



Diabetes Distress and Depression Are Not the Same Thing: Implications for Screening in Outpatient Clinics

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Abstract

Diabetes distress and depression are frequently treated as the same problem measured two ways, and the evidence does not support that. Distress affects 18 to 35 per cent of people with diabetes and is common enough that in one specialty clinic more patients endorsed it than endorsed depression. The two overlap incompletely: roughly a third to a half of people screening positive for depression report no diabetes-related distress. More importantly, they behave differently against glycaemic outcomes. In 235 adults with type 1 diabetes, distress was related to HbA1c on both the Diabetes Distress Scale and the Problem Areas in Diabetes scale, while depression, anxiety and overall well-being were not, and only the regimen-related subscale remained independently associated. A separate type 1 cohort found the same pattern, with regimen distress and low empowerment related to HbA1c while major depressive disorder and depressive symptoms were not. This review sets out what the two instruments measure and what follows for screening.

Keywords: Diabetes distress; Depression; Screening; Diabetes Distress Scale; Regimen-related distress

Introduction

Diabetes distress describes the emotional burden of living with and managing a demanding chronic condition: worry about complications, the relentlessness of self-management, and frustration with a regimen that does not reliably work [1,2]. It is measured by the Diabetes Distress Scale and the Problem Areas in Diabetes scale, both of which are diabetes-specific rather than general measures of mood [2,3].

Depression is a psychiatric diagnosis with established criteria, and it is more common in people with diabetes than in the general population [4,5]. The two constructs plainly overlap, and clinical services frequently treat them as interchangeable, screening for one and assuming the other is covered [6,7,26,27]. Position statements call for both to be addressed in routine psychosocial care [25], and the construct has accumulated twenty-five years of research without the distinction becoming routine [22,23].

This review examines whether that assumption holds. It matters because the two have different relationships with glycaemic outcomes and call for different responses.

Material and Methods

Search strategy: PubMed and the archives of the major diabetes, health psychology and psychosomatic journals were searched for studies distinguishing diabetes distress from depression. Search terms combined diabetes distress, Diabetes Distress Scale and Problem Areas in Diabetes with depression, screening, HbA1c, glycaemic control and latent class analysis. Reference lists of scale development papers [2,3] were screened by hand for primary sources.

Eligibility: Studies were included if they measured distress with a validated diabetes-specific instrument alongside a measure of depression, related either to a clinical outcome, or evaluated an intervention. Studies reporting only one of the two constructs are cited for prevalence and are identified as such.

Data extraction and handling: Design, population, the instruments used, their thresholds and the reported estimate were extracted as published. The instrument and cut-point are stated alongside every prevalence figure, and whether an association is univariate or independent is stated alongside every reported relationship, because the central question here is which measure survives adjustment for the other. No pooling or re-analysis was performed. Figures 1 to 6 and Tables 1 to 3 reproduce published values only. This is a narrative synthesis and was not registered as a systematic review.

Results

How common distress is: Reported prevalence of high diabetes distress is 18 to 35 per cent, with 18-month incidence of 38 to 48 per cent, and levels persist over time [1,2]. Distress is associated with poor glycaemic control, poor self-care, low self-efficacy and reduced quality of life even after controlling for clinical depression [1,8,20]. Systematic review places prevalence in type 2 diabetes within a similar range [21], longitudinal work links distress to worsening self-management over time [18], and cross-national benchmarking describes the same pattern across countries [28].

The two do not identify the same people: In a diabetes specialty clinic, more patients endorsed diabetes-related distress than depression, and about half of those who screened positive for depression did not have diabetes distress (Figure 1) [6]. That is consistent with earlier work in which roughly a third of people meeting criteria for depression did not have high distress scores, and with a separate study reporting nearly a third similarly [6,9,10]. There is therefore a group whose depression appears unrelated to their diabetes, and a larger group whose distress would be missed by a depression screen.

