#### ORIGINAL RESEARCH



# Distress and Living with Diabetes: Defining Characteristics Through an Online Survey

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# **ABSTRACT**

*Introduction*: There is considerable evidence for diabetes reducing quality of life. The impact of such a diagnosis on mental health is less well understood and was subsequently explored here.

*Methods*: Online PHQ-9 scores (which calculate the severity of depression), Diabetes Distress Screening Scale (DDSS) and EQ-5D-5L (quality-of-life) questionnaires were completed by patients with diabetes, followed by the extraction of data where possible from responders' clinical records.

**Results**: A total of 133 people submitted questionnaires. However, not all data items could be completed by each patient; 35% (45/130) had type I diabetes mellitus (T1DM); 55% (64/117) were women. The overall median age of 117 responders was 60 (IQR 50−68 years). The median aggregated response scores were: EQ-5D-5L 0.74 (IQR 0.64−0.85) (lower quality of life than UK population median of 0.83), DDSS 1.9 (IQR1.3−2.7) (≥ 2 indicates moderate distress) and PHQ-9 5 (IQR2-11) (≥ 5 indicates depression). Higher diabetes distress (DDSS)/lower quality of life EQ-5D-5L/higher depressive symptoms (PHQ-9) linked to female sex (DDSS)

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The Ipswich Diabetes Centre and Research Unit, Ipswich Hospital NHS Trust, Colchester, Essex, UK 0.5/25% median), above younger (< 50 years DDSS 0.7/35% above median), fewer years after diagnosis (< 10 years DDSS 0.8/40% above median), and obesity (BMI > 35 DDSS 0.6/30% above median). Additionally, a HbA1c reading of < 48 mmol/mol was associated with higher DDSS scores, as did a reduction of more than 5 mmol/mol in HbA1c over the last three HbA1c measurements. The 30 individuals with a history of prescribed antidepressant medication also showed higher diabetes distress scores (DDSS 0.9, equating to 45% above the median). The DDSS score elevation came from an increase in emotional burden and regimen-related distress. DDSS scores were not significantly linked to diabetes type, insulin use, absolute level/change in blood glucose HbA1c. Physician-related distress showed a similar pattern.

Conclusions: A low level of stress in relation to diabetes management may be associated with lower HbA1c. The larger impact of diabetes on mental health in younger women/people with shorter diabetes duration should be noted when considering psychosocial intervention/behavior change messaging. Physician-related distress is a potentially remediable factor. However, this sample was self-selecting, limiting generalization to other samples.

**Keywords:** Diabetes; Diabetes distress; Depression

## **Key Summary Points**

The presence of symptoms of depression in people with diabetes is associated with reduced self-care compared to people with diabetes alone. We conducted an online survey in which PHQ-9 (depression), Diabetes Distress Screening Scale (DDSS) and EQ-5D-5L (quality-of-life) questionnaires were completed by people with diabetes.

Higher diabetes distress (DDSS)/lower quality of life EQ-5D-5L/higher depressive symptoms (PHQ-9) linked to female sex (DDSS 0.5/25% above median), younger age (< 50 years DDSS 0.7/35% above median), fewer years after diagnosis (< 10 years DDSS 0.8/40% above median), and obesity (BMI > 35 DDSS 0.6/30% above median). Additionally, a HbA1c reading of  $\leq$  48 mmol/mol (6.5%) was associated with higher DDSS scores, as did a reduction of more than 5 mmol/mol in HbA1c over the last three HbA1c measurements.

A low level of stress in relation to diabetes management may be associated with lower HbA1c levels. The larger impact of diabetes on mental health in younger female patients and/or people with shorter diabetes duration should be noted when considering psychosocial intervention/behavior change messaging. Physician-related distress is a potentially remediable factor.

## INTRODUCTION

People with diabetes often experience low mood. Up to 19% of people with type 2 diabetes mellitus (T2DM) have been diagnosed with a major depressive disorder, and up to 25% have clinically relevant depression symptoms at any time [1–4]. The prevalence rate of depression is more than three-times higher in people with type 1 diabetes mellitus (T1DM) and nearly twice as high in people with T2DM, compared to those without these conditions [5]. Both women with and without diabetes experience a higher prevalence of depression than men [5].

