Screening tool provides insight to the depths of diabetes-related distress

Amanda Dudley, Tiffany Ballentine, Tanya Cohn

Diabetes-related distress differs from depression as it develops from the mental and emotional burden that comes from the constant management of diabetes. Despite the increased awareness and knowledge of diabetes-related distress, patients with diabetes are not routinely screened during clinic visits. In order to potentially encourage providers to implement the 17-item Diabetes Distress Scale (DDS-17) into practice and clinic appointments with patients, the authors researched and analysed results from voluntary and anonymous participants with diabetes, aged 18 years and older, who completed demographic survey questions and the DDS-17. The results revealed that areas of statistically significant distress can be found in people recently diagnosed with diabetes and occurs more often in those with type 1 diabetes compared with type 2 diabetes.

Effectively managing diabetes requires constant monitoring of not only blood glucose levels but also carbohydrate intake, hydration status, stress levels and other factors. The constant demands of diabetes management can create a significant emotional burden. In 1995, a team of psychology professionals from the Joslin Diabetes Center introduced the term "diabetes distress" to describe the negative emotional phenomenon that people with diabetes experience (Skinner et al, 2020). Diabetes distress develops from the continued emotional burdens of worry, anger, frustration and burnout that can occur as a result of the constant intricacies that one must balance to maintain ideal glycaemic control (Owens-Gary et al, 2019). In addition to diabetes distress, a person with diabetes is two to three times more likely to experience a depressive disorder than a person without diabetes (Centers for Disease Control and Prevention, 2021).

Of the 34.2 million people living with diabetes in the US, approximately 20% experience symptoms of depression and one third experience symptoms of diabetes distress (Owens-Gary et al, 2019). These two diagnoses can occur simultaneously, with approximately 4.5% of people with diabetes screening positive for both. Women, young people with diabetes, and people with lower education and lower socioeconomic status are at even higher risk of major depressive disorder and diabetes distress (Sweatman et al, 2017).

Both diabetes distress and depression can negatively impact an individual's self-care abilities and cause symptoms like changes in sleep, appetite and social relationships, all factors leading to poor diabetes management (Sweatman et al, 2017). Long-term poor glycaemic control increases the risk of vascular changes that can affect organs such as the eyes, kidneys, heart and peripheral blood vessels, as well as increasing morbidity and mortality rates.

Diabetes distress has been analysed with tools such as the Self-Management Scale, the Rosenberg Self-Esteem Scale and the 17-item Diabetes Distress Scale (Kaiser and Mehboob, 2020). Data from

Article points

1. Each day, people with diabetes are routinely faced with countless decisions regarding the management of their blood glucose levels.

2. This constant management can have emotional, psychological and physiological implications that can lead to diabetes-related distress.

3. If not identified through screening, diabetes-related distress can lead to poor health outcomes and decreased self-care. Despite this, assessment is not routinely performed.

Key words

- Burnout
- Diabetes-related distress
- Mental health

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these tools suggest that diabetes distress and poor self-management are more common in people with type 1 diabetes versus type 2 diabetes, and that self-management and self-esteem are negatively impacted by diabetes distress. Continued research on larger and more diverse populations will give even better insight into diabetes distress; however, previous research supports symptoms of diabetes distress that include burnout due to managing the chronic condition, high blood glucose readings leading to decreased self-esteem, disregard for treatment and self-care decline.

Combination therapies are recommended for diabetes distress, including psychotherapy, such as cognitive behavioural therapy and motivational interviewing, and pharmacological treatments such as antidepressants (Sweatman et al, 2017). Indeed, the American Diabetes Association (ADA, 2020) now recommends psychosocial care as a therapy for diabetes management. In addition, mindfulness-based interventions (MBIs) have been studied. MBIs are a type of psychological treatment that have been used successfully in chronic conditions, cancer and pain disorders. Although more research on which specific MBI should be utilised is needed, a meta-analysis determined that they improved diabetes distress scores by 5.81 on the Problem Areas in Diabetes scale, as well as moderately decreasing depression and stress (Ni et al, 2021).

