sites ($P < 0.001$). Patients in the TAMC, in which poor glycemic control was the critical inclusion criterion, displayed the highest standardized HbA_{1c} levels and the poorest self-reported adherence to meal planning recommendations ($P < 0.001$). The variability of the sites provided a broad range of patients on which to assess the structure, reliability, and validity of the DDS.

Exploratory factor analyses

The four within-site exploratory factor analyses of the 28 items yielded between four and eight factors, and in each case the scree plots suggested four or five viable factors. A review of the analyses for each site suggested that four factors were most consistent and interpretable, with the remaining factors comprising single items, items that accounted for a low percentage of variance, or uninterpretable item combinations. In addition, the interitem correlations for the first four factors across all four sites were highly similar. We therefore combined the sample and ran an exploratory factor analysis, this time extracting four factors only. The pattern matrix for this analysis is presented in Table 2.

A review of item content of each factor suggested that the factors matched the critical content domains proposed earlier: factor 1 reflected EB, factor 2 encompassed PD, factor 3 indicated RD, and factor 4 reflected ID. To create a brief, concise scale and set of subscales with a relatively equal number of items, we reviewed items with good factor loadings and retained those items with relatively high loadings, that displayed unique content, or that accurately represented the factor's content domain. The result was a 17-item scale, with 5 EB items, 5 RD items, 4 PD items, and 3 ID items. The correlation between the original 28-item scale total and the new 17-item scale total

Table 2— *Rotated pattern matrix for the exploratory factor analysis of the 28 items*

	EB	PD	RD	ID
DDS1	**0.678**	0.005	0.028	−0.001
DDS5	0.562	−0.009	0.309	−0.105
DDS9	**0.804**	−0.044	−0.001	0.049
DDS13	0.744	−0.004	0.066	0.056
DDS17	**0.823**	0.012	0.044	−0.036
DDS21	**0.606**	−0.019	0.205	−0.004
DDS25	**0.772**	0.041	0.043	0.062
DDS2	−0.044	**0.798**	0.034	−0.078
DDS6	0.063	0.502	0.205	0.033
DDS10	−0.090	**0.801**	0.123	−0.031
DDS14	0.121	0.482	−0.041	0.253
DDS18	0.031	**0.842**	−0.042	−0.002
DDS22	0.091	0.755	−0.121	0.090
DDS26	−0.003	**0.833**	−0.010	−0.023
DDS3	−0.018	−0.045	0.750	0.029
DDS7	0.040	0.005	0.610	−0.028
DDS11	−0.038	−0.015	**0.581**	0.133
DDS15	0.178	−0.011	**0.714**	0.030
DDS19	0.292	0.088	**0.556**	0.007
DDS23	0.028	0.059	**0.829**	−0.046
DDS27	0.013	0.025	**0.744**	0.128
DDS4	0.158	0.068	0.146	0.401
DDS8	0.231	0.097	0.015	0.358
DDS12	0.320	0.110	0.074	0.202
DDS16	−0.084	−0.007	0.118	**0.816**
DDS20	0.508	0.045	−0.128	0.257
DDS24	0.213	0.079	0.014	**0.603**
DDS28	0.043	−0.067	0.014	**0.877**

Items are listed in the APPENDIX. Note that all items selected for the final 17-item scale are in bold.

was very high ($r = 0.99$), indicating that the 17-item version captured most of the variance reflected in the 28-item version but with 40% fewer items.

The mean correlation between the subscales and the 17-item total score was 0.82. The subscales that most highly correlated with the scale total were EB and RD (for both, $r = 0.88$), whereas ID ($r = 0.76$) and PD ($r = 0.67$) were less strongly associated. The strongest links were between EB and RD ($r = 0.69$), EB and ID ($r = 0.61$), and RD and ID ($r = 0.57$). In contrast, the least highly correlated associations were between PD and the other three—EB ($r = 0.44$), RD ($r = 0.45$), and ID ($r = 0.42$). In total, these correlations (in all cases, $P < 0.001$) suggested that the subscales reflected both unique and shared variance: the DDS subscales were not totally independent, but, at the same time, they tapped into relatively different areas of diabetes-related distress.

Internal consistency

Cronbach's α was computed for the total 17-item scale and for each subscale for each site. Because the results varied little among the sites, the α values for the combined sample are presented: 17-item scale total = 0.93; EB = 0.88, PD = 0.88, RD = 0.90, and ID = 0.88. These α values are adequate, especially given the number of items per scale.

Validity

Pearson correlation coefficients (or, where appropriate, χ^2 values) were computed between the scale total, each of the four subscales, and the CESD, disease management, and metabolic variables for each site. Similar results occurred across all four sites, so the sample was again combined and the analyses were completed for the sample as a whole (Table 3).

The DDS scale total was not significantly related to patient sex, ethnicity, educational level, or diabetes duration. Age was negatively correlated with the total score ($r = −0.29$), indicating that younger subjects reported more diabetes-related distress than older subjects. Regimen type was associated with different levels of distress. Insulin users reported the highest DDS total scores (36.9 ± 17.1) followed by those taking oral hypoglycemic agents only (35.2 ± 16.2) and, finally, those whose disease was controlled by diet (26.7 ± 12.1). DDS total scores were positively associated with depressive symptomatology (CESD; $r = 0.56$), poorer adherence to meal planning recommendations ($r = 0.30$), and lower levels of exercise ($r = 0.13$). The DDS total was unrelated to glycemic control ($r = 0.01$) but was positively associated with total cholesterol ($r = 0.20$). In sum, elevated DDS total scores were associated with being younger and more depressed, using insulin, poorer self-care, and having elevated lipid levels.

