Is It Distress, Depression, or Both? Exploring Differences in the Diabetes Distress Scale and the Patient Health Questionnaire in a Diabetes Specialty Clinic

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■ **IN BRIEF** Patients (n = 314) completed the Patient Health Questionnaire and the Diabetes Distress Scale as part of standard care. Although most patients (70.4%) had no symptoms of depression or diabetes-related distress, 23.9% scored high on the distress questionnaire in at least one of its four domains. Regular screening for distress related to the demands of living with diabetes is crucial in identifying and preventing poor health outcomes associated with diabetes-related distress.

More than 30 million people in the United States have diabetes (1), a chronic medical condition with unique self-management challenges. For people with diabetes, numerous daily self-care management activities are required to maintain healthy glycemic control, including recommended fasting blood glucose and A1C levels (2). The need for a healthy diet, regular physical activity, self-monitoring of blood glucose, and daily medications has crucial implications for individuals' health and is a constant reminder of the chronicity of the disease.

The presence of diabetes doubles the odds of co-occurring depression (3,4). Recent conservative estimates indicate that comorbid depression affects 8.7% of people with diabetes (5). The prevalence of subclinical depression could be higher and has been estimated at 18.9% (6). The unadjusted rate of depression in people with diabetes may vary according to their type of diabetes and medication regimen. Li et al. (7) reported rates of 20.4% for those with type 1 diabetes, 24.0% for those with type 2 diabetes who are on insulin therapy, and 17.3% for those with type 2 diabetes who are not using insulin.

Depression can have a significant negative impact on functioning and disease course for people with diabetes. More than a decade ago, a large meta-analysis established that poor glycemic management is linked with depression (8). Depression has been consistently significantly associated with a variety of diabetes complications (e.g., macrovascular complications, retinopathy, nephropathy, neuropathy, and sexual dysfunction [9]). A more recent meta-analysis (10) identified a significant association between depression and treatment nonadherence as a possible pathway to worse clinical outcomes for individuals with depression and diabetes.

Although depression is prevalent among people with diabetes, diabetes-related distress is even more common and has potentially greater implications for the course of the disease (11–13). Diabetes-related distress may be conceptualized as a person's concerns about self-care, support, emotional burden, and quality of health care (11,14). Diabetes-related distress is understandable given that living with diabetes involves a "complex, demanding, and often confusing set of self-care directives" with

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which "patients may become frustrated, angry, overwhelmed, and/or discouraged" (14).

Most patients with diabetes identified psychological/support challenges as the primary barrier to optimal care (15), and psychosocial barriers are consistently related to poor diabetes self-management and low self-efficacy (16). The second Diabetes Attitudes, Wishes and Needs (DAWN2) study reported depression in ~13% of its international 8,596-person sample, and diabetes-related distress was found in 44.6% of these patients (4).

Diabetes distress is associated with poor glycemic management and other negative health outcomes (10,17). In cross-sectional and longitudinal analyses, Fisher et al. (12) found that diabetes-related distress, but not depression, was significantly related to poorer A1C. Another cross-sectional study also reported that diabetes-specific emotional distress was related to A1C, but that A1C was not associated with depression, anxiety, or overall well-being (13). Additionally, lower diabetes-related distress is significantly related to self-efficacy and physician support (18).

The clinical picture of diabetes-related distress and co-occurring depression is murky (19). Diabetes-related distress is distinct from depression. Recent outcome studies have reported distress to be not only more common than depression, but also more salient and crucial to address (12,13). Additionally, assessing depression has challenges in this population because depressive symptoms can also mimic symptoms of poorly managed diabetes (e.g., weight loss, fatigue, sleep disturbances, and difficulty concentrating) (3,20).

Universal screening for depression in primary care and other medical settings typically relies on the nine-item Patient Health Questionnaire (PHQ-9), developed to assist health care providers in assessing depression in adult patients (21). The PHQ-9 includes questions about symptoms of major depressive disorder over the previous 2 weeks and is easily administered and scored. It has been validated for use in patients with diabetes (22). However, based on the review mentioned above (9), screening only for depression in the diabetes population may be inadequate. Hermanns et al. (6) recommend using a diabetes-related distress scale to better assess emotional challenges in this population.

