International Journal of Diabetes in Developing Countries (January–March 2025) 45(1):141–149
https://doi.org/10.1007/s13410-024-01338-0

ORIGINAL ARTICLE

Diabetes-related distress: translation and validation of the Hindi version of Diabetes Distress Scale (DDS) for Indian type 2 diabetes mellitus patients

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Received: 1 January 2023 / Accepted: 10 April 2024 / Published online: 24 April 2024

Abstract

Background Diabetes-related distress is the emotional burden and worries while managing chronic disease like diabetes. It remains mostly undetected because most patients do not realize their emotional problems. Diabetes distress affects glycemic control and makes the patient more prone to complications. Diabetes Distress Scale (DDS-17) developed by Polonsky is widely used to measure the diabetes distress in different part of the world.

Objective To translate the DDS-17 into Hindi and validate the DDS-17 (H) among adult patients with type 2 diabetes in India.

Methods The DDS-17 was translated to Hindi and back translated by independent bilingual translators. Face and content validity of the scale was evaluated with subject experts and a sample of the target population. A cross-sectional validation study was conducted for analyzing construct, convergent validity, and reliability of DDS-17 (H). Eligible participants were enrolled from the field practice area of a tertiary care hospital.

Results The Content Validity Index of the scale was 0.99 and the Content Validity Ratio was 1, which was significant. Exploratory factor analysis of items supported a four-factor solution. Cronbach's α coefficient for the scale was 0.958. The scale had a positive correlation with Depression Anxiety Stress Scale (DASS 21), $p = 0.78$, $p < 0.000$. Among the 200 enrolled participants, DDS-17 (H) assessed 18.5% of participants with moderate diabetes distress and 16.5%, high diabetes distress.

Conclusion The DDS-17 is found to be valid and reliable in the Hindi language and can be used for early identification of diabetes distress in primary care settings.

Keywords Diabetes · Distress · Validation

Introduction

Diabetes-related distress is a term used to describe the negative emotional and psychological impact that living with diabetes can have on an individual. Even though the prevalence of diabetes distress is very high (18–35%), it remains usually undetected as most patients do not realize their emotional problems [1]. Prolonged diabetes distress can affect self-management and glycemic control and make the patient more prone to complications.

To identify diabetes-related distress, a number of self-report instruments have been developed, including the Diabetes Distress Scale 17 (DDS-17), Problem Areas in Diabetes Scale (PAID), and Questionnaire on Stress in Patients with Diabetes-Revised (QSD-R) [2–4]. The Diabetes Distress Scale (DDS-17) by Polonsky is quite popular among these scales since it addresses distress related to diabetes in four aspects: emotional burden, physician-related distress, regimen-related distress, and interpersonal distress [2]. This 17-item scale provides a reliable and valid measure of diabetes-related distress and has been used in numerous research studies and clinical settings. This scale has then been translated and validated in several languages, including

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Chinese, Polish, Mexican, Malaysian, Indonesian, Brazilian, Norwegian, and Asian Pacific Islander populations [5–10].

Translating and validating the DDS in the Hindi language are essential because Hindi is the official language of the Union of India, the most spoken language by around 43% of the Indian population, and is the official language for nine states [11, 12]. This will further help to address the unique needs of type 2 diabetes mellitus patients to improve their health outcomes and quality of life. To the best of our knowledge, this needed to be translated and validated in Hindi language. Overall, the translation and validation of the Hindi DDS-17 represent an important step towards ensuring that Indian T2DM patients have access to a culturally sensitive tool for assessing their diabetes-related distress in the primary care setting.

Methods and Materials

Study design

The study design is a validation study.

This will be included in study design

The study was conducted in the field practice area of the Department of Community and Family Medicine, AIIMS Rishikesh, Uttarakhand, from June 2020 to October 2021. After assessing for eligibility, participants were randomly selected from the noncommunicable disease register maintained in the field practice area of AIIMS Rishikesh.

Type 2 diabetes in young adults aged 18–30 years is a more aggressive condition than in older ages and may lead to more distress and management at the specialist level [13]. Therefore, for scale validation to be used at the primary level, we have included type 2 diabetes patients ≥ 30 years, diagnosed with diabetes for at least 1 year with recent blood sugar reports within the past 3 months, and can fluently read, understand, and speak in Hindi. We excluded participants who were diagnosed with mental health conditions, cognitive impairment, severe physical illness, and pregnant or lactating mothers.