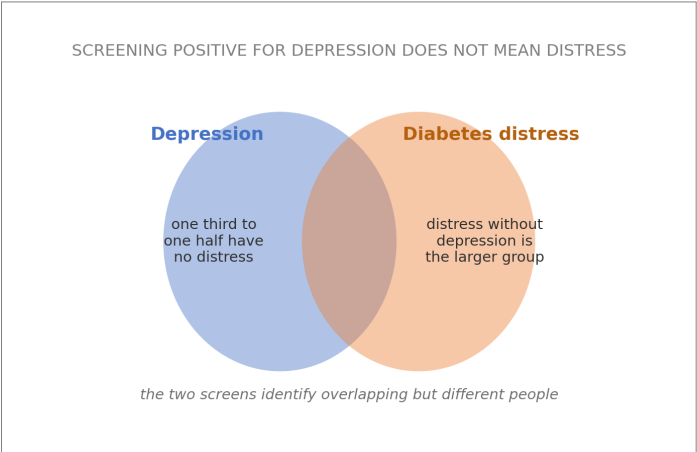


Figure 1: Overlap between screening positive for depression and for diabetes distress [6,9,10]

Which measure tracks glycaemic control: Of 319 adults with type 1 diabetes attending a university hospital endocrinology clinic, 235 (74 per cent) completed the Diabetes Distress Scale, the Problem Areas in Diabetes scale, the Hospital Anxiety and Depression Scale and a well-being index, with HbA1c measured at the same visit. Diabetes-specific distress was related to

glycaemic control on both instruments (Diabetes Distress Scale coefficient 0.038, $p < 0.001$; Problem Areas in Diabetes coefficient 0.021, $p = 0.007$), while depression, anxiety and overall well-being were not. On the Diabetes Distress Scale, only the regimen-related subscale was independently related to HbA1c (coefficient 0.056, $p < 0.001$) (Figure 2) [11].

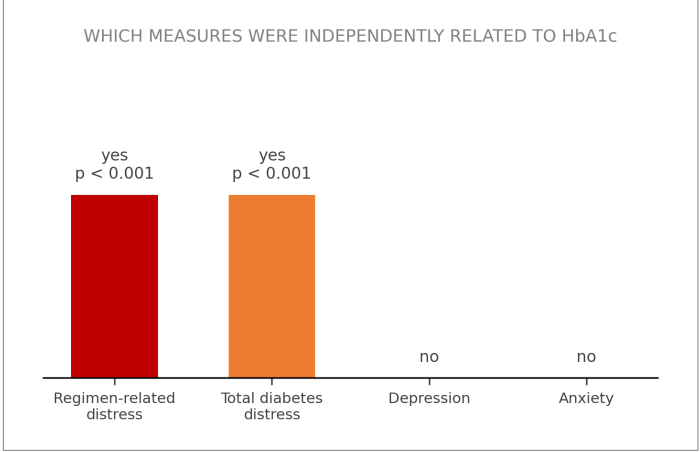


Figure 2: Measures independently related to HbA1c in a type 1 diabetes cohort [11]

The same pattern in a different population: In 63 adults with type 1 diabetes attending a Brazilian tertiary public hospital, major depressive disorder was present in 34.9 per cent, high depressive symptoms in 34.9 per cent and clinically meaningful distress in 57 per cent (Figure 3). High regimen-related distress and low empowerment were associated with HbA1c ($p = 0.003$ and $p = 0.01$), while major depressive disorder and depressive symptoms were not ($p = 0.72$ and $p = 0.97$) [12].

