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Development and validation of a scale to measure diabetes burnout

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ARTICLE INFO	A B S T R A C T
<i>Keywords:</i> Diabetes burnout Diabetes distress Depressive symptoms Type 1 diabetes Measurement development	<i>Introduction:</i> The aim of this study is to establish reliability and validity of the Diabetes Burnout Scale (DBS) among adults with type 1 diabetes (T1D). <i>Methods:</i> We used a multi-stage, mixed methods approach to developing the DBS. First, the research team identified twenty-eight candidate items through a review of the literature and 117 qualitative narratives from adults living with T1D. Next, items were revised based on the expert (n = 20) and individual with T1D (n = 10) feedback. The resulting 18-item DBS measure along with validated measures of diabetes distress, depressive symptoms, and questions related to diabetes outcomes (i.e., last reported hemoglobin A1c [HbA1c] and Time-in-Range [TiR]) were completed by 1099 adults with T1D across the U.S. The sample was randomly divided into two subsets (n1 = 561, n2 = 538) for exploratory and confirmatory factor analyses (EFA/CFA) to determine the underlying structure of the DBS. Regression analyses examined the relationships of the DBS with self-reported glycemic control and socio-demographic characteristics. <i>Results</i> : Based on the EFA three factors are identified and the DBS demonstrated strong internal consistency with Cronbach alphas (≥0.80). The validation and confirmatory analysis for the structure of the DBS provided consistent results with EFA. Higher burnout (overall DBS) was positively associated with diabetes distress (b = 0.74; p < 0.01) and depressive symptoms (b = 0.61; p < 0.01). Overall DBS, however was the strongest predictor for poorer HbA1c (r2 = 0.19; p < 0.01) and lower TiR (r2 = 0.17; p < 0.01) compared to diabetes. The results provide a weak to strong degree of association between the validated DBS scale, T1-DDS and PHQ-8. The DBS can contribute to advancement of diabetes science by measuring diabetes burnout and informing clinical interventions to improve psychosocial care in individuals with diabetes.

Introduction

T1D is one of the most challenging chronic illnesses involving consistent and complex management needs and demands. [1] Over time, emotional burden and constant distress related to T1D management can result in diabetes burnout. [2] Diabetes burnout was primarily described as an overwhelming feeling of exhaustion and frustration in managing diabetes that may ultimately lead to ignoring self-care behaviors for a period of time. [3–5] Diabetes burnout is common. Across two studies, it

appears that 36% of individuals with diabetes identified diabetes burnout as a barrier to suboptimal self-care behaviors and medication adherence. [6–7] In DAWN study along with depression, anxiety, and stress, diabetes burnout is listed as one of the main psychosocial complications of diabetes by 66%–74% of providers. [8] The American Diabetes Association [9] and Centers for Disease Control and Prevention [10] regard diabetes burnout as a barrier to adherence to recommended treatment. Diabetes burnout can lead to significant risk for adverse diabetes outcomes. [11–17] Fonda et al. (2013) suggested diabetes

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burnout as a contributing factor to poor glycemic control and emphasized the necessity of evaluating individuals with diabetes for burnout and intervening appropriately. [18] Despite early introduction of the concept [3–5] and the growing scientific awareness around the necessity to address diabetes burnout, [17–21] the concept was not clearly defined, its measurement could not be developed, and therefore diabetes burnout could not be scientifically described.

To expand existing science on diabetes burnout, our interdisciplinary research team conducted several exploratory studies to examine diabetes burnout among adults with T1D. [22-26] These preliminary studies refined our understanding of diabetes burnout as it manifests in adults with T1D, and helped establish main dimensions of the concept. According to our findings, we conceptualize diabetes burnout as a multidimensional concept comprising three distinct but related dimensions including exhaustion, detachment, and loss of control over one's illness that can form different burnout profiles. We define exhaustion as the lack of mental, emotional, and physical energy needed to make an enduring engagement in diabetes self-care. We argue that exhaustion should not only include emotional exhaustion but also mental and physical exhaustion. A feeling of loss of control over managing diabetes might exist as an accompaniment to Exhaustion. Exhaustion and loss of control may prompt individuals to detach from their illness identity, diabetes self-care, and support systems. Detachment often manifests as apathy, with an individual consciously ignoring almost all or the most challenging aspects of self-care behaviors (i.e., insulin injection, pump exchange, blood glucose monitoring, carb counting) which can result in elevated HbA1c levels, diabetic ketoacidosis (DKA), missed appointments, emergency department visits, or hospitalization if such detachment is of extended duration. [22-26]

In our earlier studies similar to other studies individuals with T1D often described their experience with T1D as being like a "full-time job." [22–26] We additionally saw other parallels to the existing literature around occupational burnout describing burnout as exhaustion, cynicism and professional inefficacy. [27–28] For example, the similarity of Maslach burnout theory and our conceptualization of diabetes burnout in terms of their three-dimension structure has been demonstrated in our preliminary research. We identified key differences in diabetes burnout relative to occupational burnout as a concept. T1D might be described as a full time job; however, occupational burnout measures do not reflect the unique characteristics of T1D as a chronic and demanding illness. Additionally, cynicism a concept similar to detachment in diabetes burnout does not include items relevant to illness identity and self-care behaviors. Loss of control over diabetes is also conceptually different from professional inefficacy in Maslach burnout theory.

Diabetes burnout is usually discussed in diabetes literature as a general term or an alternative for diabetes distress or depressive symptoms. [29-31] Although, we argue that diabetes burnout is a distinct but related concept to similar concepts. However, there is no reliable and valid instrument to assist researchers and clinicians to identify individuals with T1D who experience diabetes burnout. Currently available validated instruments primarily focus on assessment of diabetes distress [32-33] or depressive symptoms [34] while individuals with diabetes describe diabetes burnout as a unique experience. Althogh, a conceptual overlap between powerlessness subscale in T1-DDS and Loss of control in diabetes burnout has been identified in recent studies, [22-26] where both measures include items assessing emotional burden of diabetes. We argue that existing diabetes distress measurements (i.e., Problem Areas in Diabetes Scales [PAID] [33] or Type 1- Diabetes Distress Scale [T1-DDS]³²) do not assess the unique dimensions of diabetes burnout. For example, the PAID scale aims to measure emotional distress in living with diabetes; however, it includes items related to burnout (i.e., feeling "burned out" by the constant effort needed to manage diabetes) and depression (i.e., feeling "depressed" when you think about living with diabetes). The T1-DDS, focuses on sources of distress in adults with T1D which may lead to not assessing the full range of experiencing diabetes burnout.

The importance of diabetes burnout should not be underestimated. If patient center care and embedding psychosocial care in clinical settings is a recommended approach, it is crucial to assess diabetes burnout rather than falsely label it as non-compliance or misinterpret it as diabetes distress or depressive symptoms. It has been increasingly recommended that providers should screen and address diabetes burnout to improve diabetes care. [17-21] Routine monitoring and discussing diabetes burnout with individuals with T1D have also been discussed to improve psychosocial well-being and diabetes outcomes. [18,35-36] However, in our preliminary studies [22-24] individuals with T1D highlighted a lack of support system. This combined with the relentless 24/7 nature of managing T1D and demand a specific consideration toward addressing diabetes burnout. [22-25] Failure to recognize diabetes burnout, prevent burnout informed assessment and personalize management that may result in poor diabetes outcomes. Recent diabetes distress interventions offer promising strategies for effectively reducing diabetes distress. [37] While these strategies may be effective or inform elements of programs to address or prevent diabetes burnout, there is currently a paucity of existing studies in this area to evaluate. In addition, there are likely specific aspects of diabetes burnout that are worthy of consideration alongside or in addition. For example, as burnout can include a disengagement from diabetes care emotionally or behaviorally, specific strategies to connect with individuals experiencing burnout to link with or retain individuals in care programs (e.g., relationship building, motivational interviewing); and likewise healthcare provider training to re-conceptualize individuals as burned out rather than "noncompliant" may be necessary. In addition, those experiencing burnout may likely be more disengaged from care and potentially willingness to engage in interventions, thus it may be that specialized programs and approaches are needed to engage these individuals. Given disengagement from healthcare system this may need to be a community level or program outside of the healthcare sector.

