Validation of the Diabetes Distress Scale in an Asian Pacific Islander Population

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Abstract

Diabetes distress (DD) generally refers to the emotional and cognitive stress caused by the daily management of diabetes. The Diabetes Distress Scale (DDS)-17 is a 17-item instrument that is frequently used to screen DD and the Fisher's DDS2, developed by Fisher, et al, is a two-item instrument to quickly identify DD. However, these scales have been validated in Caucasian populations but not in Asian Pacific Islander (API) populations. This study aimed to 1) evaluate content validity of the DDS17 by evaluating correlation with hemoglobin A1c and 2) identify two items to develop a brief screening tool, DDS2, for an API population. We conducted a retrospective chart review of 443 patients at a diabetes center in Hawai'i.

On their initial visit, patients filled out the DDS17 as a part of the standard of care. The DDS17 showed high reliability (Cronbach's alpha = 0.94). The two items of our DDS2 with the highest phi coefficient (0.59 each) to the total DDS17 subscales were selected from the interpersonal distress and the emotional burden subscales. The phi coefficient (0.74) of our DDS2 was higher than that of the Fisher's DDS2 (0.60). All DDS items showed positive correlation with hemoglobin A1c (DDS17: r = 0.18, DDS2: r = 0.16, Fisher's DDS2: r = 0.21, respectively). Therefore, these scales can be used to measure DD in an API population and the positive correlation suggests that addressing DD may improve glycemic control and vice versa. Clinicians with limited time may consider using our DDS2 rather than DDS17 to quickly screen the API population for DD.

Keywords

Diabetes Distress, Asian Pacific Islander population, screening tools, diabetes education, validation

Abbreviations

API – Asian Pacific Islander
BMI – Body Mass Index
CDC – Centers for Disease Control and Prevention
CI – Confidence Interval
DCCT – Diabetes Control and Complications Trial
DD – Diabetes Distress
DDS17 – Diabetes Distress Scale 17
DDS2 – Diabetes Distress Scale 2
EB – Emotional Burden Subscale
EMR – Electronic Medical Record
HbA1c – Hemoglobin A1c
ID – Interpersonal Distress Subscale
IRB – Institutional Review Board
PD – Physician Distress Subscale
RD – Regimen Distress Subscale
SD – Standard Deviation

Introduction

The Centers for Disease Control and Prevention (CDC) projects that one in three adults could have diabetes by 2050.[1] The American Diabetes Association estimates that in Hawai'i over 107,000 people (approximately 1 in 10) are living with diabetes.[2] The Diabetes Control and Complications Trial (DCCT) demonstrated the impact of glycemic control on decreasing the risk of complications from diabetes. The DCCT defined glycemic control as a hemoglobin A1c (HbA1c) level below 7.0% (53 mmol/mol).[3] As of 2015, more than half of adults with Type 2 diabetes in Hawai'i had HbA1c levels above 7.0% (53 mmol/mol).[4] There are numerous barriers to achieving glycemic control such as non-adherence to diet, exercise or medication. Depression is a psychological disorder which can affect all aspects of a chronically ill client. Depression has also been frequently studied as a barrier to glycemic control.[5,6] Diabetes distress is a unique type of stress which seems to affect the ability to effectively manage diabetes.[14] Studies done by researchers have acknowledged that glycemic control remains elusive in some individuals even after addressing these barriers.[4-6]

Diabetes distress (DD), defined as the collective emotional and cognitive stresses caused by the daily management of diabetes, may be a factor in preventing people with diabetes from achieving optimal glycemic control.[6] One tool considered to be a clinically beneficial instrument to measure DD is the Diabetes Distress Scale 17 (DDS17). The DDS17 is a 17-item questionnaire examining distress experiences among patients with diabetes. Each individual item is measured on a Likert scale of 1 (no distress) to 6 (serious distress) and an average composite score is also determined .[7] The DDS17 divides DD into four subscales. These subscales are emotional distress (EB), regimen distress (RD), interpersonal distress (ID), and physician distress (PD). The second tool, the Diabetes Distress Scale 2 (DDS2), is a two item screening instrument developed by Fisher, et al (also known as Fisher's DDS2) that is used to quickly identify DD. Fisher's DDS2 is being utilized in some organizations to quickly pre-screen clients with diabetes who may benefit from completing the longer DDS17.[7] The two items on Fisher's DDS2 are items selected from the EB and the RD subscales. There is consensus that higher DD may be associated with lower levels of glycemic control but no definitive correlation has been associated between the two.[4-6] Fisher, et al, (2010) found both concurrent and time-concordant relationships between DD and HbA1c ($r = 0.17$; $P = .001$).[6]

