Development of a Brief Diabetes Distress Screening Instrument

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ABSTRACT

PURPOSE Previous research has documented that diabetes distress, defined as patient concerns about disease management, support, emotional burden, and access to care, is an important condition distinct from depression. We wanted to develop a brief diabetes distress screen instrument for use in clinical settings.

METHODS We assessed 496 community-based patients with type 2 diabetes on the previously validated, 17-item Diabetes Distress Scale (DDS17) and 6 biobehavioral measures: glycated hemoglobin (HbA_{1c}); non–high-density-lipoprotein (non-HDL) cholesterol; kilocalories, percentage of calories from fat, and number of fruit and vegetable servings consumed per day; and physical activity as measured by the International Physical Activity Questionnaire.

RESULTS An average item score of ≥3 (moderate distress) discriminated high- from low-distressed subgroups. The 4 DDS17 items with the highest correlations with the DDS17 total (r = .56-.61) were selected. Composites, comprised of 2, 3, and 4 of these items (DDS2, DDS3, DDS4), yielded higher correlations (r = .69-.71). The sensitivity and specificity of the composites were .95 and .85, .93 and .87, and .97 and .86, respectively. The DDS3 had a lower sensitivity and higher percentages of false-negative and false-positive results. All 3 composites significantly discriminated subgroups on HbA_{1c}, non-HDL cholesterol, and kilocalories consumed per day; none discriminated subgroups on fruit and vegetable servings consumed per day; and only the DDS3 yielded significant results on the International Physical Activity Questionnaire. Because of its psychometric properties and brevity, the DDS2 was selected as a screening instrument.

CONCLUSIONS The DDS2 is a 2-item diabetes distress screening instrument asking respondents to rate on a 6-point scale the degree to which the following items caused distress: (1) feeling overwhelmed by the demands of living with diabetes, and (2) feeling that I am often failing with my diabetes regimen. The DDS17 can be administered to those who have positive findings on the DDS2 to define the content of distress and to direct intervention.

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INTRODUCTION

The high prevalence of depressive symptoms among patients with diabetes—between 18% and 35%—has been well-documented in several studies.[1] Compared with patients with diabetes alone, patients with diabetes and comorbid depression display higher functional impairment and work loss[2] and poorer self-management behavior,[3] and they have more comorbidities.[4] Recent findings, however, have suggested that high levels of diabetes-specific distress, not depression, may account for many of the reported findings.[5] For example, we previously assessed major depressive disorder[6] by a standardized clinical interview,[7] depressive affect by a written questionnaire (Center for Epidemiological Studies; Depression, CES-D),[8] and diabetes-specific distress by a questionnaire (Diabetes Distress Scale, DDS[9]) in a sample of 506 patients with type 2 diabetes. We found that more than 70% of those patients who scored

above the cut-point for depressive affect on the CES-D were not clinically depressed (did not have major depressive disorder).

In equations that included scores for major depressive disorder, depressive affect, and diabetes distress, we also found previously that diabetes distress was more strongly and independently related to behavioral and clinical measures of diabetes management than was depression. We argued that major depressive disorder was related to but distinct from diabetes distress, and that many patients with high levels of depressive affect were really experiencing diabetes distress, not depression. We raised concern that although major depressive disorder remains a prevalent condition among these patients, most patients with diabetes are not clinically depressed; they are, instead, distressed about their diabetes and its management.

Although many clinicians now regularly screen for depression among their patients with diabetes, there is as yet no time-efficient tool for use in the clinical setting that can be used to screen patients for disease-related distress and, if screening criteria are met, to identify stressful areas of diabetes management for intervention. Ideally, such a clinically useful instrument would be brief, easy to score, and lead directly to intervention. The DDS was developed to address these needs. The 17-item questionnaire was developed in previous studies with 4 separate samples totaling 683 patients with diabetes.[9] The original scale statistics and factor analyses were replicated with another ethnically diverse sample of 498 patients with diabetes.[10] With all samples, the scale yielded 4 reliable subscales that targeted different areas of potential diabetes-specific distress to help clinicians and patients identify areas where interventions might be helpful: emotional burden (feeling overwhelmed by diabetes), physician-related distress (worries about access, trust, and care), regimen-related distress (concerns about diet, physical activity, medications), and interpersonal distress (not receiving understanding and appropriate support from others). In this article we report the development of a diabetes distress screening instrument, derived from the previously reported 17-item scale, for use in clinical settings.