Improved diabetes outcomes and providing patient canter care will depend on the availability of an accurate understanding of diabetes burnout and, where needed, appropriate action to eliminate gaps. Such a measure can be helpful in identifying T1D populations at particular levels of diabetes burnout so that preventative interventions can take place. We hypothesized that DBS, designed with input from adults with T1D and diabetes experts, both researchers and clinicians, would demonstrate psychometric reliability and validity and distinguish diabetes burnout from diabetes distress and depressive symptoms. This manuscript specifically discusses (1) scale structure and reliability of the newly developed DBS, and (2) external validity, assessed through associations with diabetes distress and depressive symptoms, and (3) the associations between DBS, diabetes outcomes and socio-demographic variables.

Methods and materials

Design

For DBS development, we followed multiple steps, including item generation, scale development and scale evaluation per measure development guidelines. [38]

Step 1- Item generation

In this step we used a combination of inductive and deductive methods to generate items. We ensured that the conceptualization of diabetes burnout is shaped by relevant existing occupational burnout theories and the language that individuals with T1D use to describe their experience. The initial dimensions and items relevant to diabetes burnout was informed by findings from four preliminary qualitative studies, analyzing 117 qualitative narratives. We first analyzed blog narratives (n = 35) [22] and YouTube videos [23] (n = 21) produced with a title or content saturated with diabetes burnout to realize how adults with T1D think about the focal construct in their own words, with

minimal prompting from the researcher. Then we conducted unstructured individual interviews [24] (n = 18), semi-structured individual interviews [25] (n = 31) and focus groups (n = 12) to assess whether respondents agree with certain characteristics of the concept emerged from preliminary studies. The qualitative findings provided us with insight into how adults with T1D conceptualize diabetes burnout. The illustrative quotes of specific themes and sub-themes were used to inform items generation.

We also reviewed occupational burnout theories and specific measures to identify relevant existing scales or items that might be used or adopted. We used the literature review to ensure that the concept and its dimensions aligned with prior research and theories of burnout. Through this process we identified 6 measures of burnout in occupational literature [39-44], and we mapped relevant items into the corresponding dimensions of diabetes burnout (exhaustion [n = 9 items], detachment [n = 11 items], and loss of control [n = 8 items]). The results of deductive and inductive approach were emerged to draft a comprehensive list of items (n = 28) in a language that adults with T1D can easily understand. Exhaustion items measured lack of physical, mental, and emotional energy needed to make an enduring engagement in diabetes self-care. Detachment was characterized by (1) distancing oneself from illness identity, (2) development of an apathetic attitude toward diabetes at which individuals intentionally ignore self-care behaviors, as well as (3) not seeking help to re-take the ownership of the illness. Loss of control items measured (1) loss of control over managing diabetes and (2) loss of control to re-take the ownership of the illness. Based on reports [45] that suggest the reverse scored items may be confusing to participants we developed all burnout items negatively.

Step 2: Survey development and item adjustment

During this step, we used Content Validity Index (CVI) [46] to determine if the proposed items measures all aspects of the concept of diabetes burnout, and to identify any additional/alternative items that should be considered for inclusion. Diabetes content experts, including both clinicians and researchers (n = 20), as well as a new sample of adults with T1D (n = 10), reviewed the draft burnout items to generate consensus about the concept being assessed as well as the quality and relevance of the proposed items. [47] Respondents completed a content validation form to report: (1) a score for each item on representativeness, relevance, and clarity, (2) an overall score for the survey and each dimensions on its comprehensiveness to measure diabetes burnout, (3) items that may have been missed, and (4) any additional qualitative feedback on the construct and the items. CVI was computed as the number of respondents giving a score of 3 or 4 for each item divided by the total number of respondents. We included items with CVI above 0.79 in the survey and eliminated items of low relevance (CVI below 0.70), or revised items with CVI between 0.70 and 0.79. [46] We also added or adjusted items based on feedback (Table 1).

Phase 3- Survey evaluation

To access a national sample of adults with T1D, we recruited 1099 study participants using diabetes support groups on social media and the national T1Exchange registry in the US. The following inclusion criteria were used: (1) T1D diagnosis for at least 1 year, (2) age 18 years or older, (3) able to read, write, and speak in English, and (4) being on continues glucose monitoring (CGM). We included all eligible adults with T1D without considering their current or previous experience of burnout for two main reasons: (1) diabetes burnout is a prevalent problem (prior research suggesting that up to 36% of adults experience diabetes burnout); [31-32] and (2) the dimensions of diabetes burnout that we identified in our preliminary studies [15-19] likely affect a higher percentage of adults with T1D. Participants who reported a mental illness diagnosis were excluded. To collect data we developed an online survey using QuestionPro, a user-friendly encrypted web survey tool supported by the University of Tennessee. The survey link was directed potential participants to a landing page including a consent form. After

Table 1

Item	CVI	Dimension
I'm mentally tired by having to think about my diabetes all the time.	1.00	Exhaustion
Taking care of my diabetes is physically draining.	0.81	Exhaustion
It's emotionally exhausting to face another day with diabetes.	1.00	Exhaustion
I'm mentally drained because diabetes is a full-time job.	1.00	Exhaustion
I feel physically depleted by my out of range blood glucose numbers.	0.87	Exhaustion
I'm emotionally exhausted by all I am supposed to do to manage my diabetes.	1.00	Exhaustion
I try to think about my diabetes as little as possible.	0.97	Detachment
When it comes to my diabetes management, I do the bare minimum to survive.	0.81	Detachment
I try to convince myself that is OK to ignore my diabetes management.	0.96	Detachment
I know it is important to manage my diabetes, but often I skip it anyway.	0.95	Detachment
I avoid seeking support for my diabetes management.	0.80	Detachment
I try to ignore my diabetes management as much as possible.	0.92	Detachment
I avoid anything that reminds me that I have diabetes.	0.91	Detachment
There is nothing I can do to manage my diabetes, so why bother?	0.89	Loss of control
I struggle to stay on track with my diabetes management.	0.92	Loss of control
I have to force myself to continue managing my diabetes.	0.94	Loss of control
My diabetes is out of my control.	0.96	Loss of control
I try and try but I can't get a handle on my blood sugar.	0.98	Loss of control

agreeing to participate at the study, participants were directed to screening questions followed by the survey questions if eligible to participate. Participants did not receive any incentives for their time participating at the study. All study activities were approved by the Institutional Review Board (IRB) at the University of Tennessee (#18–04540-XP).

Study measures

Diabetes burnout: Eighteen preliminary DBS items, developed as described above, assessed exhaustion, detachment and loss of control as the main dimensions of diabetes burnout. Participants scored each item using a 5 point Likert scale (1 = strongly disagree to 5 = strongly agree) to share their experiences in the last month.

Diabetes distress: We used the T1-DDS to assess diabetes distress. [32] T1-DDS assesses worries and concerns specifically related to ability to manage diabetes (alpha Cronbach = 0.93) on a six point Likert scale (1 = not a problem to 6 = a serious problem). Scores of less than 2, 2 to 2.9, and 3 or higher represent cut points for no/mild distress, moderate and high distress, respectively.

Depressive symptoms: We used the Patient Health Questionnaire-8 (PHQ-8) [34] to assess depressive symptoms. The 8-item scale is linked to DSM-V criteria for Major Depressive Disorder (alpha Cronbach = 0.89), with each item rated on a four point scale (0 = not at all to 3 = nearly every day). Scores on each item are totaled, and total scores of 5, 10, 15, and 20 on the PHQ-8 represent cut points for mild, moderate, moderately severe, and severe depressive symptoms, respectively.

Diabetes Outcomes: Survey respondents reported their last recorded HbA1c in the past year and the average percentage their daily blood glucose fell in the target range of 70–180 mg/dl [Time-in-Range (TiR)]. TiR data was based on the participants' self-report from their CGM over the last day, rather than collecting copies of the CGM data.

Sociodemographic data: Participants answered several questions related to gender, race, years of having T1D, education level, employment, marital status, income, and residential area (i.e., urban, sub

urban, rural).