None of the subscales were significantly related to patient sex, ethnicity, educational level, or diabetes duration. The EB and RD subscales were linked to poorer adherence to meal planning ($r = 0.21$ and $r = 43$, respectively) and less exercise ($r = 0.12$ and $r = 0.16$, respectively). Only RD was related to less frequent SMBG ($r = 0.19$). All four subscales were positively associated with depressive affect (in all cases, $r > 0.33$). Subscale scores were mostly unrelated to HbA_{1c} but were consistently and positively linked to total cholesterol (for EB, RD and ID, $r > 0.16$).

CONCLUSIONS — We have developed a new instrument to assess diabetes-related emotional distress and provided data regarding its factor structure, internal consistency, and validity. These data indicate that the DDS has a consistent, generalizable factor structure and good internal reliability and validity across four different clinical sites. In contrast to previous measures, the DDS is more conceptually driven, drawing items from four preestablished domains of diabetes-related distress: EB, PD, RD, and ID. Our findings of a stable factor structure matching these four domains is consistent with recent results from Snoek et al. (8), who found a relatively similar factor structure in the PAID, labeling those factors as "negative emotions," "treatment problems," "food-related problems," and "lack of social support."

The DDS has certain potential advantages over previous instruments. It is

Table 3—*Zero-order correlations between the DDS and items of interest*

DDS	Total	EB	PD	RD	ID
Age	−0.29*	−0.31*	−0.07	−0.29*	−0.20*
Years of education	0.04	0.05	0.02	0.05	−0.02
Diabetes duration	−0.02	−0.02	0.01	−0.05	0.00
CESD	0.56*	0.55*	0.34*	0.42*	0.48*
Self-care					
Meal planning	0.30*	0.21*	0.07	0.43*	0.17*
Exercise	0.13†	0.12†	0.05	0.16*	−0.07
SMBG	0.08	+0.00	0.00	0.19*	0.04
HbA_{1c}	0.01	0.02	−0.11†	0.08	0.01
Total cholesterol	0.20*	0.17†	0.03	0.20*	0.22*

*$P < 0.001$; †$P < 0.01$.

shorter, and the new subscales allow for direct comparison of four different types of distress. This may be especially useful when the instrument is used for planning clinical interventions. The DDS also appears applicable to patients from both sexes and from at least several major ethnic groups. We believe that the items are clearer than in previous instruments, allowing for less patient confusion. Indeed, the DDS has a Flesch-Kincaid grade level of 7.3, suggesting that it should be comprehensible to a majority of patients.

There are, however, a number of limitations to this study. First, the number of patients from each ethnic group was too small to permit separate factor analyses. Although the factor structure was relatively stable across sites, it will be important to verify these findings within diverse patient populations. Second, along the same lines, the samples of type 1 and type 2 diabetic patients also were too small to permit separate analyses. Third, longitudinal data are not yet available, so little can be said about the DDS's test-retest reliability or about the instrument's ability to detect change over time as a function of a clinical intervention. Finally, the measures of validity were relatively limited; this is not surprising, since none of the four studies were specifically designed to evaluate the DDS.

The DDS is a stable, internally consistent, conceptually driven measure of diabetes-related distress for use in research and clinical practice. Brief and easy to administer, it may serve as a valuable tool in identifying patients experiencing high levels of distress linked to their diabetes and pinpointing their specific concerns. All 28 of the preliminary items are listed in the APPENDIX; the final 17 items comprising the DDS are in bold.

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APPENDIX

The 28 preliminary items developed for the DDS (the final 17 items comprising the DDS are in bold)

1) **Feeling that diabetes is taking up too much of my mental and physical energy every day.**

2) **Feeling that my doctor doesn't know enough about diabetes and diabetes care.**

3) Feeling that I can't control my eating.

4) Feeling that there is no one in my life with whom I can talk really openly about my feelings about diabetes.

5) Worrying about the future and the possibility that I could develop serious long-term complications.

6) Feeling that I don't see my doctor often or long enough.

7) Feeling that I am not getting enough physical exercise.

8) Feeling that I have to hide my diabetes from others.

9) **Feeling angry, scared, and/or depressed when I think about living with diabetes.**

10) **Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.**

11) **Feeling that I am not testing my blood sugars frequently enough.**

12) Feeling that friends or family act like "diabetes police" (e.g., nag about eating properly, testing blood sugars, not trying hard enough).

13) Feeling "burned out" by the constant effort to manage diabetes.

14) Feeling that I can't tell my doctor what is really on my mind.

15) **Feeling that I am often failing with my diabetes regimen.**

16) **Feeling that friends or family are not supportive enough of my self-care efforts (e.g., planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).**

17) **Feeling that diabetes controls my life.**

18) **Feeling that my doctor doesn't take my concerns seriously enough.**

19) **Not feeling confident in my day-to-day ability to manage diabetes.**

20) Worrying that diabetes limits my social relationships and friendships.

21) **Feeling that I will end up with serious long-term complications, no matter what I do.**

22) Feeling that my doctor doesn't really understand what its like to have diabetes.

23) **Feeling that I am not sticking closely enough to a good meal plan.**

24) **Feeling that friends or family don't appreciate how difficult living with diabetes can be.**

25) **Feeling overwhelmed by the demands of living with diabetes.**

26) **Feeling that I don't have a doctor who I can see regularly about my diabetes.**

27) **Not feeling motivated to keep up my diabetes self-management.**

28) **Feeling that friends or family don't give me the emotional support that I would like.**

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