Based on the number of items in the DDS-17 scale-to-participant ratio of 1:10, the sample size was calculated as $17*10=170$ [14]. Considering the dropouts as 10%, the final sample size was 200.

Study tool

Structured pilot-tested questionnaire included baseline sociodemographic details: age, gender, education, duration of diabetes, recent laboratory parameters such as Fasting Blood Sugar (FBS), Post Prandial Blood Sugar (PPBS), glycated hemoglobin (HbA1c), Diabetes Distress Scale, Hindi version ((DDS-17 (H)), and Hindi validated version of Depression Anxiety Stress Scale (DASS-21). We used the DASS 21 scale because it has already been translated and validated in Hindi [15].

The DDS-17 consists of 17 items in four subscales: regimen-related distress (5 items), emotional burden (5 items), interpersonal distress (3 items), and physician-related distress (4 items) [2]. Response to each item was on a 6-point Likert scale, ranging from 1 (not a problem) to 6 (a very serious problem) concerned with diabetes for the last month. The mean item score is calculated by summing up all item responses and dividing by 17. A score of < 2.0 was considered "little or no distress," 2.0–2.9 "moderate distress," and ≥ 3.0 "high distress." The DASS 21 scale has 21 items and three subscales [15]. The stress scale assesses nervous arousal, difficulty relaxing, being easily upset/agitated, irritable, and impatient. Responses are rated on a 4-point Likert scale ranging from 0 to 3. The scores for stress scales are as follows: 0–14 normal, 15–18 mild, 19–25 moderate, 26–33 severe, and 34 plus extremely severe.

Translation

Steps of translation are given in Fig. 1.

Two bilingual translators (Tiwary N and Punjoth P) have independently carried out the forward translation of the scale from English to Hindi. The investigators compared the two translations, and a final questionnaire was made for back-translation. The final questionnaire was then subjected to back-translation from Hindi to English by a professional translator, unaware of the DDS-17 original English scale ((DDS-17 (E)). The investigators then compared the back-translated questionnaire with the original scale for any significant discrepancies. No such discrepancies were identified.

Content validation

Content validity of the scale was assessed by a group of six experts involved in diabetes care: one was an expert in General medicine and endocrinology, and others were public health experts. The experts evaluated the relevancy, necessity of the scale items, and the appropriateness of the language. Relevancy was measured on a 4-point Likert scale: 1, Not relevant; 2, somewhat relevant; 3, Quite relevant; 4, Highly relevant and necessity on a 3-point Likert scale, i.e., 1, not necessary; 2, useful, but not essential; and 3, essential [16]. Those who rated the items of the scale as "Quite relevant" and "Highly relevant" were counted.

Face validation

The DDS-17(H) was pilot-tested for face validation among ten type 2 diabetes mellitus patients from the field practice area. Participants were chosen purposively. All were educated, ready to devote time to reading and comprehending