The presence of symptoms of depression in people with diabetes is associated with reduced

self-care compared to people with diabetes alone [6, 7]. Depressive symptoms are also associated with adverse health outcomes, such as poor blood glucose control [8], more diabetes complications [8, 9], poorer quality of life [10], higher health care costs [11], and a higher mortality rate [12].

Diabetes distress is a prominent issue in people with T2DM and has been associated with female gender and comorbid depressive symptoms [13]. Diabetes distress has many causes including fear of complications, frustration with having diabetes itself, and perceived or real lifestyle constriction because of the diagnosis [14]. Given the high prevalence of co-morbid depression and associated adverse health outcomes, it has been recommended to screen for depressive symptoms in people with diabetes on a regular basis and to provide treatment whenever possible [15].

Most United Kingdom (UK) diabetes teams, whether based in the hospital or the community, are under-resourced with regards to access to clinical psychology. Therefore, this is an area of significant unmet need that merits an up-to-date formal evaluation how patient experience may inform effective targeting of limited resources.

We report the results of an online survey to evaluate how depression and diabetes distress affected people with diabetes in the UK in 2020 and 2021. We also considered how reports of low mood and distress related to both demographic/anthropometric factors and to blood glucose control.

## **METHODS**

We conducted an online survey utilizing the resource provided by Research for the Future (RfTF) [16] in relation to people's lived experience of diabetes regarding mood and diabetes related distress. RfTF is an NHS-supported organization which encourages people to become more involved with health research in their local area. Most people who volunteer to be part of RfTF live in the Greater Manchester conurbation but approximately 6% live elsewhere in the UK. There were no specific

inclusion criteria—rather this was online survey of our volunteers in RfTF [16].

In this study, we were particularly interested in how the DDSS scores related to other factors such as perception of care given, medical history, and mode of treatment. The survey was conducted online in late 2020 and early 2021 at the time of the COVID-19 global pandemic. Ethical approval was obtained from the Greater Manchester West Research Ethics Committee, REC reference 20/NW/0252.

There are an estimated 110,000 people living with diabetes in the Greater Manchester conurbation. There are 2800 people with diabetes in the RfTF database. Of these, 1100 were invited to participate in the online survey.

Participants gave permission for their general practice records to be accessed. Informed consent was obtained from all participants. In some cases (n = 88), this was possible through the Greater Manchester care Record [17] and in other cases (n = 42) through the NHS Digital Spine [18]. Specifically, we asked questions about mood, motivation, quality of life and diabetes distress. The questionnaires used were: EQ-5D-5L [19], PHQ-9 (depression) [20] and Diabetes Distress Screening Scale (DDSS) [21]. These were adapted for online use. Diabetes Distress (DDSS) scores were evaluated by counting the number of questions with response > 2 ("1—Not a problem" or "2—a slight problem"), in total and by sub-scale.

The DDSS is derived from 17-item five level Likert scale responses reflected into four subscales that target 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). Average scores of any sub-scale over three or more is considered to indicate significant distress for that person in that area [21].

The PHQ-9 scale is a multipurpose instrument for screening and for monitoring the severity of depression [18]. The EQ-5D-5L is a

descriptive system to estimate quality of life (QOL) [19], comprising five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. Each dimension has five levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. Participants are asked to indicate their health state by ticking the box next to the most appropriate statement in each of the five dimensions [19].

The response scores were collected and analyzed.

*EQ5D*: each patient's response profile was cross walked applying the EuroQoL (https://euroqol.org/eq-5d-instruments/eq-5d-5l-about/valuation-standard-value-sets/crosswalk-index-value-calculator/) tool using UK data to establish their EQ5D score.

*DDS*: The average score and the number of responses of three or higher for each of the five aspects plus the overall total were calculated.

*PHQ-9*: The total score over the nine items were added together (Minimal 0–4, Mild 5–9, Moderate 10–14, Moderately Severe 15–19, Severe  $\geq$  20).