METHODS

Sample

As part of a new study of diabetes and depression, patients with type 2 diabetes were recruited from several community-based medical groups and diabetes education centers in the San Francisco Bay Area. Using computerized registries for identification, patients were eligible if they were aged between 21 and 75 years, could speak and read English or Spanish fluently, had no diagnosis of dementia or psychosis, and had no severe diabetes complications (eg, on dialysis). Patients were recruited by letter and telephone, recruitment and primary assessment (interviews, questionnaires, weight, height) occurred either in the home or project office, and blood and urine specimens were collected at a community laboratory.[6] The project received institutional review board approval from the University of California, San Francisco, and from each collaborating institution.

Measures

As described above, the DDS[9] is a 17-item measure (DDS17) that uses a Likert scale with each item scored from 1 (no distress) to 6 (serious distress) concerning distress experienced over the last month (Appendix 1). Internal consistency was assessed by coefficient α (.93 for the total scale, and .88 to .90 for the 4 subscales). A mean item score of ≥3 (moderate distress) was used to distinguish high from low distress for each item, for the mean of the 17 items (DDS17), and for selected composites of potential screening items. The mean item score of each selected composite was compared to the mean item score of the DDS17, which was the primary criterion variable.

Selected composites and the 17-item scale were also compared with 6 biobehavioral measures. We reasoned that high levels of diabetes distress, measured by the composites and the DDS17, should operate similarly with respect to important diabetes variables, thus heightening our confidence in the use of the screener. The biological measures included HbA_{1c} and non-HDL cholesterol. Three measures of dietary intake during the last year, derived from the Block 2000 Brief Food Frequency Questionnaire (Block Dietary Data Systems, Berkeley, California),[11] also were used: average kilocalories, average calories of saturated fat as a percentage of total calories, and average number of fruit and vegetable servings consumed per day. The International Physical Activity Questionnaire[12] was included to measure physical activity. It reflects the number of minutes of activity in the last week at each of 3 levels of activity, each weighted by a measure of energy expenditure with multiples of resting metabolic rate for a 60-kg person (light = 3.3, moderate = 4.0, vigorous = 8.0).

Analyses

Our data analysis strategy was to identify subsets of 2, 3, and 4 scale items from the DDS17 that most accurately distinguished high- from low-distress patients using the full DDS17 mean item score as the criterion, and that had a range of distressed responses of at least 25% (≥3). Phi coefficients were used to correlate each scale item (≥3 vs <3) with the total DDS17 score (mean

item score ≥3 vs <3). The 4 items with the highest correlations with the DDS17 were combined into composites of 2, 3, and 4 items (DDS2, DDS3, DDS4), from highest to lowest. We decided on a maximum of 4 items so that the number of potential screening items did not exceed 25% of the number of items in the total scale. Cross-tabulations between each of the DDS2, DDS3, and DDS4 screening scales compared with the DDS17 indicated the number of patients correctly screened by each composite, the number of false-positive results, and the number of false-negative results. We then compared high vs low distress based on each DDS composite and the DDS17 with each of the 6 comparison measures to determine how similar the results from the analyses with the composites were in comparison with the results generated by the DDS17 (Student's *t* tests).

Table 1. Description of Sample (N = 496)

Characteristic	No. (%)	Mean (SD)	Median
Male	213 (43)	–	–
Female	283 (57)	–	–
Age, years	–	57.83 (9.86)	58.00
Family income (in $1,000)	–	52.00 (36.00)	45.50
Education, years	–	14.57 (3.33)	14.00
Number of comorbidities	–	3.80 (2.50)	4.00
Body mass index	–	32.73 (7.74)	31.70
Years with diabetes	–	8.10 (7.50)	6.00
HbA_{1C}, %	–	7.2 (1.44)	7.0
Non-HDL cholesterol, mg/dL	–	138.42 (47.52)	147.52
Ethnicity		–	–
African American	102 (20.50)	–	–
Hispanic	96 (19.30)	–	–
Asian American	83 (16.80)	–	–
Non-Hispanic white	182 (36.70)	–	–
Other	33 (6.70)	–	–

HDL = high-density lipoprotein.

RESULTS

Of the 640 eligible patients identified during screening, 506 participated (79.0%), and complete data for this report were available on 496 patients. No differences were found between those who completed data collection and those who initially refused or dropped out on age, sex, ethnicity, education, years with diabetes, and number of comorbidities. The ethnically diverse sample included a broad range of patients with diabetes found in community settings (Table 1): mean diabetes duration was 8.10 years, mean age was 57.83 years, mean glycated hemoglobin (HbA_{1c}) was 7.2%.