Assessing diabetes distress can be accomplished with the 17-question Diabetes Distress Scale (DDS-17) (14). As shown in Table 1, this scale consists of four sub-scales for Emotional Burden (EB),

TABLE 1. The DDS-17

Emotional Burden (EB)

1. Feeling that diabetes is taking up too much of my mental and physical energy every day
2. Feeling angry, scared, and/or depressed when I think about living with diabetes
3. Feeling that diabetes controls my life
4. Feeling that I will end up with serious long-term complications, no matter what I do
5. Feeling overwhelmed by the demands of living with diabetes

Physician-Related Distress (PD)

1. Feeling that my doctor doesn't know enough about diabetes and diabetes care
2. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes
3. Feeling that my doctor doesn't take my concerns seriously enough
4. Feeling that I don't have a doctor who I can see regularly enough about my diabetes

Regimen-Related Distress (RD)

1. Feeling that I am not testing my blood sugars frequently enough
2. Feeling that I am often failing with my diabetes
3. Not feeling confident in my day-to-day ability to manage diabetes
4. Feeling that I am not sticking closely enough to a good meal plan
5. Not feeling motivated to keep up my diabetes self-management

Interpersonal Distress (ID)

1. Feeling that friends or family are not supportive enough of self-care efforts (e.g., planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods)
2. Feeling that friends or family don't appreciate how difficult living with diabetes can be
3. Feeling that friends or family don't give me the emotional support that I would like

Responses options are based on a 6-point Likert scale in which 1 = not a problem, 2 = a slight problem, 3 = a moderate problem, 4 = a somewhat serious problem, 5 = a serious problem, and 6 = a very serious problem.

Physician-Related Distress (PD), Regimen-Related Distress (RD), and Interpersonal Distress (ID) (14). Higher DDS-17 scores were found in women and younger patients (18,23–25). More specifically, significantly higher RD and ID scores were found in women (26) than for men. However, despite the utility of the DDS-17, it has not been widely adopted in primary care or specialty settings.

Objective

Administering both the PHQ-9 and the DDS-17 could prove burdensome for patients and clinical staff alike, particularly in busy primary care clinics. Therefore, we aimed to identify which measure proved more sensitive in identifying the emotional concerns of patients in a diabetes specialty clinic. We hypothesized that, in a heterogeneous sample of patients with diabetes, more patients would report clinical levels of diabetes-related distress via the DDS-17 than significant levels of depression symptoms on the PHQ-9.

Design

The Wilford Hall Ambulatory Surgical Center institutional review board approved this retrospective data analysis. Data were collected at the Air Force Diabetes Center of Excellence (DCOE) in San Antonio, Tex., which specializes in diabetes care for military service members, retirees, and their families. This clinic treats complex cases of diabetes, including patients with type 1 diabetes and patients with multiple comorbidities. A chart review of clinical encounters was conducted from visits that occurred from June 2015 through August 2016.

Patients were routinely administered the PHQ-9 and the DDS-17 as standard care. All patients included in the study were adult patients with diabetes receiving their health care at this clinic. As part of the initial patient visit and as needed for reassessment, patient responses to the PHQ-9 and the DDS-17 were recorded by a licensed vocational nurse. After input,

NoteWriter, a Microsoft Excel–based clinical note-writing platform created exclusively for use in the DCOE, calculated the total DDS-17 score and scores for each subscale. These scores were entered into patients' electronic health records.

Main Outcome Measures

Depression

The PHQ-9 was developed by Kroenke et al. (21) and includes nine questions about symptoms of major depressive disorder experienced over the previous 2 weeks. Responses indicate the frequency of experiencing the given symptom using a scale in which 0 = not at all, 1 = several days, 2 = more than half of the days, and 3 = nearly every day. A score ≥10 (of a possible 27) is considered screening positive for depression.

Diabetes-Related Distress

Fisher et al. (27) developed the DDS-17, a 17-item Likert-scale questionnaire with responses that include the degree to which a patient is bothered by different symptoms (e.g., feeling overwhelmed in life), as follows: 1 = not a problem, 2 = a slight problem, 3 = a moderate problem, 4 = a somewhat serious problem, 5 = a serious problem, and 6 = a very serious problem. There are three categories for DDS-17 scores: <2.0 = little or no distress, 2.0–2.9 = moderate diabetes-related distress, and ≥3 = high diabetes-related distress. As previously mentioned, in addition to the total DDS-17 score, there are four subscales: EB, PD, RD, and ID. This analysis particularly focused on patients with overall scores ≥3, indicating high diabetes-related distress.