Early recognition and treatment of depression and diabetes distress increases medication concordance and positive self-care behaviours, potentially leading to better glycaemic control and reduced risk of long-term complications (Owens-Gary et al, 2019). Thus, the importance of screening for and identifying diabetes distress could be critical to multiple aspects of a person's health.

While research into diabetes distress has increased greatly since 1995, there remains a lack of screening, diagnosis and interventions for patients (Owens-Gary et al, 2019). In 2016, the ADA recommended that people with diabetes be psychologically evaluated for depressive disorders both annually and before prescribing insulin, due to this medication's potential deadly effects (ADA, 2016). However, routine screening for diabetes distress is not commonly performed during clinic visits. This disconnect between national recommendations and provider screening could be attributed to limited time allotted to spend with patients, healthcare professionals' lack of understanding or comfort with mental health screenings, and difficulty distinguishing somatic symptoms from physical symptoms of illness making diabetes distress more difficult to diagnose (Owens-Gary et al, 2019). Diabetes distress can also mimic major depressive disorder, and thus an accurate diagnosis is crucial for the patient (Sweatman et al, 2017).

Recommended screening tools in the literature to assist providers in identifying diabetes distress and depression include the 2-item and 17-item Diabetes Distress Scale (DDS-2 and DDS-17) and the 5-item World Health Organization Wellbeing Index (WHO-5). In addition, the 9-item Patient Health Questionnaire (PHQ-9) is commonly administered routinely as part of annual complete physical exams; however, this can only diagnose major depressive disorder, and therefore, without the administration of a specific screening tool, diabetes distress may go undiagnosed and untreated (Sweatman et al, 2017). Uniquely, the DDS-17 can help determine the specific types of distress if a person tests positive on the shorter DDS-2, and it can assist in distinguishing between major depressive disorder and diabetes distress after a positive WHO-5.

The present study used the DDS-17 and demographic questions to examine the occurrence of diabetes distress in individuals with varying durations of diagnosis and treatment methods, to determine whether there were relationships or differences based on demographics, and to assess patients' views on whether this screening tool would be beneficial for healthcare professionals and diabetes educators to use during routine diabetes clinics.

Methods

This quantitative research project with an exploratory comparative design (Polit and Beck, 2017) aimed to provide information regarding people with diabetes and their levels of distress. We utilised Facebook to host an anonymous, voluntary survey for people with diabetes, aged 18 years and older, including evaluation of diabetes distress via the DDS-17 screening tool, over an 8-week period.

Ethical approval was sought from the Institutional Review Board at Simmons University; however, this research project was deemed exempt.

We used the survey generator Qualtrics (Qualtrics International, Seattle, WA, USA) to create a self-guided experience of screening questions, the full DDS-17 survey and follow-up questions asking participants about their duration of diabetes, medications used and devices used to monitor blood glucose levels. The informed consent form was the first document to appear, and once the participant consented by agreeing to participate, the surveys, DDS-17 questionnaire and follow-up questions became available for completion. Once the survey was completed in its entirety, resources related to diabetes became available in case the participant felt they needed additional information.

Sample and setting

The target cohort included people with any type of diabetes, aged 18 years and older, who were willing to participate in the anonymous survey. Types of diabetes included but were not limited to type 1 diabetes, type 2 diabetes and latent autoimmune diabetes in adults (LADA). No responses were received from people with gestational diabetes or medication-induced diabetes.

Data collection

A recruitment statement was submitted with a Qualtrics link that directed participants to the Facebook page. Anyone who learned of this study could participate. The survey link was posted to social media group pages such as the Diabetes Support Group and Assist Diabetics, both on Facebook.

Once they had consented to participate, participants filled in a survey with specific information about demographics and the type of diabetes, followed by the DDS-17 screening tool and, finally, an exit survey to collect data on participants' perspectives of using the DDS-17 tool.