The 4 items that met the criteria described above are shown in Table 2, along with the correlations between each of the 3 derived DDS composites and the total DDS17 (corrected item-total correlations identified the same items in the same high to low order). Mixing the 4 items in different combinations of 2 or 3 items to create different composites did not increase the association with the DDS17, nor did these combinations yield improvements in any subsequent analyses. Furthermore, increasing the number of items in the composites from 2 to 4 did not increase the correlation with the DDS17 substantively.

Table 3 shows the cross-tabulations between each of the individual 4 items and the DDS2, DDS3, and DDS4, relative to the total DDS17. Cross-tabulations that included item-corrected DDS17 scores yielded similar results. Our strategy was to select an item combination with a large percentage of correctly screened patients (sensitivity/specificity) and a low percentage of

Table 2. Item and Composite Scale Correlations with DDS17

Scale Item or Scale Total	Correlation With DDS17[a]
1. Feeling overwhelmed with the demands of living with diabetes. (EB)[b]	.61
2. Feeling that I am often failing with my diabetes routine. (RD)[b]	.60
3. Not feeling motivated to keep up my diabetes self-management. (RD)[b]	.59
4. Feeling angry, scared, and/or depressed when I think about living with diabetes. (EB)[b]	.56
DDS2: above items 1 and 2	.69
DDS3: above items 1, 2, and 3	.69
DDS4: above items 1, 2, 3, and 4	.71

DDS = Diabetes Distress Scale; EB = emotion burden; RB = regimen distress.

Note: All correlations based on N = 496, $P > .001$.

[a] Correlations are φ coefficients.

[b] From EB and RD subscales.

Table 3. Cross-tabulated Results for Each Diabetes Distress Scale (DDS) Item or Composite Score With the DDS17 Criterion

Item and Scale	Correctly Screened (%)	False Positive (%)	False Negative (%)
Item 1	86.7	15.4	13.3
Item 2	92.7	23.6	3.3
Item 3	90.0	18.4	10.0
Item 4	83.3	17.3	16.7
DDS2 (items 1, 2)	96.7	15.1	3.3
DDS3 (items 1, 2, 3)	93.3	13.5	6.7
DDS4 (items 1, 2, 3, 4)	96.7	13.7	3.3

false-negative results relative to the DDS17. A relatively high number of false-positive results was of less importance, given that a false-positive screening result would require only the administration of the full 17-item scale, which would add relatively little burden to patients and clinicians. Table 3 shows that the DDS2 and DDS4 had the highest level of accuracy (96.7%), a similar percentage of false-negative results (3.3%), and very little difference in the percentage of false-positive results (DDS2 = 15.1%; DDS4 = 13.7%; Δ = 1.4%). The DDS3 did not perform as well as the DDS2 or DDS4. The sensitivity/specificity of the DDS2, DDS3, and DDS4 was .95/.85, .93/.87, and .97/.86, respectively, indicating that all 4 composites were able to classify patients accurately, relative to the DDS17 (respective positive predictive value and negative predictive value: DDS2 = 58.4% and 99.2%, DDS3 = 74.3% and 98.3%, DDS4 = 60.8% and 99.2%). α Coefficients for the DDS2, DDS3 and DDS4 were .73, .83, and .86, respectively.

Table 4 displays the comparisons between high- and low-distressed groups using the DDS17, DDS2, DDS3, and DDS4, across all 6 biobehavioral measures. Mean differences for all 3 composites were relatively similar to the findings for the DDS17, suggesting that the screening composites were associated with diabetes-related biobehavioral variables in ways similar to the DDS17, the criterion score. For all analyses (composites and criterion), those reporting high compared with low distress had higher HbA_{1c} measurements; higher non-HDL cholesterol levels; more kilocalories, more saturated fat, fewer servings of fruit and vegetables per day; and lower physical activity. High vs low distress on the DDS17 was significantly related to HbA_{1c} levels, non-HDL cholesterol levels, kilocalories per day, fruit and vegetable servings per day, and physical activity. Percentage of calories from saturated fat was the only measure that did not reach statistical significance. High vs low distress, as measured on the DDS2 and DDS4, yielded significant findings on 4 of the 6 diabetes management measures and 5 of the 6 reached significance for the DDS3. We repeated all analyses separately by patient sex, education, years with diabetes, and ethnicity (white vs nonwhite) with little difference in findings.

DISCUSSION

To develop a viable screening instrument to identify patients with high diabetes-specific distress, we selected DDS17 items with the highest relationship to the total scale score, and then constructed composites of 2, 3, and 4 items for evaluation. We compared the items and the composites to the total DDS17 score criterion (and item-corrected score criterion) in terms of accuracy, the number of false-positive results, and the number of false-negative results, and then compared high- with low-distressed groups defined by each composite and the DDS17 with 6 diabetes management measures.