Data analysis

We randomly divided the sample into two subsets. To assess the psychometric properties of DBS, we used a combination of EFA (using the Principal Components Method and oblique rotation) on a sample of 561 participants and CFA (using fixed and free parameters) on a different sample of 538 participants. The minimum acceptable number is 150 observations [48] or a minimum of 5 observations per estimated parameter. [49] In this case, the number of estimated parameters is 12 and the case ratio per parameter is 45.08: 1.

To determine the fit of the models to the data, we used the following criteria: Chi-square test for fit quality, GFI (Goodness of Fit Index) value greater than or equal to 0.85, AGFI (GFI Adjusted for Degrees of Freedom) with value greater than or equal to 0.80, CFI (Bentler's Comparative Fit Index) and NFI (Normed Fit Index) greater than or equal to 0.90 and RMSEA (Root mean square error of approximation) with a value less than or equal to 0.08. Cronbach's alpha was used to assess internal consistency. We calculated the total score for each DBS dimensions (i.e., exhaustion, detachment, and loss of control) and overall DBS.

To assess the association between continuous scores of DBS, T1-DDS, and PHQ-8, we used the Spearman correlation coefficient. To assess diabetes burnout, diabetes distress, and depressive symptoms as predictive factors for diabetes outcomes, univariate and multivariate (stepwise selection) regression analysis was used. We first added T1-DDS, following PHQ-8 and then DBS. All possible combinations were tested until achieving the final model. We also conducted joint factor analysis to identify the overlap between T1-DDS and DBS. Categorical sociodemographic data were transformed into dummy variables for application in the analysis. All analyzes were performed by SAS System for Windows (Statistical Analysis System), version 9.4. SAS Institute Inc.

Results

Overall, our analytic sample (n = 1099) was predominantly white (94.5%), female (75.6%), educated (73.5% had a Bachelor's degree or higher), and working full-time (50.6%). Almost one-quarter of the sample reported an annual income more than 108 K (24.6%). On average, respondents were approximately 46 years of age (SD = 15) and had diabetes for more than 27 years (SD = 16). Most lived in suburban locales (56.7%). Regarding marital status, the participants were predominantly married (61.7%). Participants scored an average of 6.90 out of a possible 24 on the PHQ-8 and 2.09 out of 6 on the T1-DDS. Based on the clinical cut points for the PHQ-8 and T1-DDS, 26.4% of the sample would be classified as having moderately severe (scores 10–19) to severe depressive symptoms (scores \geq 20), 45.85% would be considered to have moderate (score of 2.0–2.9) to high (scores \geq 3) distress. (Table 2).

Exploratory factor analysis of DBS

We used EFA with Varimax oblique rotation to determine if all 18 DBS initial items should be retained in the measure and if the items aligned with the categorized into hypothesized subscales. The value of the Kaiser-Meyer-Olkin (KMO) was above 0.80 indicating our sample (n = 561) was sufficient to be used in EFA. Two of the emergent factors had an eigenvalue greater than 1 and explained 62.36% of the data variability, while the third factor (eigenvalue = 0.97) increased this figure to 70.40% of the variability. Given the eigenvalue of the third factor approached 1.00, the three factor solution was accepted given the increased clarity and clinical utility of the solution. Items with factor loadings below 0.6 were excluded (n = 6) after the analysis by Principal Components Method. A second EFA was performed using the remaining 12 items. All items loaded onto one of three factors (Table 3). The

Table 2

	Descriptive Statistics -	 Sociodemographic 	characteristics and	scale results.
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	N	Mean/ Percent/	SD	Min/ Q1	Max/ Q3
		Median			
Demographics					
Age Years since T1D Diagnosis	1098 1098	46.26 27.14	15,47 16.11	18 0	81 72
Gender:	1098	27.11	10.11	0	/2
Male		23.4%			
Female		75.6%			
Prefer to not disclose Others		0.4% 0.4%			
Race:	1098	01170			
White or Caucasian		94.5%			
Black or African		1.7%			
American American Indian or		0.4%			
Alaskan native		0.490			
Asian		0.5%			
Multiracial		1.7%			
Others	1097	1.0%			
Employment: Part-Time	1097	9.8%			
Full-Time		50.6%			
Self-Employed		5.7%			
Student		4.6%			
Homemaker Unemployed		4.7% 6.9%			
Retired		14.7%			
Others		2.9%			
Residential area:	1096				
Rural Urban		18.9% 24.0%			
Suburban		24.0% 56.7%			
Marital Status:	1096				
Single		26.6%			
Married		61.7%			
Divorced Widow		7.9% 1.4%			
Other		2.5%			
Income (in dollars):	1101				
<31 k		18.5%			
31–42 k 42–64 k		9.0% 18.8%			
64–86 k		15.3%			
86–108 k		13.0%			
>108 k		24.6%			
Education:	1101	0.5%			
Less than a high school Associate's		12.2%			
High School/GED		13.7%			
Bachelor's		38.6%			
Graduate		34.9%			
Scales –scores PHQ-8	1098	6.90	5.56	0.00	24.00
T1-DDS	1070	0.90	0.00	0.00	200
T1DDS Powerlessness	1097	2.85	1.17	1.00	6.00
subscale	1007	1 74	0.04	1.00	F 75
T1DDS Management Distress subscale	1097	1.74	0,84	1.00	5.75
T1DDS Hypoglycemia	1097	2.27	1.18	1.00	6.00
Distress subscale					
T1DDS Negative Social	1097	1.83	1.00	1.00	6.00
Perceptions subscale	1007	0.51	1.10	1 00	6.00
T1DDS Eating Distress subscale	1097	2.51	1.18	1.00	6.00
T1DDS Physician	1097	1.66	1.04	1.00	6.00
Distress subscale					
T1DDS Family/Friends	1097	1.72	0.90	1.00	6.00
Distress subscale T1DDS TOTAL	1097	2.09	0.77	1.00	5.71
DBS	109/	2.09	0.77	1.00	5./1
DBS Exhaustion subscale	1099	3.22	1.00	1.00	5.00
DBS Detachment	1099	1.67	0.66	1.00	4.80
subscale	1099	2.21	0.92	1.00	5.00
	1099	2.21			
			(con	tinued on a	uext page)

Table 2 (continued)

	Ν	Mean/ Percent/ Median	SD	Min/ Q1	Max/ Q3
DBS Loss of Control					
subscale					
DBS total	1099	2.31	0.66	1.00	4.42
Diabetes Outcomes					
Hb A1C	1096	6.97	1.10	4.20	13.00
Daily TiR	1077	69.64	18.05	0.00	100.00

Table	3
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Exploratory and Confirmatory Factor Analysis of the DBS scale.

Items	Exhaustion	Detachment	Loss of control
EFA Results			
I'm mentally tired by having to think about my diabetes all the time	0.82922	0.14599	0.19774
Taking care of my diabetes is physically draining	0.83616	0.03523	0.22792
I'm mentally drained because diabetes is a full-time job	0.89051	0.16487	0.14726
I'm emotionally exhausted by all I am supposed to do to manage my diabetes	0.85052	0.20293	0.20799
When it comes to my diabetes management, I do the bare minimum to survive	0.07194	0.74682	0.30274
I try to convince myself that is OK to ignore my diabetes	0.10410	0.79087	0.17576
I try to ignore my diabetes management as much as possible	0.08357	0.82563	0.21797
I avoid anything that reminds me that I have diabetes	0.18413	0.74712	0.11941
I avoid seeking support for my diabetes management	0.13154	0.64250	0.12603
I struggle to stay on track with my diabetes management	0.27750	0.31257	0.69629
My diabetes is out of my control	0.17703	0.30050	0.78195
I try and try but I can't get a handle on my blood sugar	0.29791	0.18351	0.82023
CFA Results			
I'm mentally tired by having to think about my diabetes all the time	0.8306		
Taking care of my diabetes is physically draining	0.8043		
I'm mentally drained because diabetes is a full-time job	0.8807		
I'm emotionally exhausted by all I am supposed to do to manage my	0.8607		
diabetes When it comes to my diabetes management, I do the bare minimum to survive		0.7217	
I try to convince myself that is OK to ignore my diabetes management		0.7140	
I try to ignore my diabetes management as much as possible		0.7439	
I avoid anything that reminds me that I have diabetes		0.8434	
I avoid seeking support for my diabetes		0.6288	
management I struggle to stay on track with my			0.7195
diabetes management			0.8/11
My diabetes is out of my control			0.7611
I try and try but I can't get a handle on my blood sugar			0.8352

scales and subscales exhibited high internal consistency, with Cronbach's alphas of 0.8 or higher (exhaustion = 0.90; detachment = 0.82; loss of control = 0.80; total = 0.88). The correlation between DBS subscales was 0.31 for exhaustion and detachment, 0.51 for exhaustion and loss of control, and 0.52 for detachment and loss of control.