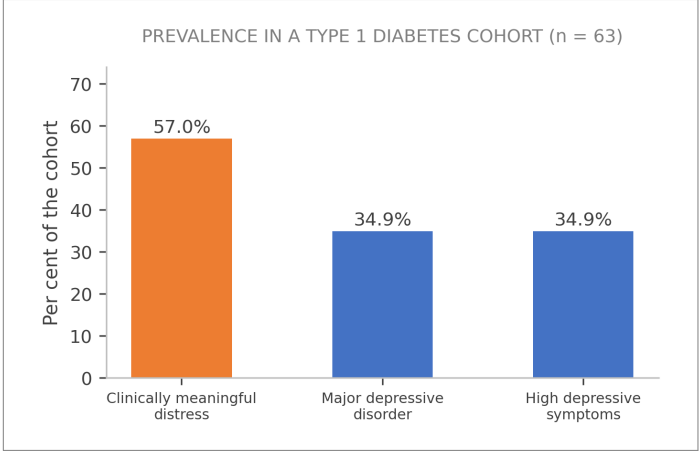


Figure 3: Prevalence of distress and depression in a type 1 diabetes cohort [12]

Study	Population	What was related to HbA1c
Norwegian cohort [11]	235 adults with type 1 diabetes	Distress on both scales; regimen subscale independently
Same cohort [11]	Same participants	Depression, anxiety and well-being were not
Brazilian cohort [12]	63 adults with type 1 diabetes	Regimen distress and low empowerment
Same cohort [12]	Same participants	Major depression and depressive symptoms were not
Glycaemic variability study [13]	Type 1 diabetes, long-term follow-up	Distress only, in those aged 25 and over

Study	Population	What was related to HbA1c
Specialty clinic [6]	Diabetes specialty clinic	More endorsed distress than depression

Table 1: Studies comparing distress and depression against glycaemic outcomes, as reported by the original investigators

Distress has structure: The Diabetes Distress Scale separates emotional burden, regimen-related distress, physician-related distress and interpersonal distress. In 414 participants of South Asian descent, high emotional burden was reported by 25.9 per cent, regimen-related distress by 21.9 per cent and physician-related distress by 6.2 per cent, and higher HbA1c was associated specifically with regimen-related distress (odds ratio 1.45, $p < 0.001$) (Figure 5) [14]. The subscale that tracks glycaemic control is consistently the one describing the burden of the regimen itself.

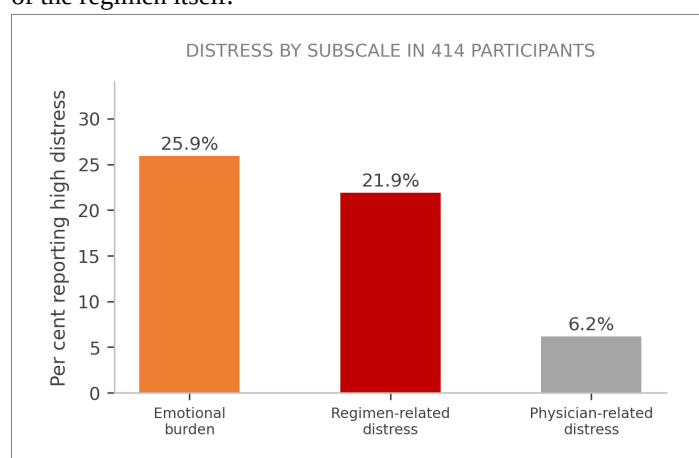


Figure 5: Distress by subscale in 414 participants [14]

How the constructs cluster: A latent class analysis in a type 2 diabetes cohort identified a class with no emotional or psychological disorder comprising 65.7 per cent, a class with somatic symptom distress at 12.7 per cent, and a class combining major depression, anxiety and distress at 7.6 per cent (Figure 4). That last class showed 56 per cent prevalence of major depression against under 1 per cent in the others, and 40 per cent generalised anxiety against under 4 per cent. The distress-only group lacked psychiatric correlates and had relatively weak independent associations with demographic and clinical variables [15].