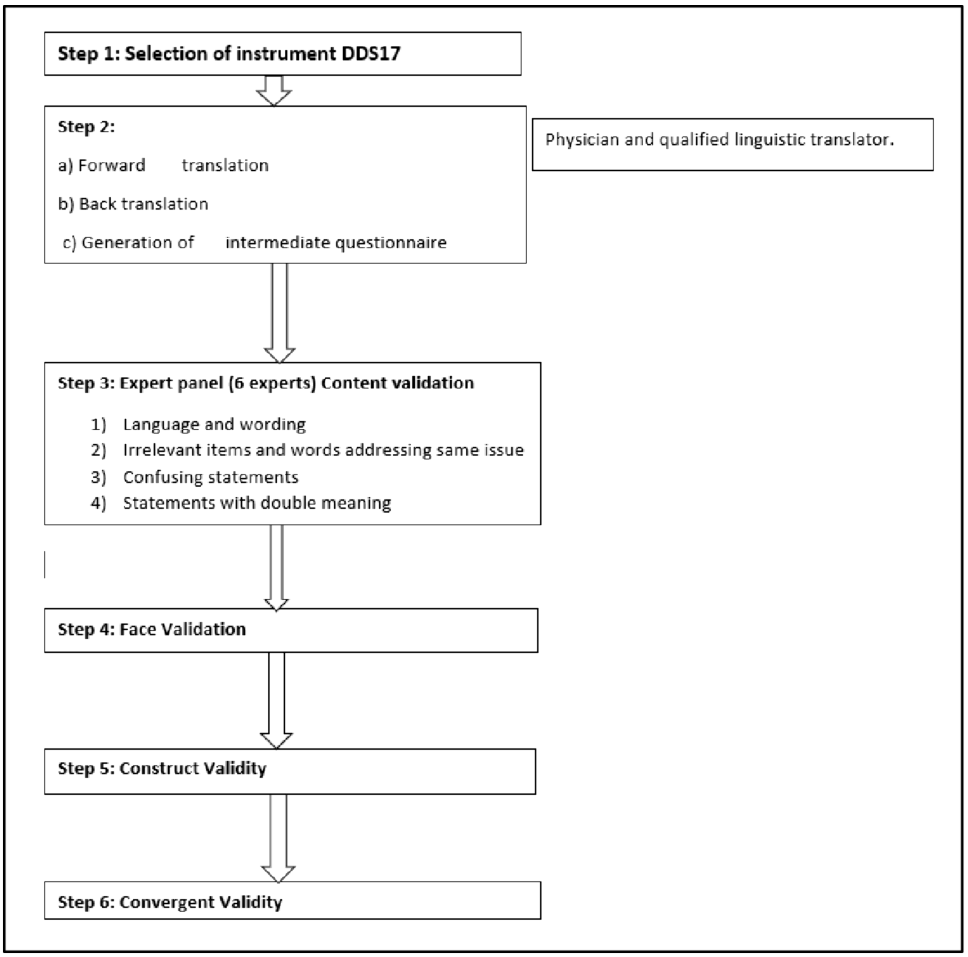

Fig. 1 Translation and validation of Diabetes Distress Scale 17 (DD-S17)

the questionnaire, not from medical backgrounds, and preferably interested in literature. Participants were asked to read and evaluate each item of questions for relevance, simplicity, and comprehensibility of content. They were also encouraged to make suggestions if required.

Construct validity, convergent validity, and reliability

After assessing eligibility criteria, 200 participants were enrolled from the field practice area to assess the construct, content validity, and reliability of DDS-17 (H).

Data collection

Written informed consent was obtained from the participants before the study. Before administering the questionnaire, the participants were explained about the questionnaire in detail. After collecting the baseline data, the questionnaire was administered to the participants in a standardized way. Care was taken into account that there should be minimal influence/interference from the data collector. The data collector was neutral regarding the responses of individual items of the scale and was available only to guide the participants to complete the questionnaire and to clear any technical queries if required.

Data analysis

Data was analyzed using IBM SPSS 25, trial version. Content Validity Index (CVI) and Content Validity Ratio (CVR) were calculated to assess content validity.

$\text{CVR} = \frac{\text{Ne}-N/2}{N/2}$ (Lawshe test) where "Ne" represents the number of experts who rated the item as essential and "*N*" is the total number of experts [16].

For six numbers of panelists, critical CVR for items at a 5% level of sig was taken as 0.99. The cut-off value for scale CVI (S-CVI) was 0.9 or higher, and item CVI (I-CVI) was 0.78 or higher [17].

Exploratory factor analysis was done to assess construct validity. Maximum likelihood estimation with orthogonal (varimax) rotations was performed. Varimax rotation and four factors were extracted using the principal component analysis method. The Kaiser–Meyer–Olkin index (KMO) was used to test the adequacy of the sample size [17]. Bartlett's

Table 1 The baseline demographic and clinical characteristics of the study participants ($N=200$)

Characteristics	$N=200$
Age in years, mean (SD)	54.6 (11.4)
Sex, *n* (%)	
Male	113 (56.5)
Female	87 (43.5)
Education, *n* (%)	
Primary	33 (16.5)
High school	71 (35.5)
Intermediate	42 (21)
Graduate	41 (20.5)
Postgraduate	13 (6.5)
Duration of diabetes, *n* (%)	
1–5 years	110 (55)
6–10 years	43 (21.5)
> 10 years	47 (23.5)
HbA1c in %, mean (SD)	8.5 (2.9)
RBS in mg/dl, mean (SD)	192.1 (52.6)
FBS in mg/dl, mean (SD)	170.5 (63.8)
PPBS in mg/dl, mean (SD)	241.1 (90.7)

test of sphericity was used to test whether the correlation matrix is significantly different from an identity matrix [18]. The minimum threshold for factor loading was set at 0.40 for a sample size of 200 [19]. The communality was assessed to find whether the items meet acceptable levels of explanation. Items with communalities < 0.50 was considered insufficient. In doubtful cases, we placed the items in certain factors based on the conceptual foundation and meaning underlying the analysis in consensus with all authors.