Both the DDS17 and DDS2 were validated primarily in a Caucasian population with diabetes. Polonsky, et al, (2005)'s study population which tested the DDS17 across 4 clinical sites consisted of 53% non-Hispanic white, 13% African American, 7% Hispanic, and 19.6% Asian Pacific Islander (API) adults.[6] Fisher, et al, (2008)'s study population which tested the DDS2 consisted of 40% non-Hispanic white, 21% African American, 19% Hispanic, and 17% API adults.[7] Both of these studies acknowledge that the DDS17 and DDS2 could not be validated in the API population because of the low percentage of study participants from this ethnic group. To the best of our

knowledge, these tools have never been validated for the API population with diabetes. Thus, the purpose of this study was to: (1) evaluate content validity of the DDS17 by evaluating correlation with HbA1c and (2) identify two items to develop a brief screening tool, DDS2, for an API population. The findings of this study will help clinicians identify the specific areas of potential diabetes-specific distress warranting intervention or follow-up to improve glycemic control of their API patients with diabetes.

Methods

A retrospective chart review was conducted at a suburban outpatient diabetes management and education center clinic over 14 months from October 2014 to December 2015 on the island of O'ahu, Hawai'i. Participants were patients with Type 1 or 2 diabetes, aged 18 to 80 years old who were able to read and write English. Individuals were excluded if there was a lack of English proficiency as evidenced by patients needing an interpreter or if they had difficulty understanding the DDS17. As part of standard of care at our clinic, all new patients (who are English proficient) completed a DDS17 questionnaire which was scored and recorded in the patient's electronic medical record (EMR) in the progress notes. Other data collected within the EMR included age, sex, ethnicity, body mass index (BMI), and HbA1c level.

The investigator reviewed the clinic schedules electronically and extracted the DDS17 scores from the patient's EMR. The ethnicity of the study participants were based on self-report from the patient and extracted from the demographics in the EMR. Ethnicity options included Filipino, Japanese, Chinese, Korean, Native Hawaiian, Pacific Islander (ie, Samoan, Tongan, Chuukese, Chamorro), other Asian, Caucasian, and other (if participant chose not to self-identify). Diabetes status was based on documented HbA1c levels of 6.5% or higher.

The study was reviewed by The Queen's Medical Center Institutional Review Board (IRB) and received approval prior to data extraction from the EMR (IRB-#RA-2015-047). The study was determined to be low risk, therefore no written consent was required by our IRB. All data was de-identified and kept confidential.

Data Analysis

Univariate analysis was performed on the individual demographic variables. Average item scores of ≥ 3 were used to differentiate high from low distress on each item, subscale (EB, RD, ID, and PD), Fisher's DDS2 and DDS17. A score of <2.0 was defined as little or no distress; 2.0-2.9 as moderate distress; and ≥ 3.0 as high distress.[16] Phi coefficients were used to measure association between each item and the total DDS17 score on the dichotomized scales. Two items with the highest phi coefficients to the total DDS17 were identified to develop a revised DDS2 specific to our API population. Due to the small variation in phi coefficients, Pearson's correlation was also computed between each item and the total of DDS17 to investigate linear association on the original scale. Cronbach's alpha was computed to evaluate reliabilities of the subscales, Fisher's DDS2, our revised DDS2 and DDS17. Two sample t tests were used to validate the DDS17 and our DDS2 tools by evaluating whether the tools can discriminate between DD and non-DD patients on the similarity between HbA1c and BMI results. Pearson's correlation coefficient was calculated to determine correlation between our DDS2, the DDS17, and its subscales with HbA1c level and BMI. All analyses were conducted using SAS 9.4 (SAS Institute Inc, Cary, NC) and a P-value $< .05$ was considered statistically significant.

Results

Descriptive statistics are presented in Table 1. Of the 443 patients, 54.2% were female, 33.6% were Filipino, and just below 20% were Hawaiian and Caucasian respectively. Mean BMI was 33.9 (SD = 8.4) and the mean HbA1c level was 8.9% (74 mmol/mol) (SD = 2.2). The average age of sample was 55.4 years (SD = 14.2) and 95.5% had Type 2 diabetes and 4.5% had Type 1 diabetes.