Table 2: How the two constructs differ on the dimensions that matter for a clinic [1,2,4,11]

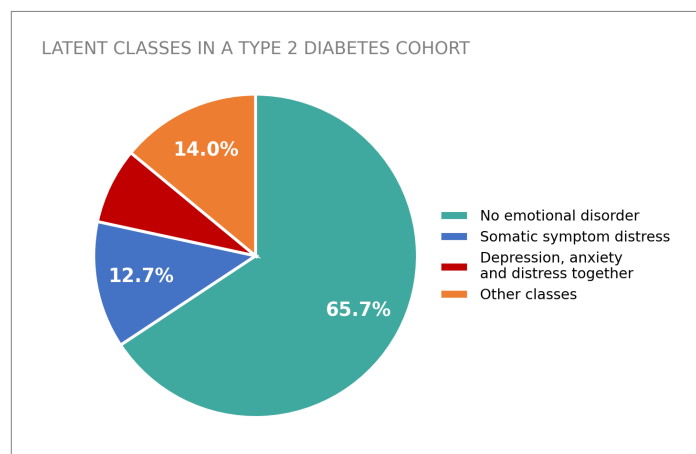


Figure 4: Latent classes identified in a type 2 diabetes cohort [15]

Cut points and screening tools: Curvilinear relationships between the Diabetes Distress Scale and HbA1c, self-efficacy, diet and physical activity were used to derive three bands of little or no, moderate and high distress in samples of 506 and 392 adults with type 2 diabetes, and a two-item screener was evaluated alongside the full 17-item scale [1]. Both the Diabetes Distress Scale and the Problem Areas in Diabetes scale have satisfactory psychometric properties for individual clinical use, with the former offering the advantage of identifying subdomains [11,16]. Comparative evaluation of screening characteristics supports using a diabetes-specific instrument alongside a depression questionnaire rather than either alone [27,33,34], and the sources of distress in type 1 diabetes have been characterised separately [31].

What intervention has shown: A randomised trial in adults with type 2 diabetes and comorbid depression assigned 192 participants each to monthly telephone psychoeducational support delivered by trained nurses or to usual care. Over 18 months HbA1c fell from 8.72 per cent (SD 1.49) to 7.03 (1.09) in the intervention group while rising from 8.65 (1.40) to 8.84 (1.38) in controls ($p < 0.001$) (Figure 6) [17].

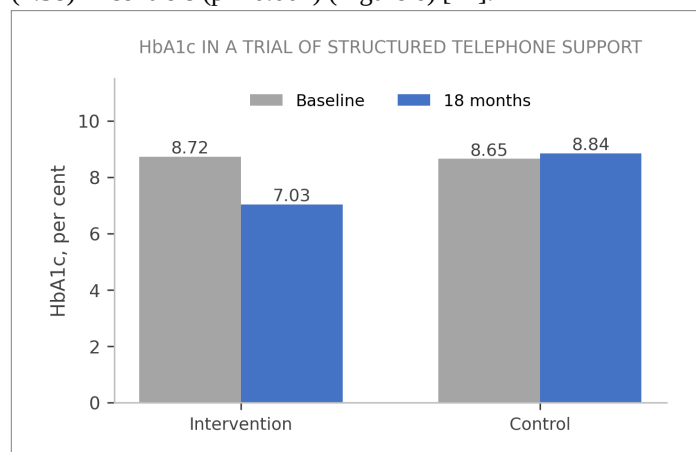


Figure 6: HbA1c over 18 months in a trial of structured telephone support [17]

	Diabetes distress	Depression
What it is	Emotional burden specific to the condition	A psychiatric diagnosis
Typical prevalence	18% to 35%	Lower in most diabetes cohorts
Related to HbA1c	Yes, chiefly the regimen subscale	Frequently not, after adjustment
Instrument	DDS-17, DDS-2, PAID	PHQ-9, HADS, diagnostic interview
First-line response	Address the regimen and its burden	Psychological or psychiatric care
Screening approach	What it detects	What it misses
Depression screen alone	Psychiatric morbidity	Distress in those without depression
Distress screen alone	Condition-specific burden	Depression unrelated to diabetes
Both together	Overlapping and separate groups	Requires two instruments

Table 3: What each screening strategy identifies and leaves out [6,9,10,15]

Discussion

The finding that should change clinic practice is narrower and more useful than the general claim that distress matters. In two separate type 1 diabetes cohorts, using different instruments in different countries, diabetes distress was related to HbA1c and depression was not [11,12]. In the Norwegian cohort only the regimen-related subscale survived adjustment, and in the South Asian cohort it was again regimen distress that carried the association with HbA1c [11,14].