Convergent validity between DDS-17 (H) and DASS21 and between HbA1c and DDS-17 (H) was assessed using the Spearman correlation coefficient since the data were not normally distributed. Cronbach's alpha was calculated to determine the reliability of the scale, and the acceptable alpha level was ≥ 0.70.

Characteristics such as gender, age, glycemic control status, and duration of diabetes were examined for possible associations with DDS-17 (H) using Pearson's chi-squared test.

Results

Face and content validity

Among the ten participants approached for face validation, six agreed that the questionnaire was well drafted and no problems were identified. As per the suggestions put forward by the remaining four participants, minor modifications in the language in items no 1, 9, 10, and 11 were made. The scale S-CVI was 0.99, and the individual items I-CVI was > 0.79, which was significant as per the cut-off values. We decided to include all 17 items in the scale based on the CVR value of one.

Construct validity

The baseline demographic and clinical profile of the participants

Among the 200 participants, the majority were male (56.5%). The mean age of the participants was 54.6 (11.4) years. Nearly one-third (35.5%) of the participants were educated up to high school, whereas only 6.5% were post-graduates. Almost half of the participants (55%) had diabetes for 1–5 years. Mean HbA1c of the study participants was 8.5% (2.9). Mean FBS and PPBS were 170.5 (63.8) and 241.1(90.7) mg/dl, respectively (Table 1).

Table 2 describes the distribution of participants according to distress assessed by DDS-17 (H). The proportion of participants identified with moderate distress was 18.5% and with high distress, 16.5%. Regarding the four domains of distress, the majority of the participants had emotional burdens (moderate distress 14.5% and high 26.5%), followed by regimen distress and interpersonal distress. DDS-17 (H) identified a few people as having physician-related distress (moderate 9.5% and high 9%). The proportion of participants with little/ no distress was 65%.

On performing the principal component analysis of DDS-17 (H), we got a KMO index of 0.904 and a significant level of Bartlett's test of sphericity ($\chi 2 = 2349.54$, $p = 0.000$), indicating that the correlation matrix was significantly different from identity matrix. That is, there was a substantial correlation between the two data sets. The scree-plot also supported a four-factor solution (Fig. 2).

Item numbers 1, 3, 6, 8, 10, 11, 12, 14, and 16 loaded on factor 1. Items 7, 13, and 17 loaded together with 11, 14,

Table 2 Distribution of participants according to distress assessed by DDS-17 (H)

DDS-17 categories	Little/no distress	Moderate distress, *n* (%)	High distress, *n* (%)
Distress total	130 (65)	37 (18.5)	33 (16.5)
Physician related distress	163 (81.5)	19 (9.5)	18 (9)
Regimen distress	124 (62)	26 (13)	50 (25)
Interpersonal distress	154 (77)	17 (8.5)	29 (14.5)
Emotional burden	118 (59)	29 (14.5)	53 (26.5)