Other patients' characteristics were taken from the response questionnaire and heath records where available; these included diabetes type, sex, age, body mass index (BMI), duration with diabetes in years, diabetes medication being used, history of antidepressant use, HbA1c (self-reported in questionnaire and taken from health records) over various time frames. Univariant analysis was applied linking average response levels to various classes of patients. To highlight differences, the ratio of the response level within a class was taken against the overall average response.

Multivariant analysis was applied by regression linking the overall DDS average score to diabetes type, sex, age, BMI, duration, HbA1c, antidepressant use, insulin use, and self-health score. Factors with the highest p values were removed stepwise.

## **RESULTS**

A total of 133 people completed the questionnaire; however, not all data items could then be extracted for all responders' medical records; 35% (45/130) were T1DM, 55% (64/117) were women. The median age was 60 (interquartile range (IQR) 47-67) years. The overall median scores were: EQ-5D-5L = 0.74 (IQR 0.64-0.85) (lower QOL than UK population median 82.8), DDSS = 1.9 (IQR1.3-2.7) (> 2 indicates moderate distress) and PHQ-9 = 5 (IQR 2-11) ( $\geq$  5 indicates depression). Compared with UK prevalence figures, there was a fivefold overrepresentation of people with T1DM and consequent under-representation of people with T2DM (68%). The questionnaire's 31 items were internally consistent both across and within each questionnaire with overall Cronbach's alpha (measure of the internal consistency of the scales) [31 items] 0.95, EQ-5D-5L (raw scores) (five items) 0.85, overall DDSS (17 items) 0.95 and PHQ-9 (nine items) 0.95.

#### **Diabetes Distress Scale Scores**

Figure 1A shows the level of response for all patients across each question. The most serious concerns and related distress were related to: the prospect of longer-term complications; a sense that diabetes controls the person's life; concerns about not sticking closely to a good meal plan; failing with the diabetes routine; being overwhelmed by the demands of living with diabetes and not having a doctor that they can see regularly enough about their diabetes.

Figure 1B shows the sum of response levels for each participant as a percentage of the 17 items. The *y*-axis shows the % rank for each participant out of total of 133 providing responses. This varied considerably, with the top 20% participants having 90% responses > 2 and the lowest 30% having almost no responses > 2.

Figure 1C shows the total number of responses > 2 for each participant as % of 17 for each sub-class of items. Forty-one (31%) individuals had no significant distress in any subscale, 16 (12%) had distress in one sub-scale and 26 (20%) had distress in two, 24 (18%) in three subscales, and 26 (20%) had at least one distress score > 2 in all sub-scales.

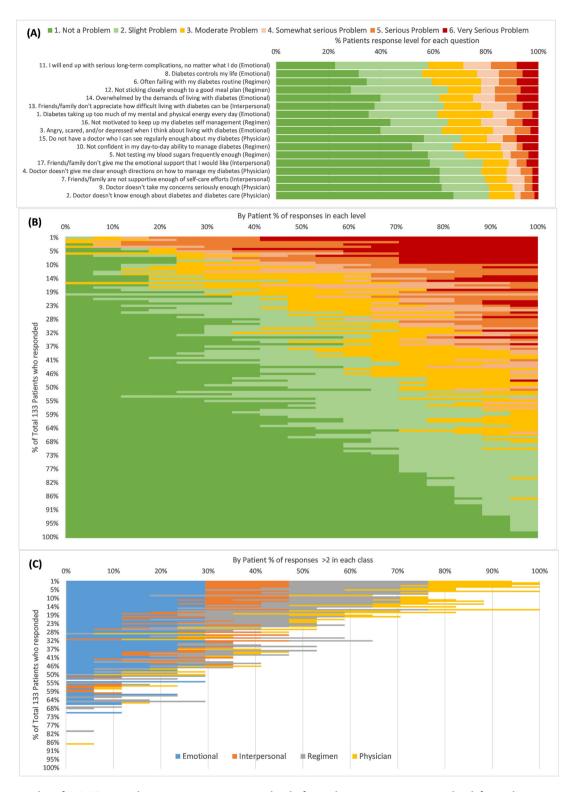


Fig. 1 Results of DDSS scores by patients A % response levels for each question B response level for each patient C % of questions with response > 2

The split of the 92 (69%) participants with at least 1 score > 2 across the sub-scale was emotional burden 77 (58% of total patients), regimen-related distress 69 (52%), interpersonal distress 51 (38%), and physician-related distress 47 (35%).