Confirmatory factor analysis of DBS

CFA was performed for the 12 items on the scale with the structure defined by the EFA. A different sample of 538 participants included after the EFA were used. The theoretical model is presented in where exhaustion, detachment and loss of control are the latent variables and the items the observed variables. The relationships among three factors were estimated using the weighted least squares (WLS) method. All the criteria used to verify the adequacy of the instrument's structure were largely satisfactory, indicating acceptable fit of the proposed model to the data. The results were: Goodness of Fit Index (GFI) equal to 0.9451 (greater than 0.85), Adjusted GFI (AGFI) equal to 0.9160 (greater than 0.80), Bentler Comparative Fit Index equal to 0.9585 (greater than 0.90), Bentler-Bonett NFI equal to 0.9440 (greater than 0.90) and RMSEA Estimate equal to 0.0702 (less than 0.08). All parameters in the model were significant. No parameter can be dropped in the Wald tests (Table 3). The distribution of standardized waste is symmetrical around zero.

Associations between DBS, T1-DDS, and PHQ-8

The validity test, Spearman correlation coefficients between the DBS and the T1-DDS and PHO-8 scores, summarized in Table 4 suggest significant, positive relationships across all the concepts (p < 0.001). The associations with the DBS and PHO-8 ranged from weak to strong, with detachment showing the weakest relationship with the PHQ ($\rho = 0.38$), followed by a moderate relationships with the loss of control ($\rho = 0.48$) and exhaustion subscales ($\rho = 0.59$), and a strong relationship with the DBS overall score ($\rho = 0.61$). The correlations between the DBS and diabetes distress as measured by the T1-DDS suggested weak to strong associations between the two scales. The T1-DDS Friends and Family and Hypoglycemia subscales exhibited consistently weak associations with the DBS and its subscales. The T1-DDS Eating, Negative Social Perceptions, and Physician subscales demonstrated weak to moderate relationships with DBS. The T1-DDS Management subscale exhibited moderate to strong associations with the DBS, while the Powerlessness subscale had the most consistently strong correlations with the DBS and its subscales, with the exception of the detachment subscale ($\rho = 0.37$). The T1-DDS overall score was moderately to strongly related to the DBS and its subscales, with detachment showing a moderate association ($\rho =$ 0.49), loss of control ($\rho = 0.61$), exhaustion ($\rho = 0.65$), and overall burnout ($\rho = 0.74$) all exhibiting strong correlations with overall distress (Table 4).

Considering the strong relationship between diabetes distress and diabetes burnout, we conducted a joint factor analysis using individual items of DBS and T1-DDS, to determine factor structure across the measures. Analysis resulted in seven distinguishable factors (eigenvalue > 1.00). Items proposed for DBS-Exhaustion and DBS-Detachment subscales were categorized exactly under two distinct factors consistent with the EFA that included DBS items only. DBS-Loss of control items all loaded under one factor (factor 1) along with items from the T1-DDS Powerlessness, T1-DDS Management and T1-DDS Eating distress subscales. Items for T1-DDS Hypoglycemia distress, Friends/Family distress, Physician distress and Negative social perceptions were all categorized under distinct factors similar to T1-DDS original subscales (Table 5). Excluding items with low loading factors did not alter the model and internal correlations were low to moderate (between 0.1 and 0.53).

Overall, the results of joint factor analysis are consistent with regression analysis and support the distinction between DBS and T1-DDS measures. The DBS Exhaustion and Detachment subscales did not have overlap with T1-DDS subscales. DBS Loss of control overlapped with T1-DDS Powerlessness, Management, and Eating distress on a single large factor in this sample, suggesting this aspect of DBS Loss of control may share content and some conceptual overlap with multiple aspects of diabetes distress.

Table 4

Associations between DBS, T1-DDS, and PHQ-8.

	PHQ-8	T1-DDS Powerlessness	T1-DDS Management	T1-DDS Hypoglycemia	T1-DDS Neg Social Perc	T1-DDS Eating	T1-DDS Physician	T1-DDS Friend/Family	T1-DDS Total
DBS Exhaustion	0.5931	0.6888	0.4604	0.3990	0.4214	0.5132	0.3656	0.2836	0.6523
DBS Detachment	0.3828	0.3792	0.5272	0.2203	0.3220	0.3876	0.3797	0.3016	0.4933
DBS Loss of control	0.4892	0.5991	0.6323	0.3139	0.3203	0.5328	0.3534	0.2291	0.6183
DBS Total	0.6199	0.7174	0.6636	0.3972	0.4476	0.6038	0.4574	0.3305	0.7435

The correlation coefficient (ρ) can vary from -1 (indicating a strong negative correlation between the two variables, that is, when one grows the other decreases) to 1 (indicating a strong positive correlation between the two variables. When the ρ is close to 0 concludes that there is no linear correlation between the two variables.

Table 5

Joint factor analysis- T1-DDS and DBS.

Factor Pattern							
	Loss of control/Powerlessness	Detachment	Exhaustion	hypoglycemia	Physician	family/friend	Neg Soci Perception
T1-DDS item 23	0.70284	0.18984	0.17609	-0.07724	0.05581	0.06510	0.30728
T1-DDS- Item 2	0.66779	0.13357	0.24417	0.01200	-0.02747	0.08856	0.20835
T1-DDS- Item 28	0.60900	0.07716	0.50971	0.06724	0.14222	0.07637	0.13044
T1-DDS- Item 25	0.59432	0.44130	0.12080	0.25648	0.22085	0.11859	0.16814
T1-DDS- Item 16	0.57557	0.38361	-0.03662	0.01260	0.13827	0.12065	0.36862
T1-DDS- Item 1	0.57139	0.25690	0.17249	0.16931	0.19113	0.12084	-0.05831
T1-DDS- Item 8	0.54157	-0.00391	0.36452	0.07175	0.19516	0.11579	0.01329
T1-DDS- Item 12	0.53898	-0.03147	0.45167	0.18150	0.10088	0.11852	-0.02989
T1-DDS- Item 5	0.53675	0.39938	0.02967	0.31981	0.17193	0.12333	0.07401
T1-DDS- Item 21	0.50684	0.36793	-0.02970	0.23791	0.14704	0.11646	0.22794
DBS- Item 10	0.50675	0.31566	0.42393	0.11340	-0.01017	0.03431	-0.04376
DBS- Item 7	0.50209	0.39038	0.32576	0.21373	0.06092	0.03754	-0.16238
T1-DDS- Item 13	0.47224	0.36776	0.12904	0.30922	0.19531	0.06165	0.15617
DBS- Item 12	0.45904	0.28818	0.41044	0.10528	0.10820	0.09897	-0.18306
DBS- Item 4	0.20054	0.83600	0.13555	0.13030	0.07394	0.10148	0.13472
DBS- Item 6	0.13434	0.80931	0.09674	0.16495	0.06314	0.08705	0.05751
DBS- Item 8	0.27721	0.79304	0.17767	0.11141	0.08688	0.07582	0.11279
DBS- Item 1	0.22112	0.77923	0.15139	0.13016	0.10346	0.05643	0.08605
T1-DDS- Item 9	0.23874	0.39258	0.05695	0.26774	0.09143	0.20514	0.34168
DBS- Item 3	0.23890	0.05006	0.77866	-0.01620	0.11535	0.10698	0.15493
DBS- Item 2	0.15890	0.12602	0.77803	-0.05496	0.06344	0.09594	0.05327
DBS- Item 11	0.18229	0.10951	0.75925	-0.01126	0.05595	0.03979	0.07875
DBS- Item 9	0.16611	0.11897	0.64879	0.09560	0.02383	0.17437	0.31108
DBS- Item 5	0.06389	0.11535	0.60560	0.14183	0.23819	0.02880	-0.01161
T1-DDS- Item 27	0.18724	0.21927	0.07302	0.76334	0.12395	0.09115	0.15740
T1-DDS- Item 5	0.15151	0.23929	0.00232	0.76010	0.14916	0.04544	0.15609
T1-DDS- Item 22	0.14600	0.15602	0.08429	0.70278	0.12906	0.19296	0.19578
T1-DDS- Item 3	0.00111	0.03145	0.02439	0.68270	0.02199	0.16553	0.06492
T1-DDS- Item 26	0.06760	0.03393	0.08166	0.03387	0.84182	0.15111	0.12687
T1-DDS- Item 14	0.17094	0.15707	0.11502	0.17900	0.83360	0.01018	0.04143
T1-DDS- Item 18	0.09156	0.14404	0.16147	0.13049	0.81007	0.19927	0.14914
T1-DDS- Item 7	0.31062	0.08169	0.23336	0.14875	0.66074	0.16445	0.15899
T1-DDS- Item 6	0.17249	0.05537	0.15175	0.06565	0.13132	0.80172	0.10626
T1-DDS- Item 11	0.04863	0.02515	0.05502	0.21562	0.07234	0.74317	0.10303
T1-DDS- Item 17	0.04402	0.13710	0.10520	0.14657	0.15945	0.72948	0.28821
T1-DDS- Item 20	0.20157	0.17125	0.12323	0.11084	0.11514	0.70780	0.21498
T1-DDS- Item 24	0.17847	0.15000	0.10809	0.25454	0.23023	0.22322	0.69669
T1-DDS- Item 10	0.06097	0.03511	0.21091	0.24286	0.12411	0.25397	0.69415
T1- DDS- Item 4	0.13278	0.18245	0.12051	0.19492	0.10624	0.36168	0.62395
T1- DDS- Item 19	0.18188	0.20082	0.06401	0.36884	0.21046	0.23419	0.39199