The raw (and item-corrected) correlations between each of the 4 items and the DDS17 ranged from .56 to .61, whereas the correlations between the scale composites and the DDS17 ranged from .69 to .71, indicating that a composite score of 2 to 4 items performed

Table 4. Comparisons Between High- and Low-Distressed Patients on 6 Biobehavioral Measures

DDS Scale	HbA_{1c}	Non-HDL Cholesterol	Kilocalories	Saturated Fat %	Number of Fruit, Vegetable Servings	IPAQ (Physical Activity)
DDS17						
High	7.65 (1.49)	146.96 (49.73)	1815.96 (1211.48)	0.12 (0.03)	6.28 (5.11)	1914.87 (2386.94)
Low	7.17 (1.42)	136.34 (46.02)	1277.65 (641.83)	0.12 (0.04)	5.21 (3.41)	2540.63 (2751.22)
t(p)[a]	2.84 (0.005)	1.94 (0.05)	5.97 (0.00)	1.12 (0.26)	2.44 (0.02)	1.98 (0.05)
DDS2						
High	7.74 (1.61)	144.45 (51.70)	1629.30 (1065.87)	0.13 (0.03)	5.61 (4.59)	2229.64 (2777.99)
Low	7.05 (1.32)	135.74 (44.44)	1263.24 (627.33)	0.12 (0.04)	5.31 (3.40)	2510.38 (2666.78)
t(p)[a]	5.00 (0.00)	1.90 (0.05)	4.78 (0.00)	2.08 (0.04)	0.81 (0.42)	1.06 (0.29)
DDS3						
High	7.66 (1.46)	145.50 (53.17)	1688.38 (1065.51)	0.13 (0.03)	5.80 (4.76)	1967.59 (2317.29)
Low	7.10 (1.42)	135.62 (44.03)	1253.15 (631.88)	0.11 (0.04)	5.26 (3.34)	2603.36 (2823.23)
t(p)[a]	3.86 (0.00)	2.11 (0.04)	5.61 (0.00)	2.31 (0.02)	1.42 (0.16)	2.35 (0.02)
DDS4						
High	7.61 (1.51)	145.16 (50.04)	1693.82 (1077.53)	0.13 (0.03)	5.82 (4.69)	2085.87 (2668.92)
Low	7.12 (1.40)	135.65 (45.38)	1246.06 (613.61)	0.12 (0.04)	5.25 (3.36)	2563.21 (2711.00)
t(p)[a]	3.50 (0.001)	2.05 (0.04)	5.83 (0.00)	2.76 (0.006)	1.54 (0.13)	1.77 (0.08)

DDS = Diabetes Distress Scale; HbA_{1c} = glycated hemoglobin; HDL = high-density lipoprotein; IPAQ = International Physical Activity Questionnaire.

[a] Student's t test (probability).

better than any single item. It is interesting to note that all 4 of the most highly correlated items came from the emotional burden and regimen distress subscales of the DDS17. Although not reported above, we ran additional analyses that included the highest correlated items from the interpersonal and physician distress subscales, but their inclusion did not substantively increase the correlation with the DDS17 criterion or improve the results of any subsequent analysis. Thus, items from the emotional burden and regimen distress subscales appear to capture most, but not necessarily all, of the distress assessed by the DDS17. Although the scale composites did not include item content from all 4 DDS17 subscales, the composites each have significant associations with the total DDS17 scale total, which was the primary objective of the study.

Measures of sensitivity and specificity were relatively similar for the DDS2, DDS3, and DDS4. Of the 3 composites, however, the cross-tabulations indicated that the DDS3 displayed the lowest percentage of accuracy and the highest percentage of false-negative results. The DDS2 and DDS4 displayed the highest level of accuracy (96.7%) and the same percentage of false-positive results (3.3%), but the DDS4 had a 1.4% lower rate of false-positive results than the DDS2. Similar results across composites were found in the comparisons with the biobehavioral measures for the DDS2 and DDS4.