All the 17 DDS items correlated moderately to highly to the total DDS17 score: the phi coefficients ranged from 0.410 to 0.593 (see Table 2). The DDS17 showed high reliability (Cronbach's alphas = 0.938 for total DDS17, 0.906 for EB, 0.896 for PD, 0.889 for RD, and 0.880 for ID).

Table 2 presents descriptive statistics and correlation of each item or subscale with the total DDS17. The average DDS17 score was 2.48 (SD = 1.06), correlating to a moderate level of distress, and 142 patients (32.1%) scored high distress levels. The subscales of RD and EB had the highest level of DD at 2.92 (SD = 1.32) and 2.86 (SD = 1.34), respectively. The percentages of DD were 42.2% for EB, 17.8% for PD, 45.6% for RD, and 21.9% for ID.

Table 1. Descriptive statistics of the sample (n=443)

Variable	n (%)
Age (years), (Mean +(SD)	55.4 + 14.2
Gender	
Male	203 (45.8)
Female	240 (54.2)
Body Mass Index, Mean +SD	33.9 + 8.4
HbA1c (%), Mean +SD	8.9 + 2.2
Race/Ethnicity	
Caucasian	84 (18.9)
Hawaiian	75 (16.9)
Filipino	149 (33.6)
Pacific Islanders	37 (8.4)
Chinese	17 (3.8)
Japanese	53 (11.9)
Other Asians	10 (2.3)
Other	18 (4.1)
Diabetes Mellitus Type	
Type 1	20 (4.5)
Type 2	423 (95.5)

SD=Standard Deviation; HbA1c=Hemoglobin A1c

To develop a DDS2 specific to the API population in Hawai'i, we computed the phi coefficients and Pearson's correlation. Item 13 (feeling that friends or family don't appreciate how difficult living with diabetes can be) from the ID subscale and item 14 (feeling overwhelmed by the demands of living with diabetes) from the EB subscale were found to have the highest association (phi coefficients 0.593 and 0.589, respectively) with the total DDS17 score in this sample. Since the difference in phi coefficients were only within 0.02 among the top 5 items, we utilized Pearson's correlation in the original scale. Among the top five items, items 13 and 14 showed the highest Pearson's correlation (0.720 and 0.827, respectively). We selected these two items as the components of the revised version of the DDS2 in our sample. The DDS17 score and our DDS2 based on items 13 and 14 were highly associated (phi coefficient = 0.736 (95% confidence interval [CI] = 0.674, 0.799)) and is significantly greater than the phi coefficient of 0.604 with Fisher's DDS2 (95% CI = 0.542, 0.667). The Cronbach's alpha for our modified DDS2 was 0.736, indicating good reliability, and it was comparable to the alpha of 0.750 for the Fisher's DDS2.

Two sample t-tests and Pearson's correlation analyses were conducted to validate subscales of DDS17, total DDS17, and our revised DDS2 with HbA1c level and BMI (see Table 3). Significant differences were found between high DD group and low DD group on items 13 and 14, subscales, our revised DDS2, and DDS17 in HbA1c level except in the PD subscale. The means of HbA1c level in the high DD group were greater than those in the low DD group. Positive correlation was also found between HbA1c and the same items/subscales, ranging from 0.105 to 0.199 (Table 3).

Table 2. Descriptive Statistics and Correlation of Each Item or Subscale with the Total Diabetes Distress Scale 17 Score