Assessment of scales as predictors of diabetes outcomes

The regression analyses showed significant relationships between the PHQ-8, T1-DDS, DBS and the two primary outcomes (last selfreported HbA1c and a daily TiR, p < 0.05). In univariate analysis, on average, the participants with higher scores on the diabetes burnout, diabetes distress, or depressive symptoms scales tended to report higher HbA1c and lower percentage of daily blood glucose in target range. DBS Loss of control score explained the most variation in last recorded HbA1c (r2 = 0.22) and the percentage of daily TiR (r2 = 0.23). The total DBS score similarly explained 19% of the variation in HbA1c and 17% of the variation in TiR. The exhaustion component showed weak coefficients (r2 < 0.1). The detachment component presented coefficients that explain around 11% of the variability of the outcomes. For these outcomes, the PHQ-8 and T1-DDS and its subscales (except Management subscale) had low indices (r2 < 0.1), indicating a weak level of prediction. T1-DDS Management subscale explained 21% of the variation in HbA1c and 17% of the variation in TiR. However, in stepwise multivariate analysis, the only predictor for HbA1c included the total DBS score (r2 = 0.19). Among subscales, the DBS Exhaustion and Loss of control subscale, and T1-DDS Powerlessness and Management subscales, also significantly predicted HbA1c; however, the DBS Exhaustion (r2 =0.29) and Loss of control (r2 = 0.22) were stronger predictors. Total T1-DDS and total DBS also were predictors of TiR, with total DBS score explaining the most variation in the outcome (r2 = 0.18). While T1-DDS Powerlessness and Management were the predictors of TiR, DBS Loss of control subscale explained the most variation in the outcome (r2 = 0.23) (Table 6).

Table 6

Dependent: Hb A1c Univariate model	Beta (CI95%)	P-value	r2	r-adj
Parameter				
DBS Exhaustion	0,29 (0,22; 0,35)	<0.0001	0.0685	0.067
DBS Detachment	0,56 (0,47; 0,66)	<0.0001	0.1129	0.112
DBS Loss of control	0,56 (0,50; 0,63)	<0.0001	0.2235	0.222
DBS TOTAL	0,74 (0,65; 0,82)	<0.0001	0.1977	0.196
PHQ8	0,06 (0,04; 0,07)	<0.0001	0.0773	0.07
T1-DDS Powerlessness	0,22 (0,16; 0,27)	<0.0001	0.0541	0.053
T1-DDS Management	0,61 (0,54; 0,68)	<0.0001	0.2165	0.21
T1-DDS Hypoglycemia	0,10 (0,04; 0,15)	0.0006	0.0106	0.00
T1-DDS Neg Social Percep	0,18 (0,12; 0,25)	<0.0001	0.0280	0.022
T1-DDS Eating	0,26 (0,21; 0,31)	<0.0001	0.0788	0.07
T1-DDS Physician	0,22 (0,16; 0,28)	<0.0001	0.0418	0.040
T1-DDS Friend;/Family	0,15 (0,08; 0,22)	<0.0001	0.0103	0.014
T1-DDS TOTAL	0,43 (0,35; 0,51)	<0.0001	0.0882	0.08
Multivariate model 1				
Step 1 – entered 1) T1-DDS total and 2)	PHQ-8			
Parameter	Beta (CI95%)	P-value	r2	r-mo
T1DDS total	0.29 (0.18; 0.30)	<0.0001	0.0878	0.08
PHQ-8	0.03 (0.02; 0.04)	0.0001	0.0121	0.09
Step 2 – entered DBS total				
Parameter	Beta (CI95%)	P-value	r2	r-mo
T1DDS total	-0.05 (-0.15; 0.05)	0.4050	0.0005	0.19
PHQ-8	0.01 (-0.01; 0.02	0.3665	0.0003	0.19
DBS total	0.74 (0.61; 0.87)	<0.0001	0.1952	0.19
Multivariate model 2	0.7 (0.01, 0.07)	0.0001	0.1902	0.19
Step 1 – entered T1-DDS subscales				
Parameter	Beta (CI95%)	P-value	r2	r-mo
T1-DDS Powerlessness	-0.07 (-0.15; 0.01)	0.0699	0.0005	0.219
T1-DDS Powerlessness T1-DDS Management	0.63 (0.54; 0.72)	<0.0001	0.2164	0.21
-		0.3237		0.21
T1-DDS Hypoglycemia	-0.03 (-0.09; 0.03)	0.4361	0.0006 0.0004	0.22
T1-DDS Neg Social Percep	0.03 (-0.05; 0.11)			
T1-DDS Eating	0.05 (-0.02; 0.12)	0.1192	0.0018	0.219
T1-DDS Physician	0.03 (-0.04; 0.10)	0.3494	0.0007	0.22
T1-DDS Friend;/Family	-0.04 (-0.12; 0.04)	0.3135	0.0004	0.222
Step 2 – entered DBS subscales	D-t- (CIOF0())	Develop	-0	
Parameter	Beta (CI95%)	P-value	r2	r-mo
T1-DDS Powerlessness	-0.20(-0.29; -0.11)	<0.0001	0.0187	0.29
T1-DDS Management	0.44 (0.34; 0.54)	<0.0001	0.0504	0.27
T1-DDS Hypoglycemia	-0.05 (-0.11; 0.01)	0.1087	0.0013	0.293
T1-DDS Neg Social Percep	0.05 (-0.03; 0.13)	0.1665	0.0014	0.294
T1-DDS Eating	0.003 (-0.057; 0.063)	0.9182	0.0001	0.297
T1-DDS Physician	0.03 (-0.05; 0.11)	0.3969	0.0005	0.296
T1-DDS Friend;/Family	-0.03 (-0.11; 0.05)	0.4270	0.0003	0.296
DBS Exhaustion	0.08 (0.001; 0.16)	0.0326	0.2936	0.29
DBS Detachment	0.04 (-0.07; 0.15)	0.4425	0.0004	0.292
DBS Loss of control	0.40 (0.31; 0.49)	<0.0001	0.2217	0.22
Dependent: TiR Univariate model	Beta (CI95%)	P-value	r2	r-adj
Parameter				
DBS Exhaustion	-4,19 (-5,25; -3,14)	<0.0001	0.0535	0.052
DBS Detachment	-8,60 (-10,19; -7,02)	<0.0001	0.0955	0.094
DBS Loss of control	-9,65 (-10,69; -8,60)	<0.0001	0.2336	0.233
DBS TOTAL	-11,67 (-10,17; -13,17)	<0.0001	0.1787	0.17
PHQ8	-0,76 (-0,95; -0,56)	<0.0001	0.0526	0.05
T1-DDS Powerlessness	-3,28 (-4,19; -2,37)	<0.0001	0.0443	0.043
T1-DDS Management	-9,07 (-10,26; -7,88)	<0.0001	0.1713	0.17
T1-DDS Hypoglycemia	-1,54 (-2,45; -0,63)	0.0010	0.0101	0.00
T1-DDS Neg Social Percep	-1,87 (-2,95; -0,79)	0.0007	0.0106	0.00
T1-DDS Eating	-3,54 (-4,44; -2,65)	<0.0001	0.0535	0.05
T1-DDS Physician	-2,44 (-3,50; -1,39)	<0.0001	0.0187	0.01
T1-DDS Friend/Family	-1,36 (-2,56; -0,16)	0.0262	0.0046	0.00
T1-DDS TOTAL	-5,73 (-7,12; -4,34)	<0.0001	0.0576	0.05
Multivariate model 1	2 X Y Y Y Y			
Step 1 – entered 1) T1-DDS total and 2)	PHQ8 total			
Parameter	Beta (CI95%)	P-value	r2	r-mo
T1DDS total	-3.80 (-5.58; -2.02)	<0.0001	0.0574	0.05
PHQ-8	-0.42 (-0.67; -0.17)	0.0009	0.0096	0.05
Step 2 – entered DBS total	-0.12 (-0.07, -0.17)	0.0009	0.0090	0.00
Parameter	Beta (CI05%)	D voluo	*2	
T1DDS total	Beta (CI95%)	P-value 0.0139	r2 0.0049	r-mo 0.18
	2.44 (0.49; 4.33)	0.0139	0.0049	0.18
		0 7000	0.0001	0.100
PHQ-8 DBS total	-0.05 (-0.19; 0.21) -13.46 (-15.60; -11.28)	0.7098 < 0.0001	0.0001 0.1780	0.18 0.17