DDS-17 screening tool

The DDS-17 is a 17-item screening tool that can be utilised to determine the severity of distress experienced by a person with diabetes (Sweatman et al, 2017). It uses a 6-point Likert scale and is divided into four subscales, including interpersonal distress, regimen distress, physician distress and emotional burden distress (Sweatman et al, 2017). When

scoring DDS-17, a score of greater than or equal to 3 equals high distress, a score of 2.0–2.9 equals moderate distress and a score of less than 2 equals little or no distress (Wardian et al, 2019).

The DDS-17 has previously been validated and was deemed to have a consistent, generalisable factor structure and good internal reliability and validity across four different healthcare settings (Polonsky et al, 2005). For the present study, the internal consistency of the DDS-17 and the four subscales was sufficient, with Cronbach's alpha values as follows: total DDS-17, 0.935; interpersonal distress, 0.885; regimen distress, 0.844; physician distress, 0.906; and emotional burden distress, 0.916.

The DDS-17 can be reduced to the DDS-2, which comprises the two questions of **(1)** Feeling overwhelmed by the demands of living with diabetes; and **(2)** Feeling that I am often failing with my diabetes regimen. Therefore, for this study, the relationship of the DDS-17 and DDS-2 was investigated using Spearman's rho, and it was determined that there was a strong positive correlation (r=0.901; P<0.001). This supports parallel reliability of the two assessment versions.

Data analysis

All data were exported from Qualtrics into Microsoft Excel for data review and cleaning. Participants who did not complete the DDS-17 were excluded. All data were then imported into SPSS 27.0 (IBM Corp., Armonk, NY, USA) for analysis.

Descriptive statistics were completed on all demographics, other questions and DDS-17 scores. Due to the lack of normality of the data, non-parametric tests were used to identify the occurrence of diabetes distress in relation to demographics, and whether participants felt that this screening tool would be beneficial for providers and diabetes educators to use during clinics. Specifically, chi-squared tests with cross-tabulation and Spearman's rho were used for relationship analysis, while Kruskal–Wallis one-way ANOVA tests and Mann–Whitney U tests were used for comparative analysis. Statistical significance was determined at the P-value of 0.05 or less, except if multiple *post hoc* Mann–Whitney U tests were used, when the P-value of 0.05 was divided by the number of groups compared. Effect sizes were also calculated.

Results

A total of 143 people completed the surveys over the 8-week study period. The median age of the participants was 48 years. Of the 143 participants, 85 (59.4%) had type 1 diabetes, 50 (35.0%) had type 2 diabetes and eight (5.6%) had LADA. A majority of participants, 44 (31.2%), had been diagnosed for more than 25 years and just 13 (9.2%) had been diagnosed for 1–3 years.

Utility of the DDS-17

Only two participants (1.4%) reported having taken the DDS-17 prior to this study. However, 105 (74.5%) felt the tool would be beneficial for use during clinic visits to identify problems that could arise as a result from managing diabetes.

DDS-17 scores

Median DDS-17 total and subscale scores were as follows:

- Total: 2.47 (interquartile range [IQR], 1.76–3.29).
- Emotional burden: 3.00 (IQR, 2.20–4.40).
- Regimen distress: 2.40 (IQR, 1.60–3.20).
- Physician distress: 1.50 (IQR, 1.00–2.75).
- Interpersonal distress: 2.00 (IQR, 1.33–3.00).

A DDS-17 score of ≥3 is suggestive of diabetes-related distress. Accordingly, 92 participants (64.3%) scored as moderately distressed or greater, while 51 (35.7%) did not. In terms of subtypes, 75.5% of participants had moderate or greater scores for emotional burden distress, 54.5% for regimen distress, 33.6% for physician distress and 46.9% for interpersonal distress.