#### **Medication Prescription**

Of those for whom medication information was available (116/133), 30% of people were being prescribed antidepressant treatment or had been prescribed an antidepressant in the previous 10 years; 3% were prescribed propranolol and 2% were prescribed diazepam. As shown in Fig. 2, the most prescribed antidepressant medication was sertraline (37.5% of those on an antidepressant) followed by citalogram (28% of those on an antidepressant). Other antidepressants prescribed are shown in Fig. 2. Amitriptyline was prescribed to manage neuropathic pain (at the dose of 10–50 mg) in 6% of individuals. Duloxetine was prescribed for both treatment of neuropathic pain and/or for treatment of low mood (at the dose of 60-120 mg daily).

In univariate analysis, lower scores reflecting higher DDSS/lower quality of life EQ-5D-5L/and higher depression (PHQ-9) were linked to female sex (DDSS 0.5 = 25% above median for the whole sample), younger age (< 50 years DDSS 0.7 = 35% above median), fewer years after initial diagnosis (< 10 years DDSS 0.8 = 40% above median), and obesity (BMI > 35 DDSS 0.6 = 30% above median). Lower

DDSS scores were associated with a longer duration of diabetes.

Patients with a history of prescribed antidepressant medication showed higher diabetes distress scores (average DDSS score 2.8) compared to those with no history of antidepressant use (1.9, i.e., 47% higher). The DDSS score elevation particularly came from increases in emotional burden and regimen-related distress (Table 1).

The DDSS responses > 2 related closely to the total DDSS score ( $r^2 = 0.9$ ) as shown in Fig. 3A. There was a stronger relation between total DDSS scores for the respondents and the PHQ-9 score ( $r^2 = 0.4$ ) and a weaker relation between a higher DDSS score and lower EQ-5D-5L score ( $r^2 = 0.1$ ). (Fig. 3B). Each of the DDDS domains related strongly to the total DDSS score (Fig. 3C). There was no relation between self-assessed general health and the total DDSS score (Fig. 3D).

In Table 1, we describe how the scores for EQ-5D-5L, PHQ-9, and DDSS related to participant characteristics, body mass index (BMI), and HbA1c. Scores are described as a percentage of the median score for the scale or subscale. Higher DDSS and PHQ-9 scores and lower EQ-5D-5L scores were reported for women, those with a shorter duration of diabetes and those with history of antidepressant use, with insulin use associated higher EQ-5D-5L scores and lower DDSS and PHQ-9 scores. Body mass index (BMI) was only associated with less favorable life experience for people with a BMI of 40 kg/