Table 6 (continued)

Dependent: TiR Univariate model	Beta (CI95%)	P-value	r2	r-adj
Multivariate model 2				
Step 1 – entered T1-DDS subscales				
Parameter	Beta (CI95%)	P-value	r2	r-model
T1-DDS Powerlessness	0.29 (-1.11; 1.67)	0.6765	0.0025	0.2164
T1-DDS Management	-9.93 (-11.53; - 8.33)	<0.0001	0.1713	0.1713
T1-DDS Hypoglycemia	-0.09 (-1.17; 0.99)	0.8643	0.0001	0.1788
T1-DDS Neg Social Percep	0.53 (-0.85; 1.91)	0.4507	0.0005	0.1780
T1-DDS Eating	-0.36 (-1.148; 0.86)	0.5256	0.0002	0.1785
T1-DDS Physician	0.49 (-0.66; 1.64)	0.4011	0.0009	0.1771
T1-DDS Friend;/Family	1.21 (-0.85; 2.57)	0.0797	0.0057	0.1771
Step 2 - entered DBS subscales				
Parameter	Beta (CI95%)	P-value	r2	r-model
T1-DDS Powerlessness	2.46 (1.04; 2.88)	0.0007	0.0208	0.2724
T1-DDS Management	-6.01 (-7.67; -4.34)	<0.0001	0.0233	0.2563
T1-DDS Hypoglycemia	0.23 (-0.79; 1.25)	0.6551	0.0001	0.2824
T1-DDS Neg Social Percep	-0.01 (-1.29; 1.29)	0.9832	0.0001	0.2825
T1-DDS Eating	0.56 (-0.50; 1.62)	0.3003	0.0006	0.2805
T1-DDS Physician	0.51 (-0.58; 1.60)	0.3571	0.0007	0.2817
T1-DDS Friend;/Family	1.03 (-0.25; 2.31)	0.1138	0.0024	0.2771
DBS Exhaustion	-0.66 (-1.82; 0.60)	0.3041	0.0007	0.2810
DBS Detachment	-1.18 (-3.00; 0.64)	0.2059	0.0010	0.2795
DBS Loss of control	-8.21 (-9.66; -6.74)	<0.0001	0.2330	0.2330

Association between sociodemographic characteristics and DBS

Compared to participants with lower DBS score, results of univariate analysis showed that individuals with relatively higher total DBS scores were relatively younger, and more likely to identify as female, nonwhite race and lower educational level and income. <u>However, in</u> <u>multivariate analysis, Exhaustion, Detachment, and total DBS scores</u> were associated with age and educational level. However, Loss of control subscale was associated with age and gender. The complete results are shown in the supplementary table.

Discussion

This study advances psychosocial assessment of diabetes by providing a reliable and valid 12-item measure specific to diabetes burnout. The DBS relies on conceptualization of adults with T1D by assessing three main dimensions including exhaustion, detachment, and loss of control. Items in each dimension and total DBS reflect experiences of adults with T1D while experiencing diabetes burnout. We presented the scores on each burnout dimensions (i.e., exhaustion, detachment, and loss of control) and overall burnout score. While the overall burnout score gives a sense of how an individual is doing across these dimensions of burnout, scores on each dimensions can inform specific interventions and clinical discussions around diabetes burnout since individuals experiencing diabetes burnout may be high in one dimension and low in the others. For example, some potentially reporting only exhaustion and others reporting only loss of control while others may experience exhaustion, detachment and/or loss of control.

Participants scored an average of 2.31 out of 5 on the DBS. The mean score of diabetes burnout is not uniform across the three burnout dimensions. Exhaustion display the highest mean score (Mean = 3.22), reflecting the ongoing mental, emotional and physical exhaustion related to diabetes that individuals with diabetes may experience. Loss of control with the second highest mean score (Mean = 2.21) represents individuals struggles and frustrations of managing diabetes when is outside of one's control. Detachment with the last highest mean score (Mean = 1.67) reflects how individuals may distance themselves from illness identity, support systems, and self-care behaviors. Our findings also suggest 25.0% of participants had high (over average) scores for exhaustion, detachment and loss of control simultaneously. This high rate is similar to the 36% of individuals with diabetes who identified diabetes burnout as a main barrier for optimal diabetes care in other

studies. [6,7] The significant association of DBS with glycemic control and high scores of DBS subscales in the study participants highlights the need to address diabetes burnout in clinical settings as a way to improve psychosocial care and diabetes outcomes. With existing literature supporting the negative impact of diabetes burnout on diabetes outcomes [10–18], the DBS represents an important advancement to assess diabetes burnout as a distinct yet related concept to diabetes distress and depressive symptoms.

Our findings showed strong associations between the DBS subscales and total DBS score with the PHQ and T1-DDS supporting external validity. The high correlation between the DBS and T1-DDS appeared to be driven by the associations between T1-DDS Powerlessness subscale and the DBS Loss of control and Exhaustion subscales. In line with our previous work, [22-26] these associations were expected given the conceptual overlap. However, DBS is a combination of emotions and behaviors related to diabetes burnout grounded in individuals' description of diabetes burnout. More specifically, the DBS Exhaustion subscale includes items focused on mental, emotional, and physical exhaustion related to diabetes, making this a related yet broader assessment. Powerlessness in T1-DDS refers to a broad sense of feeling discouraged about diabetes no matter what actions they take (i.e., Feeling discouraged when I see high blood glucose numbers that I can't explain; and Feeling that no matter how hard I try with my diabetes, it will never be good enough). [32] In contrast, Loss of control, as conceptualized in DBS, is more specifically focused on individuals' struggles in managing diabetes and keeping the ownership of diabetes when is outside of one's control. Feeling powerless for a while, may then put individuals as risk for loss of control and giving up that seem in line with the DBS loss of control items.

Interestingly, the DBS Detachment subscale is the least correlated with the PHQ and T1-DDS scales (weak to moderate correlation) and the content is not covered in other scales, suggesting that this dimension of burnout is unique as it measures intentional distance from illness identity, self-care behaviors and support system.