A Kruskal–Wallis test revealed a statistically significant difference in interpersonal distress score in regard to length of time diagnosed with diabetes (P=0.006). With the adjusted P-value of 0.008 or 0.01, only two groups in terms of diabetes duration showed statistically significant differences. First, those with diabetes of more than 25 years' duration recorded higher scores (median, 3.00; n=44) compared to those diagnosed for less than one year (median, 1.6667; n=24; U=265; z=–3.396; P=0.001; r=0.41, a small to medium effect). Second, those with a diabetes duration of more than 25 years also recorded higher scores (median, 3.00; n=44) compared with those diagnosed for

9–15 years (median, 2.00; n=19; U=254.500; z=–2.462; P=0.014; r=0.31, a small to medium effect). There was no significant difference in scores for any other subscales or the total.

Kruskal–Wallis tests revealed significant differences in scores for Emotional burden (P=0.018), Regimen distress (P=0.009), and Interpersonal distress (P=0.012) between the different diabetes types. Differences in subscale scores also reached the adjusted P-value of 0.017. Mann–Whitney U tests showed that, with regard to Emotional burden, the type 1 diabetes group had a higher median score (3.40; n=85) than the LADA group (2.00; n=8; U=156.000; z=–2.525; P=0.012; r=0.26, a small to medium effect). With regard to Regimen distress, the type 2 diabetes group had a higher median score (2.80; n=50) than the LADA group (1.2000; n=8; U=79.500; z=–2.724; P=0.006; r=0.36, a medium to large effect). With regard to Interpersonal distress, the type 1 diabetes group recorded a higher median score (2.3333; n=85) than the type 2 diabetes group (1.6667; n=50; U=1532.000; z=–2.721; P=0.007; r=0.23, a small to medium effect). There was no significant difference between these groups in terms of total DDS or Physician distress scores.

Diabetes treatments and diabetes distress

Participants gave a total of 382 responses regarding monitoring devices used to manage diabetes. On average, they reported using three monitoring tools. Using cross-tabulation, it was determined that the top three devices patients reported using included continuous glucose monitors (24.1%), traditional glucometers (22.5%) and insulin pumps (14.15%).

Spearman's rho correlations showed no statistically significant relationship between the median number of treatments used for diabetes and a patient's level of distress.

Regarding management frequencies based on type of diabetes, the LADA group had a majority of participants who reported using continuous glucose monitors (30.8%), and the minority reported using oral medications (3.8%). In the type 1 diabetes group, a majority used continuous glucose monitors (28.2%) and the minority reported using oral medications (4.1%). In the type 2 diabetes group, the majority of participants used oral medications

(32.4%) and only one participant (0.9%) used an insulin pump.

Chi-squared tests revealed a significant association between level of distress and different diabetes treatments. Among those who reported using an insulin pump (n=54), 12 (22%) were moderately distressed or greater (χ^2=4.421; df=1; P=0.036; Phi=0.192, a small to medium effect). Among those using rapid-acting insulin in multiple daily injections (n=48), 22 (46%) were moderately distressed or greater (χ^2=3.913; df=1; P=0.048; Phi=0.18, a medium effect). Among those using basal insulin (n=45), 21 (47%) were moderately distressed or greater (χ^2=4.066; df=1; P=0.044; Phi=0.185, a small to medium effect).

Discussion

This study has shown that people with type 1 diabetes have a statistically significant occurrence of emotional burden and interpersonal distress. However, those with type 2 diabetes have a statistically significant occurrence of regimen distress. Individuals with a longer diabetes duration were more likely to experience moderate or greater distress. This finding indicates that the time frame immediately following diagnosis is a crucial one to identifying gaps in understanding of diagnosis, therapy regimens, and support resources.

Only two participants reported having previously taken the DDS-17, despite 64.3% of participants scoring as moderately distressed or greater. Of the 143 participants, 105 felt that use of the survey could be helpful in identifying problems or potential problems in diabetes management. This finding highlights that diabetes-related distress is a problem among people with diabetes, but the DDS-17 is not being used by clinicians as part of routine diabetes care.

There was no statistically significant correlation between the median number of treatments used to manage diabetes and the level of distress an individual experienced. This finding could be helpful to clinicians who may be hesitant to add additional treatment modalities to a patient's regimen due to concern for overwhelming or overburdening them.