Other Measures

In addition to PHQ-9 and DDS-17 scores, data collected included patient demographics (sex, age, ethnicity/ race, rank, and military status), vital signs (e.g., blood pressure and weight), and laboratory test results (i.e., a comprehensive metabolic panel, including A1C). Data were stored

on military computers that are protected by password and firewall.

Data analyses were conducted with SPSS version 22.0 (IBM Corp., Chicago, Ill.) statistical software. Univariate analysis was conducted to describe the patient population and analyze patterns of diabetes-related distress and depression in this population, including overall and by sex. In addition, bivariate correlations assisted in understanding the strength of the relationship between total and subscale DDS-17 scores and PHQ-9 scores. In addition, cross-tabulation was conducted to establish how many patients were experiencing diabetes-related distress, depression, neither, or both.

Results

A total of 314 patients completed both the DDS-17 and the PHQ-9 as part of standard care from June 2015 through August 2016.

Demographics

Table 2 summarizes characteristics of the sample. There were slightly more men than women, and the average age was ~57 years (range 19–87 years). Mean age at diagnosis of diabetes was older for men (42.84 years) than for women (36.59 years); thus, duration of diabetes was also longer for women. About 42% of the sample were white, and about one-third were Hispanic/ Latino.

The majority of military members (retired and active duty) were enlisted (i.e., non-officer; 86.8%) and male (92.2%). Concerning military status, most men were retired, and most women were dependent family members. About one-fourth of the patients were diagnosed with type 1 diabetes, and the majority of those were women (58.4%), whereas the majority of patients with type 2 diabetes were male (54.6%). Mean BMI was 32.31 kg/m², and mean A1C was ~8.0%; these characteristics were similar for both sexes.

TABLE 2. Sample Characteristics by Sex

	Overall (n = 314)	Female (n = 153, 48.7%)	Male (n = 161, 51.3%)
Mean age, years	56.82	56.59	57.03
Mean age at diagnosis, years	39.81	36.59	42.84
Mean duration of diabetes, years	17.19	20.24	14.28
Ethnicity/race			
White, n (%)	131 (41.7)	64 (42.1)	67 (41.6)
African American, n (%)	69 (22.0)	25 (16.4)	44 (27.3)
Hispanic/Latino, n (%)	92 (29.4)	49 (32.2)	43 (26.7)
Asian/Pacific Islander, n (%)	19 (6.1)	12 (7.9)	7 (4.3)
Military status			
Active duty, n (%)	10 (3.2)	2 (1.3)	8 (5.0)
Retired, n (%)	143 (45.5)	10 (6.5)	133 (83.6)
Family member, n (%)	159 (50.6)	141 (92.2)	18 (11.3)
Military rank (if military/retired)			
Junior enlisted, n (%)	58 9 (18.5)	5 (3.3)	53 (32.9)
Senior enlisted, n (%)	74 (23.6)	4 (2.6)	70 (43.5)
Officer, n (%)	20 (6.4)	4 (2.6)	16 (9.9)
Type of diabetes			
Type 1, n (%)	77 (24.5)	45 (29.4)	32 (19.9)
Type 2, n (%)	229 (72.9)	104 (68.0)	125 (77.6)
Other, n (%)	8 (2.5)	4 (2.6)	4 (2.5)
Mean BMI, kg/m^2	32.31	31.67	32.91
Mean A1C, %	8.04	8.03	8.06

Note: due to rounding and missing data, percentages may not total 100%.

Relationship Between DDS-17 and PHQ-9 Scores

Of the 314 patients who completed the DDS-17, 75 (23.9%) scored high in at least one domain. High total DDS-17 was found in 5.1% of the population (Figure 1). The highest diabetes-related distress subscale scores were found in EB (15.6%) and RD (14.6%). Women scored higher than men in each subscale of the DDS-17 and were twice as likely as men to score high in ID.