When comparing the DDS4 with the DDS2 as a potential screening tool, the addition of 2 items to the DDS2 to achieve a relatively small improvement in the false-positive rate may not be worth the added time and complexity. We therefore suggest that the DDS2 (Appendix 2) be used as an initial screening instrument to assess diabetes-specific distress, to be followed by the administration of the complete 17-item scale for those patients whose average of the 2 screening items is ≥3, or whose sum is ≥6. The use of the full DDS17 after a positive screening test can then provide the clinician with indicators of the content of the patient's distress across all 4 of the DDS17 factors, which can direct subsequent intervention. Furthermore, skimming through the patient's responses to each of the 17 individual items scored ≥3 can be used to begin a conversation with the patient during the clinical encounter about specific sources or areas of distress. This process saves time and focuses the interaction on areas of major patient concern, thus allowing the clinician and patient to develop a focused plan that addresses specific needs. We provide both English and Spanish versions of the DDS17 and DDS2, along with instructions for use in the Supplemental Appendix, available online-only at http://www.annfammed.org/cgi/content/full/6/3/246/DC1.

We do not view the use of the DDS2 and DDS17 as a substitute for depression screening. The prevalence of both diabetes-specific distress and major depressive disorder is high among patients with diabetes, and both conditions warrant careful, regular assessment. To date, however, we know of no study that compares distress and depression screening in the same sample of patients with diabetes. Given previous findings,[5,6] however, we suspect that 3 groups will emerge: a large group with diabetes distress alone, a relatively small group with major depressive disorder alone, and a much smaller group with both conditions. We urge careful assessment of these groups because there is good documentation that interventions that address one condition do not necessarily address the other, eg, interventions that effectively treat major depressive disorder do not also improve diabetes behavioral and biological outcomes,[13,14] and interventions that treat diabetes management do not necessarily reduce major depressive disorder.[15] Interventions are needed for each separately.

Diabetes-specific distress is a common condition that often includes high levels of negative affect. It is linked to poor biobehavioral disease management, and it can be easily confused with major depressive disorder or minor depression, which we suspect are distinct conditions. The DDS2 is an easily scored screening instrument to detect diabetes-specific distress. Future research should determine whether similar distress constructs apply to other chronic conditions.

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Appendix 1. Diabetes Distress Scale, English (DDS17)

Directions Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 17 potential problems that people with diabetes may experience. Consider the degree to which each of the items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1." If it is very bothersome to you, you might circle "6."

Problems	Not a Problem		Moderate Problem		Serious Problem		Office Use Only
1. Feeling that diabetes is taking up too much of my mental and physical energy every day.	1	2	3	4	5	6	[A]
2. Feeling that my doctor doesn't know enough about diabetes and diabetes care.	1	2	3	4	5	6	[B]
3. Feeling angry, scared and/or depressed when I think about living with diabetes.	1	2	3	4	5	6	[A]
4. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes.	1	2	3	4	5	6	[B]
5. Feeling that I am not testing my blood sugars frequently enough.	1	2	3	4	5	6	[C]
6. Feeling that I am often failing with my diabetes regimen.	1	2	3	4	5	6	[C]
7. Feeling that friends or family are not supportive enough of my self-care efforts (eg planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods).	1	2	3	4	5	6	[D]
8. Feeling that diabetes controls my life.	1	2	3	4	5	6	[A]
9. Feeling that my doctor doesn't take my concerns seriously enough.	1	2	3	4	5	6	[B]
10. Not feeling confident in my day-to-day ability to manage diabetes.	1	2	3	4	5	6	[C]
11. Feeling that I will end up with serious long-term complications, no matter what I do.	1	2	3	4	5	6	[A]
12. Feeling that I am not sticking closely enough to a good meal plan.	1	2	3	4	5	6	[C]
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be.	1	2	3	4	5	6	[D]
14. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6	[A]
15. Feeling that I don't have a doctor who I can see regularly about my diabetes.	1	2	3	4	5	6	[B]
16. Not feeling motivated to keep up my diabetes self-management.	1	2	3	4	5	6	[C]
17. Feeling that friends or family don't give me the emotional support that I would like.	1	2	3	4	5	6	[D]

Appendix 2. The 2-Item Diabetes Distress Screening Scale (DDS2)

Directions Living with diabetes can sometimes be tough. There may be many problems and hassles concerning diabetes and they can vary greatly in severity. Problems may range from minor hassles to major life difficulties. Listed below are 2 potential problem areas that people with diabetes may experience. Consider the degree to which each of the 2 items may have distressed or bothered you DURING THE PAST MONTH and circle the appropriate number.

Please note that we are asking you to indicate the degree to which each item may be bothering you in your life, NOT whether the item is merely true for you. If you feel that a particular item is not a bother or a problem for you, you would circle "1." If it is very bothersome to you, you might circle "6."

Feeling	Not a Problem		Moderate Problem		Serious Problem	
1. Feeling overwhelmed by the demands of living with diabetes.	1	2	3	4	5	6
2. Feeling that I am often failing with my diabetes regimen.	1	2	3	4	5	6