Study limitations

This study was limited as it was conducted solely on social media and was performed as a self-selected and self-reported survey. We did not include demographic questions to determine the gender and ethnicity of participants. In addition, there was no opportunity for dialogue between participants and researchers regarding question clarification or meaning; therefore, participants may not have fully understood the questions' goal.

It is recommended that similar studies be performed on a larger scale and in different settings, such as clinics and during diabetes education, to further investigate the occurrence of diabetes-related distress. Future studies should also be performed longitudinally to determine whether use of the DDS-17 can assist clinicians in identifying and implementing patient-specific interventions, thus potentially reducing distress, improving self-care behaviours, increasing patient–provider collaboration and improving glycaemic control. This research could be used to support a recommendation for annual screening of all patients with diabetes for diabetes distress with the DDS-17.

Conclusion

The interventions required to maintain ideal glycaemic control are intricate and require constant monitoring and adaptation on a daily basis. These unending tasks can contribute to changes in emotional, physical and self-care behaviours and, if not properly identified and optimised, can result in diabetes-related distress. While research and awareness regarding diabetes distress have increased greatly since the term was first coined in 1995, there remains a lack of consistent screening and identification of the phenomenon. Results from this study show that Emotion, Regimen and Interpersonal distress scores vary significantly depending on the type of diabetes. There was also a significant difference in the level of interpersonal distress based on the number of years a person had been diagnosed with diabetes. Furthermore, people with type 1 diabetes had higher, statistically significant Emotional burden and Interpersonal distress scores; however, those with type 2 diabetes had higher Regimen distress scores. While this study gives insight to the prevalence of distress among patients with diabetes, it is merely a starting point for further research and potential practice changes. ■

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American Diabetes Association (2016) Standards of medical care in diabetes – 2016. *Diabetes Care* **39**(Suppl 1): S1–109

American Diabetes Association (2020) 5. Facilitating behavior change and well-being to improve health outcomes: Standards of Medical Care in Diabetes – 2020. *Diabetes Care* **43**(Suppl 1): S48–65

Centers for Disease Control and Prevention (2021) *Diabetes and Mental Health*. CDC, Atlanta, GA, USA. Available at: https://bit.ly/3KSdYzQ (accessed 28.01.22)

Kaiser A, Mehboob N (2020) Impact of diabetes distress on self-management, and self-esteem among diabetics. *Pakistan Journal of Medical Research* **59**: 51–4

Ni YX, Ma L, Li JP (2021) Effects of mindfulness-based intervention on glycemic control and psychological outcomes in people with diabetes: a systematic review and meta-analysis. *J Diabetes Investig* **12**: 1092–103

Owens-Gary MD, Zhang X, Jawanda S et al (2019) The importance of addressing depression and diabetes distress in adults with type 2 diabetes. *J Gen Intern Med* **34**: 320–4

Polit DF, Beck CT (2017) *Resource Manual for Nursing Research, Generating and Assessing Evidence for Nursing Practice* (10th edition). Wolters Kluwer, Philadelphia, PA, USA

Polonsky WH, Fisher L, Earles J et al (2005) Assessing psychosocial distress in diabetes: development of the Diabetes Distress Scale. *Diabetes Care* **28**: 626–31

Skinner TC, Joensen L, Parkin T (2020) Twenty-five years of diabetes distress research. *Diabet Med* **37**: 393–400

Sweatman C, Lauerer JA, Pruitt C, Drayton SJ (2017) Major depressive disorder or diabetes-related distress? Screening, evaluation, and treatment in adults with diabetes. *Journal for Nurse Practitioners* **13**: e117–23

Wardian JL, Kanzler KE, True MW et al (2019) Is it distress, depression, or both? Exploring differences in the Diabetes Distress Scale and the Patient Health Questionnaire in a diabetes specialty clinic. *Clin Diabetes* **37**: 124–30