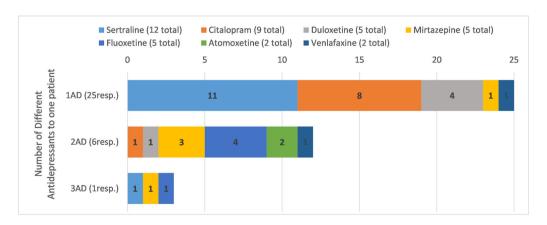


Fig. 2 Description of prescribing antidepressants

History

Table 1 Patient characteristics related to average scores

Average Score (% of overall sample												
Total					average)		DDS Component Scores					
								Emotional	Physician		Interperson	
			Pati	ents	EQ5D	PHQ9	DDS	(5)	(4)	Regimen (5)	al (3)	
	Total	Overall	133		0.68	7.3	2.2	2.5	1.8	2.3	2.0	
TYPE	130	DM1	45	35%	0.79 (115%)	6.4 (88%)	2.2 (100%)	2.8 (111%)	1.8 (99%)	2 (87%)	2.2 (108%)	
		DM2	85	65%	0.63 (93%)	7.7 (105%)	2.2 (100%)	2.3 (94%)	1.9 (103%)	2.5 (107%)	1.9 (97%)	
SEX	117	M	53	45%	0.71 (104%)	5.7 (79%)	2 (90%)	2.2 (89%)	1.6 (88%)	2.1 (93%)	1.9 (96%)	
		F	64	55%	0.67 (99%)	8.3 (113%)	2.3 (105%)	2.7 (108%)	2 (113%)	2.3 (101%)	2 (101%)	
AGE	117	>80	6	5%	0.75 (111%)	3.2 (43%)	1.1 (51%)	1.1 (44%)	1.1 (63%)	1.2 (54%)	1 (50%)	
		65-79	37	32%	0.71 (105%)	5.3 (72%)	1.8 (84%)	2 (82%)	1.8 (99%)	1.8 (78%)	1.7 (83%)	
		40-64	55	47%	0.63 (92%)	8.6 (118%)	2.3 (106%)	2.7 (108%)	1.8 (100%)	2.6 (112%)	2 (99%)	
		<40	19	16%	0.8 (117%)	7.5 (103%)	2.7 (121%)	3.1 (125%)	2.2 (122%)	2.4 (105%)	2.9 (144%)	
BMI	92	BMI Normal (<25)	16	17%	0.8 (117%)	4.8 (66%)	2.2 (100%)	2.8 (114%)	1.9 (103%)	1.9 (84%)	2.1 (104%)	
		BMI Overweight (25-	29	25%	0.77 (113%)	5.3 (73%)	2 (92%)	2.3 (90%)	1.9 (107%)	2 (87%)	1.9 (93%)	
		30)										
		BMI Obese (30-35)	20	17%	0.66 (97%)	6.7 (92%)	2.1 (96%)	2.3 (93%)	1.7 (96%)	2.3 (102%)	1.9 (96%)	
		BMI Very Obese (35-40)	16	14%	0.64 (95%)	9.7 (133%)	2.4 (110%)	2.7 (107%)	1.9 (108%)	2.6 (113%)	2.3 (115%)	
		BMI Highest Risk (>40)	11	9%	0.69 (101%)	8.2 (112%)	2.5 (116%)	2.5 (99%)	2.2 (124%)	3 (129%)	2.4 (120%)	
DM	100	>=20	28	28%	0.72 (106%)	6.1 (84%)	1.9 (88%)	2.3 (93%)	1.5 (85%)	1.9 (82%)	2 (98%)	
Duration		10-19	40	40%	0.69 (101%)	5.6 (77%)	2 (91%)	2.3 (90%)	1.7 (95%)	2.1 (90%)	1.8 (90%)	
years		5-9	17	17%	0.68 (100%)	9.6 (131%)	2.6 (118%)	2.7 (109%)	2.5 (139%)	2.7 (118%)	2.4 (119%)	
		<5	15	15%	0.65 (96%)	8.5 (116%)	2.6 (117%)	2.9 (117%)	1.9 (106%)	2.9 (125%)	2.4 (119%)	
DM	92	insulin and medicines	14	15%	0.71 (105%)	9 (123%)	2 (89%)	2.4 (95%)	1.6 (89%)	1.9 (81%)	1.8 (92%)	
Medication		insulin	30	33%	0.78 (114%)	7.5 (103%)	2.4 (109%)	2.9 (114%)	2.1 (116%)	2.2 (96%)	2.3 (117%)	
		medicines only	48	52%	0.62 (91%)	7.5 (102%)	2.3 (103%)	2.5 (99%)	1.9 (107%)	2.5 (107%)	2 (102%)	
Anti	116	No History	81	70%	0.75 (110%)	5.1 (70%)	1.9 (87%)	2.2 (87%)	1.7 (92%)	1.9 (85%)	1.8 (88%)	
depressant		Have been prescribed	35	30%	0.54 (80%)	11.9 (163%)	2.8 (127%)	3.2 (130%)	2.2 (125%)	2.9 (128%)	2.5 (125%)	

Please comparison is within columns. Percent scores relate to comparison vs. the mean score Green = 10% more favorable than the mean score (in terms of higher EQ-5D-5L or lower DDSS/ PHQ-9) Amber = 10% less favorable than the mean score (in terms of higher EQ-5D-5L or lower DDSS/ PHQ-9) Red = 30% less favorable than the mean score (in terms of higher EQ-5D-5L or lower DDSS/ PHQ-9)

 ${\rm m}^2$  or more. Greater physician-related distress was associated with female sex, younger age, BMI  $\geq 40$ , shorter duration of diabetes and insulin treatment plus history of antidepressant use.