Likewise, the PHQ-8 includes items related to both affect and behavioral experience, yet are not diabetes focused. Although, we argue that despite the overlap, DBS measure distinct concept from diabetes distress and depressive symptoms considering its specific subscales, conceptualizations, and different purpose. Even though these scales are related, DBS conceptually is not just about emotions but how mentally and physically someone is experiencing diabetes burnout. Different subscales of DBS can also form different burnout profiles (i.e., Exhausted, Disengaged). [23] We argue that DBS and its subscales can help identifying a different group of individuals that usually are missed in healthcare systems. For example, the DBS detachment subscale can be driving toward identifying disengaged individuals in diabetes care that differs from what are chosen to focus on in T1-DDS and PHQ-8. So for circumstances when research and practice is really focus on identifying disengaged individuals, DBS may be a suitable measure. The DBS can help identifying individuals in Loss of control profile in healthcare systems to prevent detachment from diabetes care.

Our findings also reveal a significant linear association between selfreported last HbA1c, the daily TiR and higher scores of DBS in study participants. Diabetes burnout is more strongly associated with glycemic control than diabetes distress and depressive symptoms. Among DBS subscales and other scales, Loss of control and Exhaustion were significantly predicted diabetes outcomes. Although Loss of control was the consistent predictor. Regardless the overlap between the DBS Loss of control and T1-DDS Powerlessness subscales, this result suggest DBS Loss of control as a potentially stronger variable in addressing losing control over the illness as part of burnout experience. While in univariate results, we saw a significant association between DBS Detachment and the diabetes outcomes (HbA1c and TiR) in line with our hypotheses; in the multivariate models incorporating the additional aspects of burnout, we see linkages for DBS Detachment weaken. This appears to be in part, if not largely driven by the introduction of the DBS Loss of control subscale; which is moderately (0.52) correlated with DBS Detachment and which remained a significant predictor of both HbA1c and TiR. DBS Loss of control items describe an individuals' current experience struggling with their management and are thus theoretically more closely linked with diabetes management outcomes. In contrast, while DBS Detachment items describe the experience of avoidance, ignoring or distancing from engaging in behavioral management, this distancing may or may not directly result in a change in glycemic outcomes and this likely varies by the individual and their context. Thus, while Detachment is associated with diabetes outcomes; when considered alongside the other dimensions of burnout it is not significant over and above Loss of Control, which has a closer link conceptually to the diabetes outcomes. Further longitudinal work can help to elucidate the relationship between the three dimensions of DBS and the outcomes over time.

This study also identified total diabetes burnout and each burnout dimensions are significantly related to a variety of socio-demographic and diabetes related characteristics in adults with T1D. Our findings revealed that younger adults with T1D, along with non-white, female participants, lower education level are at a higher risk for diabetes burnout. The findings are in line with literature suggesting diabetes population with these sociodemographic characteristics are more vulnerable to psychosocial challenges in living with diabetes [37,50]. These findings highlights the importance of targeted interventions to address the needs of more vulnerable individuals with diabetes.

Study limitations

The current study has some limitations that should be taken into consideration. We exclusively relied on self-reported Hb A1c and TiR, which introduces more error due to limitations in respondent recall relative to direct measures. Future studies need to include more direct measures, particularly to determine the predictive validity of the DBS. Although, the study sample was nation based derived from social media and T1D Exchange registry, it resulted a sample dominated by white educated females. All study sample also were using CGM which is not a representative sample of adults living with T1D in the US. This could have impacted the results and it does limit generalizability. Replication of findings will allow for greater generalizability. The sample may not be a representative of individuals experiencing burnout since burned out individuals more likely do not participate in diabetes related research studies. A significant percentage of study participants experienced higher scores in a combination of different burnout dimensions, suggesting existence of different profiles for burnout. We argue that future examination of different burnout profiles is worth exploring to inform clinical interventions. Distinguishing among the different burnout profiles will inform initiating specific interventions sensitive to specific burnout profiles as these profiles can be differently developed and differently correlated with the contextual factors. Our sample had fairly well managed diabetes. Therefore it is not clear how the results regarding burnout would generalize to more diverse population. More studies are needed to explore the association between burnout and diabetes outcomes. The study is cross-sectional, therefore the direction between diabetes burnout, diabetes distress, and depressive symptoms and the stability and changes of burnout profiles need more investigations. Data was also collected during the COVID-19 pandemic. As such, it is likely that relative levels of key variables including burnout, distress and depression symptoms may be elevated in response to the pandemic. While we do not have reason to believe that the pandemic will have influenced the underlying factor structure or associations between the items or concepts, the relative frequency and their associations with other management variables may have been impacted by the pandemic. Further research is needed in order to generalize our findings to diabetes populations.

Conclusion

The high prevalence of diabetes burnout and its impact on diabetes outcomes highlight the importance of addressing diabetes burnout in clinical conversations and potentially integrating assessment and management of diabetes burnout in clinical settings. The DBS is brief and low burden and have the potential to be integrated in clinical practice and diabetes research to advance psychosocial diabetes care. The development of DBS can initiate a new line of research to address burnout as an unexplored and significant concept in psychosocial diabetes care. Development of DBS can help clinicians and researchers to acknowledge different manifestations of diabetes burnout (i.e., exhaustion, detachment, and loss of control or a combination of different dimensions) and the total burnout scale to inform specific clinical intervention to address burnout. For example, preventive interventions can be placed to support an individual with high scores of exhaustion and/or loss of control before detachment from self-care behaviors, support systems and illness identity occurs.

Our study suggests that regardless the overlap between diabetes burnout, diabetes distress, and depressive symptoms, there are some relevant differences between the concepts, and that diabetes burnout, diabetes distress and depressive symptoms can occur both separately as well as simultaneously. Little is known about the differences or similarities between diabetes burnout, diabetes distress, and depressive symptoms in empirical research. Future studies need to focus more on utilizing longitudinal designs which will mostly aim at examining these relationships. The complex relationship between DBS and its subscales with T1-DDS and PHQ-8 point to the complexity of these three concepts. A longitudinal study of burnout, distress, and depressive symptoms may provide valuable information as to whether and how these concepts are related and differ.

CRediT authorship contribution statement

Samereh Abdoli: Conceptualization, Methodology, Supervision, Writing - original draft. Katherine Miller-Bains: Visualization, Writing - review & editing. Paulo Fanti: Visualization, Writing - review & editing. Monica S.V.M. Silveira: Writing - review & editing. Danielle Hessler: Methodology, Writing - review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial

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interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