Thirty-seven patients (11.8%) screened positive for depression using the PHQ-9. However, about half (5.7%) were not experiencing high diabetes-related distress according to the DDS-17. There was no difference by sex in depression as measured by the PHQ-9, with 18 males and 19 females meeting the threshold.

Bivariate correlations revealed a significant association between PHQ-9 and total DDS-17 scores (0.264, P <0.01); as well as among DDS-17 subscales EB (0.291, P <0.01), RD (0.205, P <0.01), and ID (0.129, P <0.05). Further investigation of patients who screened positive for depression (n = 37) revealed that a higher percentage of these patients scored high for total DDS-17 (18.9%), EB (40.5%), RD (37.8%), and ID (18.9%) compared to those who did not screen positive for depression. Furthermore, those who had a high DDS-17 score in any domain were nearly double the number of those experiencing depressive symptoms (Figure 2).

No significant relationship was observed between A1C and screening positive for depression (0.043, P = 0.45). However, total DDS-17 (0.314, P <0.01), EB (0.251, P <0.01), and RD (0.344, P <0.01) were significantly associated with A1C.

Cross-tabulation analyses revealed that most patients (70.4%) did not screen positive for depression or have high scores in any DDS-17 domain (Figure 3). About one in five patients (17.8%) had high DDS-17 scores in at least one domain but did not screen positive for depression. Of the 11.8% of patients who screened positive for depression, 19 patients (51.4%) also had a high DDS-17 score in at least one of the domains; however, 18 patients (48.6%) did not have a high DDS-17 score in any domain. Thus, almost one in four patients (23.9%) had a high DDS-17 score in at least one domain.

Discussion

Our study found that more patients endorsed diabetes-related distress than depression. Our hypothesis was supported in that greater levels of clinical distress were detected via
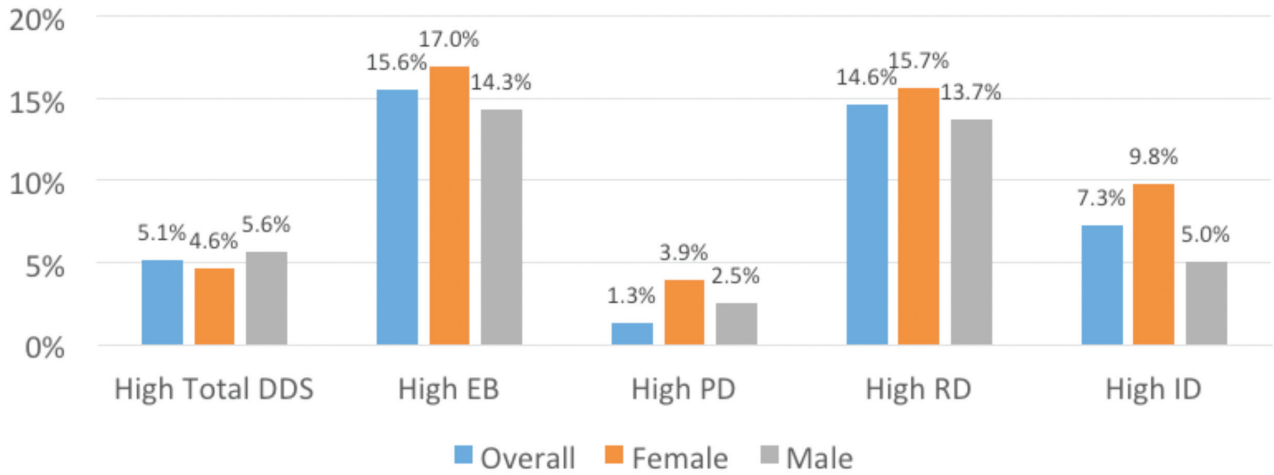
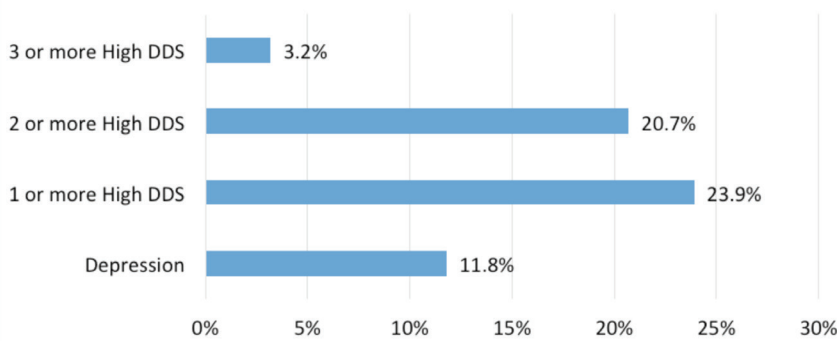**FIGURE 1**. Sex differences in elevated DDS-17 scores.