In Table 2, we describe how the average DDSS related to HbA1c. Both a high and low self-reported HbA1c was associated with higher DDSS scores as was HbA1c  $\leq$  48 mmol/mol and the perception that HbA1c was higher than it was in reality. A reduction of more than 5 mmol/mol in HbA1c over the last three HbA1c measurements was associated with higher DDSS scores. A similar pattern was seen for physician-related distress.

In multivariate analysis ( $r^2$  for the model 0.2) including all factors described in Tables 1 and 2 (Fig. 4), after stepwise removal only two variables remained with statistically significant low p values in relation to DDSS score; these were younger age (p = 0.045) and a shorter duration of diabetes (p = 0.002). Each of these was associated with a higher overall average DDSS score.

# DISCUSSION

In this study, we have characterized the experience of living with diabetes in those people who have responded to the online survey. The main findings were that higher diabetes distress, lower quality of life, and more depressive symptoms were associated with female sex, younger age, obesity, and being less than 10 years from diagnosis. Multiple regression analyses indicated that younger patients were more likely to experience severe diabetes distress as were people with a shorter duration of diabetes and those with a history of antidepressant use.

The Diabetes Distress Screening Scale (DDSS) score elevation came from increases in emotional burden and regimen-related Distress. It was apparent that people who could be considered to have excellent blood glucose control (HbA1c 48 mmol/mol (6.5%) or less) had higher levels of reported distress than those with higher HbA1c. This raises the question of

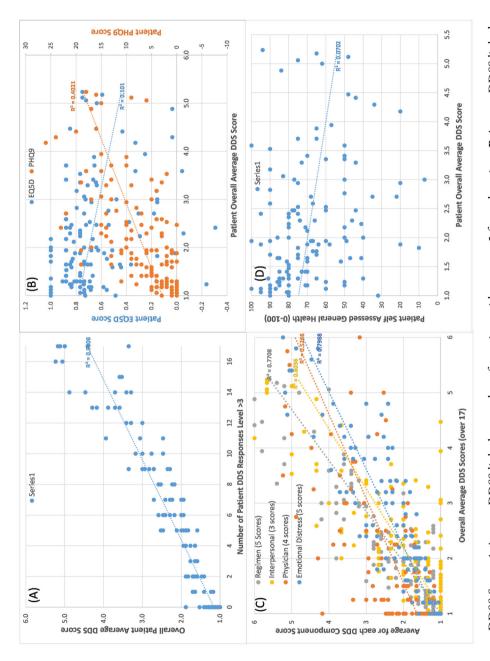


Fig. 3 Link between DDSS Scores A Average DDSS linked to number of questions with scores > 2 for each patient. B Average DDSS linked to average EQ5D and PHQ9. C Link between average component DDSS scores and overall average DDSS score. D Link between overall average DDSS and patient self-estimated health