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References

- Shrivastava SR, Shrivastava PS, Ramasamy J. Role of self-care in management of diabetes mellitus. J Diabetes Metab Disord. 2013;12(1):14. https://doi.org/ 10.1186/2251-6581-12-14.
- [2] Center for Disease Control and Prevention. Diabetes 2017 report card. Retrieved from www.cdc.gov/diabetes/library/reports. [Accessed 12 June 2020].
- [3] Hoover JW. Patient burnout and other reasons for noncompliance. Diabetes Educ. 1983;9:41–3.
- [4] Polonsky WH. Understanding and treating patients with diabetes burnout. In Practical Psychology for Diabetes Clinicians. Edited by Anderson BJ, Rubin RR. Alexandria, VA: American Diabetes Association. 1996; 183–192.
- [5] Polonsky WH. Diabetes burnout: What to do when you can't take it anymore. Virginia: American Diabetes Association; 1999.
- [6] Mulvaney SA, Rothman RL, Dietrich MS, Wallston KA, Grove E,... Johnson KB. Using Mobile Phones to Measure Adolescent Diabetes Adherence. Health Psychol. 2012;31(1):43–50.
- [7] Nelson LA, Wallston KA, Kripalani S, LeStourgeon LM, Williamson SE, Mayberry LS. Assessing barriers to diabetes medication adherence using the Information-Motivation-Behavioral Skills Model. Diabetes Res Clin Pract 2018;142: 374–84.
- [8] Peyrot M, Rubin RR, Lauritzen T, Snoek FJ, Matthews DR, Skovlund SE. Psychosocial problems and barriers to improved diabetes management: results of the Cross-National Diabetes Attitudes, Wishes and Needs (DAWN) Study. Diabet Med 2005;22:1379–85.
- [9] American Diabetes Association. Understanding diabetes and mental health. Retrieved from https://www.diabetes.org/diabetes/mental-health. [November 22 2020].
- [10] Center for Disease Control and Prevention. Dealing with diabetes burnout. Retrieved from https://www.cdc.gov/diabetes/library/spotlights/diabetesburnout.html. [November 26 2020].
- [11] Anderson BJ. Can we break down barriers to excellent diabetes healthcare for teenagers with diabetes? Diabetes Manage 2012;2(6):471–3.
- [12] Bollepalli S, Smith LB, Vasquez A, Rodriguez H, Vehik K. Addressing the burdens of type1 diabetes in youth. Clinical Practice 2012;9(4):409–24.
- [13] Gonder-Frederick LA, Cox DJ, Ritterband LM. Diabetes and behavioral medicine: The second decade. J Consult Clin Psychol 2002;70(3):611–25.
- [14] Hood K, Peterson C, Rohan J, Drotar D. Association between adherence and glycemic control in pediatric type 1 diabetes: A meta- analysis. Pediatrics 2009; 124:1171–9.
- [15] Barnard KD, Peyrot M, Holt RIG. Psychosocial support for people with diabetes: past, present and future. Diabet Med 2012;29(11):1358–60. https://doi.org/ 10.1111/j.1464-5491.2012.03727.x.
- [16] Darsa C. How to stay positive and avoid diabetes burnout. Diabetes Health. 2018;3: 6–8.
- [17] Tasi A. Motivating a loved one who has diabetes burnout. Diabetes Forecast. 2017. Available at https://www.diabeteforecast.org [Accessed 26 March 2019].
- [18] Fonda SJ, Graham C, Munakata J, Powers JM, Price D, Vigersky RA. The costeffectiveness of real-time continuous glucose monitoring (RT-CGM) in type 2 diabetes. J Diabetes Sci Technol. 2016;10(4):898–904.
- [19] Phelan H, Lange K, Cengiz E, Gallego P, Majaliwa E, Pelicand J, Smart C, Hofer SH. Clinical Practice Consensus Guidelines 2018: Diabetes education in children and adolescents Pediatric Diabetes. 2018;19(Suppl. 27):75–83.
- [20] Karahan TF, Yalcin BM. The effects of an emotional intelligence skills training program on anxiety, burnout and glycemic control in type 2 diabetes mellitus patients. Turkiye Klinikleri J Med Sci. 2009;29(1):16–24.
- [21] Girouard R. Nurses' guide to teaching diabetes self-management. 2012; Springer publishing company, NY.

- [22] Abdoli S, Hessler D, Vora A, Stuckey H. Improving diabetes care: should we reconceptualize diabetes burnout? Diabetes Educ. 2019;45.
- [23] Abdoli S, Hessler D, Vora A, Smither B, Stuckey, H. Experiences of diabetes burnout: A qualitative study among people with type 1 diabetes. Am J Nurs. 2019; 119 (12).
- [24] Abdoli S, Hessler D, Vora A, Smither B, Stuckey H. Descriptions of diabetes burnout from individuals with Type 1 diabetes: an analysis of YouTube videos. Diabet Med 2019.
- [25] Abdoli S, Hessler D, Smither B, Miller-Bains K, Erin B, Stuckey H. New insights into diabetes burnout and its distinction from diabetes distress and depressive symptoms: A qualitative study. Diabetes Res Clin Pract 2020.
- [26] Abdoli S, Miller-Bains K, Burr E, Smither B, Hessler D. Burnout, distress, and depressive symptoms in Adults with Type 1 Diabetes. J Diabetes Complications. 2020;34(7).
- [27] Maslach C, Leiter PM. Understanding the burnout experience: recent research and its implications for psychiatry. World Psychiatry. 2016;15(2):103–11.
- [28] Maslach C, Schaufeli WB, Leiter MP. Job burnout. Annu. Rev. Psychol. 2001;52: 397–422.
- [29] Fisher L, Hessler D, Polonsky W, Strycker L, Masharani U, Peters A. Diabetes distress in adults with type 1 diabetes: prevalence, incidence and change over time. J Diabetes Complications. 2016;30(6):1123–8.
- [30] Pyatak EA, Florindez D, Weigensberg MJ. Adherence decision making in the everyday lives of emerging adults with type 1 diabetes. Patient Prefer Adherence. 2013;7:709–18.
- [31] Nash J. Depression, low mood and burnout. In: Nash J, ed. Diabetes and wellbeing: Managing the psychological and emotional challenges of diabetes types 1 and 2. Oxford, UK: Wiley-Blackwell; 2013:49-79. https://doi.org/10.1002/ 9781118485415.
- [32] Fisher L, Polonsky WH, Hessler DM, Masharani U, Blumer I, Peters AL,...& Bowyer V. Understanding the sources of diabetes distress in adults with type 1 diabetes. J Diabetes. 2015;29(4):572–7.
- [33] Welch GW, Jacobson AM, Polonsky WH. The Problem Areas in Diabetes Scale. An evaluation of its clinical utility. Diabetes Care 1997;20(5):760–6.
- [34] Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. J Affect Disord. 2009; 114(1-3):163–73.
- [35] Culman M, Guja C, Miulescu RD. Diabetes burnout. Review. Proc. Rom. Acad. 2016;18(1):25–30.
- [36] Snoek FJ, Skinner TC. Psychological aspects of diabetes management. Medicine. 2014;34(2):61–2.
- [37] Hessler DH, Fisher L, Glasgow RE, Stryker LA, Dickinson LM, Arean PA, Masharani U. Reductions in diabetes distress are associated with improved management and glycemic control over time. Diabetes Care 2014;37:617–24.
- [38] Schwab DP. Construct validity in organization behavior, Pp, 3-43 in BM, Staw & LL, Cummings (Eds), Research in organizational behavior, Vol, 2, Greenwich, CT: JAI Press; 1980.
- [39] Schwab DP. Construct validity in organization behavior, Pp, 3-43 in BM, Staw & LL, Cummings (Eds), Research in organizational behavior, Vol, 2, Greenwich, CT: JAI Press; 1980.
- [40] Pines A, Aronson E. Career burnout: Causes and cures (2nd edn., pp. 80–96). New York: Free Press; 1988.
- [41] Demerouti E, Bakker AB. The Oldenburg Burnout Inventory: A good alternative to measure burnout and engagement. In J. Halbesleben (Ed.), Stress and burnout in health care (pp. 65–78). Hauppauge, NY: Nova Science; 2008.
- [42] Shirom A. Burnout in work organizations. In C.L. Cooper & I. Robertson (Eds.), International review of industrial and organizational psychology (pp. 26–48). New York: Wiley; 1989.
- [43] Montero-Marín J, García-Campayo J. A newer and broader definition of burnout: Validation of the "Burnout Clinical Subtype Questionnaire (BCSQ-36)". BMC Public Health. 2010;10:302.
- [44] Kristensen TS, Borritz M, Villadsen E, Christensen KB. The Copenhagen Burnout Inventory: A new tool for the assessment of burnout. Work & Stress 2005;19(3): 192–207.
- [45] Rodebaugh TL, Woods CM, Heimberg RG. The reverse of social anxiety is not always the opposite: The reverse-scored items of the Social Interaction Anxiety Scale do not belong. Behav Ther 2007;38:192–206.
- [46] Zamanzadeh V, Ghahramanian A, Rassouli M, Abbaszadeh A, Alavi- H. Design and implementation content validity Study: development of an instrument for measuring patient-centered communication. J Caring Sci. 2015;4(5):165–78.
- [47] Rubio DM, Berg-Weger M, Tebb SS, Lee ES, Rauch S. Objectifying content validity: Conducting a content validity study in social work research. Soc Work Res. 2003; 27(2):94–104.
- [48] Boomsma A. Robustness of LISREL against small sample sizes in factor analysis models. In: Joreskog KG, Wold H, editors. Systems under indirection observation: Causality, structure, prediction (Part I) Amsterdam, Netherlands: North Holland; 1982: 149–173.
- [49] Bentler PM, Chou CH. Practical issues in structural modeling. Sociological Methods Res 1987;16:78–117.
- [50] Hessler DM, Fisher L, Mullan JT, Glasgow RE, Masharani U. Patient age: a neglected factor when considering disease management in adults with type 2 diabetes. Patient Educ Couns 2011;85:154–9.