FIGURE 2. Comparison of depression and high scores in DDS-17 subscales.

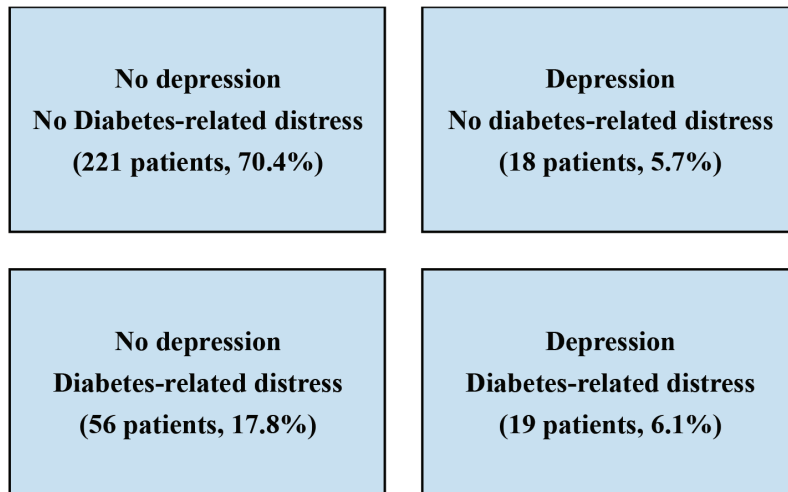| No depression No Diabetes-related distress (221 patients, 70.4%)	Depression No diabetes-related distress (18 patients, 5.7%)
No depression Diabetes-related distress (56 patients, 17.8%)	Depression Diabetes-related distress (19 patients, 6.1%)

FIGURE 3. Co-occurrence of depression and diabetes-related distress.

the DDS-17 than significant levels of depression symptoms on the PHQ-9. This is consistent with current literature, which reflects that, in patients with diabetes, diabetes-related distress is common and distinct from depression (12,15). Distress in this sample was highest in the subscales EB and RD. Additionally, women reported greater distress than men, which is consistent with other studies (18,23,24,26–28).

Our sample reported lower diabetes-related distress than in the DAWN2 study (4) or the BENCH-D (Benchmarking Network for Clinical and Humanistic Outcomes in Diabetes) study (29). This may be due to the setting, because the DCOE, which is situated in a military health system, exclusively treats patients with complex diabetes. In addition, military beneficiaries do not have to pay out-of-pocket costs for health care, medication, or supplies.

The extremely low rate of reported PD (1.3%) may suggest that patients have greater confidence in this specialty clinic's ability to manage diabetes, which may also help to explain the overall lower rates of distress. In addition, the DCOE employs several proactive strategies that may reduce diabetes-related distress (30). For example, at new patient orientation, it is ensured that patients have a primary care manager to address other health issues as they arise.

It is important to highlight that about half of our patients who screened positive for depression did not have diabetes-related distress. This is consistent with findings from Fisher et al. (31), who found that about one-third of people with diabetes who met the criteria for depression did not have high DDS-17 scores. In addition, the 3 Dimensions of Care for Diabetes Study found that nearly one-third of people with diabetes who screened positive for depression did not have high diabetes-related distress (32).

Thus, screening for depression is important; however, these findings suggest that there is a subgroup of people with diabetes who experience depression that appears to be unrelated to diabetes. This unique group of patients requires identification and evidence-based interventions aimed at general depression.