Table 2 Linking to HbA1c

Тс				tal	Average Score (% of overall sample)			DDS Component Scores			
								Emotional			Interperson
			Pati	ents	EQ5D	PHQ9	DDS	(5)	Physician (4)	Regimen (5)	al (3)
	Total	Overall	133		0.68	7.3	2.2	2.5	1.8	2.3	2.0
Patient Self Reported HbA1c	69	<49	15	22%	0.66 (97%)	9.2 (126%)	2.3 (104%)	2.7 (110%)	2.1 (117%)	1.9 (83%)	2.3 (117%)
		49-58	26	38%	0.74 (109%)	6.3 (87%)	2.1 (93%)	2.4 (97%)	1.6 (91%)	2.1 (92%)	1.9 (96%)
		58-73	16	23%	0.71 (105%)	6.3 (86%)	2.3 (102%)	2.6 (106%)	1.8 (97%)	2.4 (104%)	2 (102%)
		73-86	6	9%	0.51 (76%)	8.8 (121%)	2.4 (107%)	2.9 (115%)	1.4 (76%)	2.7 (119%)	2.2 (108%)
		>86	6	9%	0.51 (74%)	12.5 (171%)	3.1 (141%)	3.6 (145%)	2.1 (118%)	3.6 (158%)	2.6 (131%)
Latest	56	<49	15	22%	0.6 (88%)	8.9 (122%)	2.3 (103%)	2.7 (107%)	2.4 (131%)	1.9 (82%)	2.1 (103%)
Recorded HbA1c		49-58	15	22%	0.73 (108%)	7.8 (107%)	1.9 (88%)	2.2 (89%)	1.5 (81%)	2.2 (97%)	1.6 (79%)
		58-73	16	23%	0.53 (78%)	6.8 (92%)	2.2 (100%)	2.7 (107%)	1.6 (87%)	2.4 (105%)	1.8 (92%)
		73-86	9	13%	0.76 (111%)	6.8 (93%)	2.5 (116%)	2.6 (104%)	2.7 (150%)	2.3 (101%)	2.6 (131%)
		>86	1	1%	0.64 (93%)	14 (192%)	3.3 (150%)	4 (160%)	3.8 (208%)	3.4 (148%)	1.3 (67%)
HbA1c	56	Increase by >5	13	23%	0.59 (87%)	6.3 (86%)	1.8 (81%)	1.9 (74%)	1.6 (91%)	1.8 (79%)	1.8 (88%)
Change last 3 results		Stable+/-5	24	43%	0.69 (101%)	7.5 (103%)	2.1 (96%)	2.5 (101%)	2 (111%)	2.1 (91%)	1.6 (78%)
		Reduce by >5 months	19	34%	0.62 (91%)	9 (123%)	2.7 (121%)	3.1 (123%)	2.2 (120%)	2.7 (118%)	2.5 (127%)
HbA1c Status	56	>=48 or stable/increasing	23	41%	0.69 (101%)	6.4 (88%)	1.9 (88%)	2.2 (86%)	1.8 (99%)	2.1 (90%)	1.6 (78%)
		<=49 or falling	33	59%	0.61 (90%)	8.7 (119%)	2.4 (110%)	2.8 (114%)	2.1 (117%)	2.4 (102%)	2.2 (111%)
		NA	77	138%	0.71 (104%)	7 (96%)	2.2 (99%)	2.4 (97%)	1.8 (97%)	2.3 (101%)	2.1 (103%)
HbA1c	37	Patient Under	17	46%	0.69 (102%)	7.2 (98%)	2.2 (100%)	2.6 (104%)	1.8 (99%)	2.2 (94%)	2.2 (110%)
Patient		+/-5%	11	30%	0.66 (97%)	8.2 (112%)	2.1 (97%)	2.5 (100%)	1.9 (104%)	2.3 (99%)	1.7 (83%)
Estimates		Patient Over	9	24%	0.51 (75%)	11.7 (160%)	2.7 (125%)	3.1 (125%)	2.3 (127%)	2.9 (127%)	2.4 (122%)

Comparison is within columns. Percent scores relate to comparison vs. the mean score Green = 10% more favorable than the mean score (in terms of higher EQ-5D-5L or lower DDSS/ PHQ-9) Amber = 10% less favorable than the mean score (in terms of higher EQ-5D-5L or lower DDSS/ PHQ-9) Red = 30% less favorable than the mean score (in terms of higher EQ-5D-5L or lower DDSS/ PHQ-9)

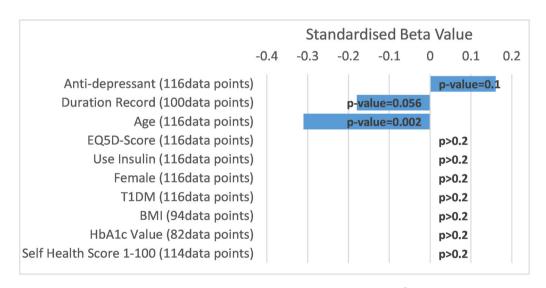


Fig. 4 Multivariate regression linking overall average DDSS scores to other factors ( $r^2 = 0.2$ )

whether it may be helpful to the achievement of optimal blood glucose control to have a low level of concern about the condition and its management. This requires further evaluation as stated by Nouwen et al. recently [22].