That specificity is informative rather than incidental. Regimen distress describes difficulty with the demands of treatment: the injections, the monitoring, the calculations, the sense that effort is not rewarded. It is the component of distress closest to the behaviour that determines glycaemic control, and it is also the component most amenable to a clinical response, since a regimen can be simplified or renegotiated in a way that a mood disorder cannot.

The screening implication follows directly. If about a third to a half of people screening positive for depression have no diabetes distress, and distress is commoner than depression in clinic populations, then a single depression screen will systematically miss the group whose emotional burden is driving their glycaemic outcome [6,9,10]. The converse also holds: depression unrelated to diabetes is a real condition requiring treatment, and a distress screen will not find it. Neither instrument substitutes for the other.

There is a legitimate counter-argument that should be stated. The latent class analysis found that the distress-only group lacked psychiatric correlates and had relatively weak independent associations with clinical and demographic variables [15]. That raises the possibility that what these scales capture in many people is an appropriate response to a demanding treatment rather than a disorder. On that reading, high regimen distress is a signal about the regimen rather than

about the patient, which is a different thing from a mental health problem and arguably a more actionable one.

The intervention evidence is thinner than the descriptive evidence and does not settle this. The telephone support trial produced a substantial HbA1c improvement, from 8.72 to 7.03 per cent against a control group that worsened, but it enrolled people with diagnosed depression, delivered a package combining psychoeducation, motivational interviewing and collaborative care, and cannot attribute the effect to any one component [17]. It shows that structured contact helps; it does not show that treating distress specifically is what helped. Trials designed to reduce distress directly report modest effects in meta-analysis [19,29], and a randomised trial in type 1 diabetes reduced distress against an active comparator [30]. Practical guidance on addressing distress in the clinic has been published [24,32].

Study limitations

The limitations belong to the underlying literature. Most of the evidence distinguishing the two constructs is cross-sectional, so the direction of any association with HbA1c is not established, and poor control may generate distress as readily as the reverse [11,12,14]. Cohorts are small: the Brazilian study includes 63 participants and the Norwegian study 235 of 319 approached, so non-response may be informative [11,12]. Depression was measured variously by questionnaire and by diagnostic interview, and questionnaire measures overlap with somatic symptoms of diabetes itself [7,15]. Cut points for the distress scales derive from curvilinear modelling in type 2 diabetes and are applied to type 1 populations [1,11]. The age interaction reported in one cohort, with distress associated in those aged 25 and over and anxiety in those younger, is a single finding requiring replication [13]. The intervention trial enrolled only people with comorbid depression and used a multi-component package [17]. And most cohorts come from specialist clinics in high-income settings, with one exception drawn from a low-income population [12,14].

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Conclusion

Diabetes distress and depression are related but separate, and treating a screen for one as coverage for the other leaves people unidentified in both directions. The more precise finding is that it is regimen-related distress, not total distress and not depression, that tracks glycaemic control across cohorts and instruments. That points somewhere useful: when a patient reports high regimen distress alongside a rising HbA1c, the evidence supports looking at the treatment they have been asked to follow before concluding that the problem is their mood. Whether what these scales measure is a disorder or a reasonable reaction to a demanding regimen is unresolved, and the answer changes who should respond to it.

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Conflict of Interest

The authors declare no competing interests.

Ethics Statement

This article reviews previously published studies only. No new patient data were collected and no participants were recruited, so ethical approval was not required.

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