The PHQ-9 may overestimate the prevalence of depression, especially in patients with chronic illness (3,25). In fact, although the PHQ-9 was validated in patients with diabetes, depressive symptoms may be confused with pathology related to complications or symptoms of poorly managed diabetes (22,25). In a recent review of self-reported measures for depression, 44–77% of people with diabetes were found to have had false-positive depression screening results (33). Furthermore, Gonzalez et al. (34) suggest that depression screening tools rely solely on self-assessment of symptoms, while ignoring the context in which these symptoms occur. This may unduly pathologize patients with diabetes, while discounting the role chronic illness plays in emotional symptoms. Thus, it is important for providers to not simply look at the total PHQ-9 score, but also inquire about the context for a score on a particular item of concern.

If patients with diabetes are only screened for depression, they may not receive treatment for diabetes-related distress, which is distinctly different from depression. Although there were significant correlations between the PHQ-9 and the DDS-17, clinical cutoffs on each identified subgroups of patients with distress alone or depression alone. In our study, twice as many patients screened high in diabetes-related distress in any domain than patients who screened positive for depression. In fact, nearly half of patients who screened positive for depression did not have high diabetes-related distress in any domain. This is consistent with literature, which suggests that only ~23% of patients with diabetes-related distress also have depressive symptoms (11).

Significance and Implications

Our findings suggest that it is important to screen patients with diabetes for diabetes-related distress in addition to depression as a standard of care, because patients with significant distress will be missed if they are only screened for depression. Additionally, because of the distinct nature of diabetes-related distress and depression, treatment implications must be considered. Medical providers, ideally an interprofessional team, can use the information from the DDS-17 to collaborate with patients on an evidence-based, patient-centered treatment plan to effectively reduce distress (35). The plan can be tailored to meet individual patient needs, improving both patients' experience and health outcomes (2). For example, if a particular patient has elevated scores in the DDS-17 domains of ID and RD, it may be clinically indicated to include key significant others in diabetes self-management education classes to address distress. Additionally, the DDS-17 allows the medical team to determine whether referrals are needed to alleviate specific sources of diabetes-related distress.

Limitations

Because this study was conducted in a U.S. Air Force diabetes specialty clinic, its findings may not be transferable to other military or civilian primary care settings for several reasons. This population represents those who require more complex diabetes care, including all patients with type 1 diabetes, patients with multiple comorbidities, and patients using U-500 insulin therapy. Therefore, rates of diabetes-related distress in this population may differ from the general population of people with diabetes. In addition, all of our patients are part of the Department of Defense health care system and therefore may not be representative of the general population.

However, this study represents a robust sample of patients who concurrently responded to the DDS-17 and PHQ-9 questionnaires. Findings are from a real-world clinical setting from a heterogeneous group of patients with either type 1 or type 2 diabetes. This is the first study to our knowledge to examine differences in diabetes-related distress and depression in a clinical military health system sample.

Future Directions

Future research should evaluate the relationship between DDS-17 scores, depression, and A1C in a clinical setting, with attention to how interventions designed to reduce diabetes-related distress may influence A1C. In addition, exploring the context, including individual, clinical, and environmental predictors of elevated scores on the DDS-17 and its subscales may enable providers to identify those at risk for diabetes-related distress and proactively intervene. Such intervention may include a menu of strategies tailored to reduce distress as measured by the four domains of the DDS-17 that can be delivered by providers in the clinical setting.

Diabetes distress is a normal experience for many patients; it is associated with daily management of a chronic illness (and sometimes several chronic conditions). Regularly assessing how patients are coping with the demands of living with diabetes and addressing those stressors may improve outcomes (36). Congruent with the American Diabetes Association's *Standards of Medical Care in Diabetes—2018* (2), regular psychosocial assessment allows providers to intervene to promote better outcomes and quality of life for patients. This study provides additional support for use of the DDS-17 as an essential psychosocial assessment for people with diabetes.

Disclaimer

The views expressed in this article are those of the authors and do not reflect the official

policy or position of the U.S. Air Force, the U.S. Department of Defense, or the U.S. government.

Duality of Interest

No potential conflicts of interest relevant to this article were reported.

Author Contributions

J.L.W. collected the data, conducted the analysis, and wrote the manuscript. K.E.K., M.W.T., M.A.G., and T.J.S. contributed to the discussion and reviewed/edited the manuscript. J.L.W. is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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