Item or Subscale	Mean ± SD	High Distress[c] n (%)	Phi Coefficient with DDS17 (binary)[a]	Pearson's Correlation with DDS17 (continuous)
Emotional Burden Subscale[b]	2.86 ± 1.34	187 (42.2)	0.716	0.907
Feeling that diabetes is taking up too much of my mental and physical energy every day [Item 1].	2.75 ± 1.43	226 (51.0)	0.460	0.703
Feeling angry, scared and/or depressed when I think about living with diabetes [Item 3].	2.81 ± 1.57	239 (54.0)	0.479	0.741
Feeling that diabetes controls my life [Item 8].	2.84 ± 1.64	218 (49.2)	0.562	0.791
Feeling that I will end up with serious long-term complications, no matter what I do [Item 11].	3.08 ± 1.62	260 (58.7)	0.508	0.798
Feeling overwhelmed by the demands of living with diabetes [Item 14].	2.80 ± 1.58	225 (50.8)	0.589	0.827
Physician-Related Distress Subscale[b]	1.82 ± 1.18	79 (17.8)	0.590	0.713
Feeling that my doctor doesn't know enough about diabetes and diabetes care [Item 2].	1.80 ± 1.35	103 (23.3)	0.492	0.601
Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes [Item 4].	1.90 ± 1.39	115 (26.0)	0.586	0.622
Feeling that my doctor doesn't take my concerns seriously enough [Item 9].	1.59 ± 1.15	78 (17.6)	0.483	0.607
Feeling that I don't have a doctor who I can see regularly about my diabetes [Item 15].	2.00 ± 1.53	115 (26.0)	0.586	0.652
Regimen-Related Distress Subscale[b]	2.92 ± 1.32	202 (45.6)	0.682	0.847
Feeling that I am not testing my blood sugars frequently enough [Item 5].	2.67 ± 1.67	211 (47.6)	0.410	0.571
Feeling that I am often failing with my diabetes regimen [Item 6].	3.05 ± 1.58	252 (56.9)	0.500	0.758
Not feeling confident in my day-to-day ability to manage diabetes [Item 10].	2.70 ± 1.49	210 (47.4)	0.530	0.787
Feeling that I am not sticking closely enough to a good meal plan [Item 12].	3.36 ± 1.53	298 (67.3)	0.438	0.752
Not feeling motivated to keep up my diabetes self-management [Item 16].	2.82 ± 1.65	220 (49.7)	0.575	0.774
Interpersonal Distress Subscale[b]	2.00 ± 1.26	97 (21.9)	0.619	0.766
Feeling that friends or family are not supportive enough of my self-care efforts (eg, planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods) [Item 7].	1.98 ± 1.40	127 (28.7)	0.549	0.670
Feeling that friends or family doesn't appreciate how difficult living with diabetes can be [Item 13]	2.14 ± 1.47	226 (51.0)	0.593	0.720
Feeling that friends or family don't give me the emotional support that I would like [Item 17].	1.87 ± 1.36	107 (24.2)	0.584	0.671
Fisher's DDS2 (Items 6 and 14)[b]	2.93 ± 1.41	220 (49.7)	0.604	0.886
Revised DDS2 (Items 13 and 14)[b]	2.47 ± 1.36	159 (35.9)	0.736	0.867
DDS17[b]	2.48 ± 1.06	142 (32.1)	-	-

DDS = Diabetes Distress Scale. [a]Phi coefficient was computed on average item or total score of ≥3 (high distress). [b]All were averaged to the item scale (1-6). [c]High distress defined as a DDS score of >3.0 on Likert scale of DDS questionnaire.

Table 3. Pearson's Correlation and Comparisons between High- and Low-Distressed Patients on Hemoglobin A1c (HbA1c) and Body Mass Index (BMI)

DDS Item and Subscale	HbA1c		BMI	
	Mean ± SD	Correlation	Mean ± SD	Correlation
Item 13				
High (≥3)	9.20 ± 2.30*	0.120*	33.23 ± 8.03	-0.016
Low (<3)	8.71 ± 2.11		34.17 ± 8.50	
Item 14				
High (≥3)	9.14 ± 2.22**	0.159*	33.90 ± 8.64	0.027
Low (<3)	8.58 ± 2.10		33.84 ± 8.08	
Revised DDS2 (Items 13 and 14)				
High (average ≥3)	9.20 ± 2.27*	0.157**	33.18 ± 8.36	0.007
Low (average <3)	8.67 ± 2.11		34.26 ± 8.35	
EB				
High (average ≥3)	9.25 ± 2.19**	0.199***	34.27 ± 9.15	0.025
Low (average <3)	8.58 ± 2.13		33.58 ± 7.73	
PD				
High (average ≥3)	9.10 ± 2.15	0.067	33.05 ± 7.66	-0.058
Low (average <3)	8.81 ± 2.18		34.05 ± 8.50	
RD				
High (average ≥3)	9.25 ± 2.22***	0.189***	34.58 ± 8.91	0.072
Low (average <3)	8.54 ± 2.09		33.28 ± 7.84	
ID				
High (average ≥3)	9.27 ± 2.27*	0.105*	33.58 ± 8.01	-0.019
Low (average <3)	8.75 ± 2.14		33.96 ± 8.46	
Fisher et, al,'s DDS2 (Items 6 and 14)				
High (average ≥3)	9.27 ± 2.22***	0.207***	34.27 ± 8.92	0.075
Low (average <3)	8.46 ± 2.07		33.48 ± 7.76	
DDS17				
High (average ≥3)	9.19 ± 2.17*	0.182**	34.40 ± 9.11	0.016
Low (average <3)	8.70 ± 2.17		33.62 ± 7.98	

*P<.05; **P<.01; ***P<.001. DDS = Diabetes Distress Scale; EB = Emotional Burden; PD = Physician-Related Distress; RD = Regimen-Related Distress; ID = Interpersonal Distress; SD=Standard Deviation.