Individuals with the highest DDSS score [21] also reported on average a lower quality of their relationships with health care professionals, and more physical health-related distress (Fig. 3C). The importance of this observation is that it relates to opportunities for healthcare

professionals to put more emphasis on psychological aspects during diabetes care consultations, as recently highlighted [23]. However, in a recent systematic review, it was concluded that psychological approaches in diabetes management need to be matched to the person and their life course [24].

Importantly, greater physician-related distress was associated with female sex, younger age, BMI > 40, shorter duration of diabetes and history of antidepressant use. This is relevant to the targeting of resources to the most at-risk individuals and to the way that people with diabetes interact with and experience the health care system and their appointments is something that can be influenced by health policy and by resource allocation.

Clinically significant depression was reportedly present in up to one of every four people with T2DM [25]. The findings of this study should be placed in the context of that and similar observations. It has previously been reported that women without diabetes experience a higher prevalence of depression than men [5]. The same review showed that women with and without diabetes have higher prevalence of depression. It is also the case that in our study, longer duration of diabetes was associated with less severe symptoms. Previously it was described that the association between duration of diabetes and risk of current depression was 'J-shaped' with the odds ratios decreasing and then increasing with greater duration of diabetes since diagnosis [26-28].

The finding of no statistically significant differences in DDSS scores for people taking insulin vs. those not on insulin may relate to the greater contact that people taking insulin have with health care professionals and greater personal support. This contrasts with several previous studies in this area [9].

The period since March 2020 in relation to the COVID-19 pandemic has been a very difficult time for anyone with diabetes in relation to the elevated risk of serious consequences of a COVID-19 infection [29–31], coupled with the way many general practices in the UK had to direct services away from long-term conditionmonitoring clinics [32]. This has impacted the HbA1c testing interval and regularity [33] and

other aspects of routine clinical care for people with all forms of diabetes [34].

To contextualize our findings, in a landmark systematic review, Nouwen et al. recently reported a bidirectional longitudinal association between depressive symptoms and HbA1c [9]. However, the observed effect sizes were small. The authors recommended that future studies should investigate the role of type of diabetes and depression, diabetes distress, and diabetes self-management behaviors.

In relation to the matter of self-management, we previously described the way that perception of current/future consequences of blood glucose level relate to blood glucose levels [35, 36] and found that in T2DM, for those with reported HbA1c > 65 mmol/mol (8.1%), most people questioned (70%) were either concerned or really concerned about the shorter-term consequences of running a high HbA1c level. The group surveyed comprised engaged people with T2DM, but even within this group there was significant variation in (a) awareness of shorter-term risks, (b) confidence in their ability to implement appropriate insulin dosage, and (c) awareness of the limitations of BG monitoring technology. The authors suggested that this is an area where changes in education/support would benefit many.

We accept that this study has a small sample size and that the respondents were self-selecting in that they responded to an online survey. This was not intended as a prevalence study, but rather a study aiming to describe the characteristics of depression and distress in people with diabetes. However, we were able to gain information from the digital health records in most cases in relation to age, duration of diabetes since diagnosis, medication, and HbA1c/BMI with their explicit permission. There was an over-representation of people with T1DM vs. T2DM in relation to National Diabetes Audit (NDA) proportions [37]. This has also been noted in other surveys of patient experience.

## **CONCLUSIONS**

The larger impact of diabetes on mental health in younger women and in people with a shorter duration of diabetes, or who are overweight, should be noted when considering psychosocial intervention and behavior change messaging. A low level of stress in relation to diabetes management appears to be associated with the achievement of better blood glucose control.

We suggest that these factors be considered when planning psychosocial interventions and behavior change messaging to support people with diabetes, in relation to the multiple challenges that they face, particularly given the impact of the COVID-19 pandemic on routine care for people with diabetes in the UK and elsewhere. Furthermore, physician-related distress, as reported here, can be addressed by changing the way that people with diabetes interact with and experience the health care system.

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Compliance with Ethics Guidelines. The survey was conducted online in late 2020 and early 2021 at the time of the COVID-19 global pandemic. Ethical approval was obtained from the Greater Manchester West Research Ethics Committee, REC reference 20/NW/0252. Informed consent was obtained from all participants.

**Data Availability.** The data that support the findings of this study are available from the corresponding author upon reasonable request.

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