Discussion

The DDS17 questionnaire was found to be valid and reliable in predicting the level of DD in an English-speaking API population. The average level of DD in the study group indicated a moderate level of distress (mean score = 2.48). The subscales of RD and EB had the highest level of diabetes distress with mean scores at 2.92 and 2.86, respectively. These findings mirror those of similar studies which had wide ranging locations of diverse populations.[8-10] Findings also indicated a correlation between high DD levels and poor glycemic control, similar to other studies findings.[4-6] These findings support that high DD levels might be a factor which is associated with poor glycemic control across all population groups or vice-versa.

Item 13 (feeling that friends and family don't appreciate how difficult living with diabetes can be) and item 14 (feeling overwhelmed by the demands of living with diabetes) best correlated with the DDS17 total scores in this study. These two questions are part of the ID and the EB subscales. The original study for the DDS2 had 640 subjects with an ethnic background breakdown of 21% African American, 19% Hispanics, 37% non-Hispanic White, and 17% Asian and was conducted in San Francisco. They identified item 6 (feeling that I am often failing with my diabetes regimen) from the RD subscale and item 14 from the EB subscale as the two screening questions for DD.[7] A possible explanation for the ID subscale question may be that the Hawai'i API population relies more on family and friends for support than the Caucasian population. A previous study showed similar distinctions when the researchers compared the Chinese population with the Caucasian population and concluded that the Chinese group relied more on the social support of family and friends than the Caucasian group.[12]

Our results were consistent with and similar other studies in that the level of DD was found to be significantly associated with glycemic control. Polonsky, et al, (2005), which developed and validated the DDS17, found that the level of DD was not associated with HbA1c level.[6] However, Fisher, et al, (2010), found a significant time-concordant relationship between DD and HbA1c levels ($P<.0001$) but could not definitively state a causative relationship between the two factors.[4] In other studies by Fisher, et al, they reported a significant positive association between high DD and higher HbA1c levels.[5,7]

There were a number of limitations identified in this study. First, the sample was limited to a single site of primarily an API population. As such, it is unknown if the findings can be generalized to a larger API population. Second, we excluded API patients who were not proficient in English thus results may not be applicable to this portion of the population related to possible differences in socio-economic and cultural values. The DDS17 has also been studied in wide ranging locations of diverse populations (ie, Iran, China, Thailand, Japan) and have had similar findings.[8-11]

Implications

The DDS17 can help identify four areas of DD—emotional burden, regimen distress, physician distress, or interpersonal distress so the health care team can focus on collaborating with the patient and/or family to reduce DD and possibly improve diabetes self-care and glycemic control. For example, if a patient has a high EB score, the health care team may be able to use motivational interviewing to support the patient in developing strategies to help improve EB. If a patient has a high RD score, the health care team may be able to simplify the diabetes regimen. If a patient has a high PD score, the health care team may be able to plan with the patient on how to improve the doctor-patient relationship. Finally, if a patient has a high ID score, the health care team may be able to help the patient work on strengthening the social bonds of family and friends. A meta-analysis study found that a psycho-education intervention delivered by primary care health care professionals helped to lower DD compared to controls.[13] Fischer, et al, (2013) concluded that DD was highly responsive to different types of self-management interventions which were delivered by internet, computer assisted, or in-person.[15]

The two screening items identified in our study would allow the health care team to quickly assess if a patient is at high risk for DD, especially in Hawai'i. This would help any health care team working with clients with diabetes to quickly screen for high risk patients. If the screened patient has a positive screening questionnaire, then the health care team can administer the DDS17 to further delineate the specific areas and levels of DD. DD is a common condition among patients with diabetes, often associated with poor disease management, which could easily be confused with major or minor depression as a separate chronic condition. The new DDS2 specific to the API population can be used as an easy to score screening instrument to detect DD and apply interventions as needed to reduce the associated negative effects on glycemic control.

Conflict of Interest

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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