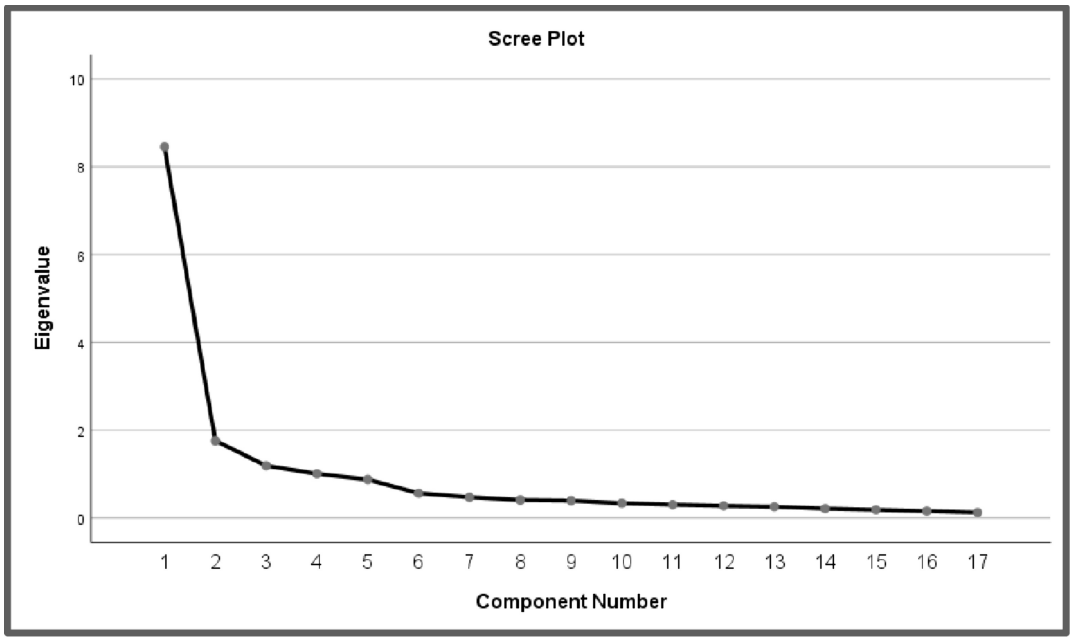

Fig. 2 Scree plot

and 16 in factor 2. Items 4, 9, and 15 are loaded together in factor 3. Items 5, 6, and 12 loaded on factor 4. Item 2 did not load on any factors based on our cut-off point (Table 3). These four factors determined 65% of the variance in all the questions. Nearly 49% of the variance was explained by factor 1 and 10.3% by factor 2, whereas 7% of the variance was explained by factor 3 and 5.1% by factor 4. Their respective eigenvalues were 8.45, 1.76, 1.19, and 1.01 respectively. The communalities ranged from 0.50 to 0.83.

Convergent validity

DDS-17 (H) had a significant correlation with DASS 21 ($p = 0.78$, $p < 0.000$) and HbA1c ($p = 0.71$, $p < 0.000$). The four subscales of DDS also had a significant correlation with DASS 21, where emotional burden had maximum correlation, $p = 0.77$, $p < 0.000$ (Fig. 3a–e).

Reliability of the scale

Cronbach's alpha coefficient for DDS-17 (H) was 0.96. The corrected item's total correlation ranged from 0.47 to 0.82 (Table 4). Item number "2" had a corrected item–total correlation, $r = 0.47$, but it was not unacceptably low. If separate items were deleted from each subscale, Cronbach's alpha showed a lower or a similar value as if the items were not deleted, which supports that every item belongs to each subscale. The intraclass correlation coefficient is 0.96 (95% CI, 0.95–0.97), significant at $p < 0.00$ level.

Association of DDS with the characteristics of participants

There was no significant association of diabetes distress with age, gender, or education of the participants. Hba1c values were significantly associated with the levels of distress.

Table 3 Exploratory factor analysis of DDS-17 scale (H)

Rotated factor matrix					
	Factor				**Communality**
	1(EB)	2 (IPD)	3(PD)	4(RD)	
DDS-1	**0.75**	0.14	0.13		0.72
DDS-2	0.15	0.24	0.39	0.23	0.50
DDS-3	**0.67**	0.38	0.27		0.72
DDS-4	0.12	0.11	**0.83**	0.19	0.79
DDS-5	0.38		0.32	**0.42**	0.60
DDS-6	**0.71**		0.20	**0.42**	0.77
DDS-7		**0.59**	0.36	0.23	0.74
DDS-8	**0.77**	0.31	0.32	0.13	0.82
DDS-9	0.24	0.31	**0.66**	0.16	0.71
DDS-10	**0.74**	0.20		0.39	0.79
DDS-11	**0.65**	**0.48**	0.20		0.74
DDS-12	**0.61**	0.29	0.10	**0.52**	0.77
DDS-13	0.22	**0.72**	0.29	0.21	0.78
DDS-14	**0.41**	**0.60**	0.23	0.19	0.71
DDS-15	0.20	0.32	**0.55**		0.76
DDS-16	**0.54**	**0.45**		0.39	0.76
DDS-17	0.28	**0.73**	0.26	0.38	0.83

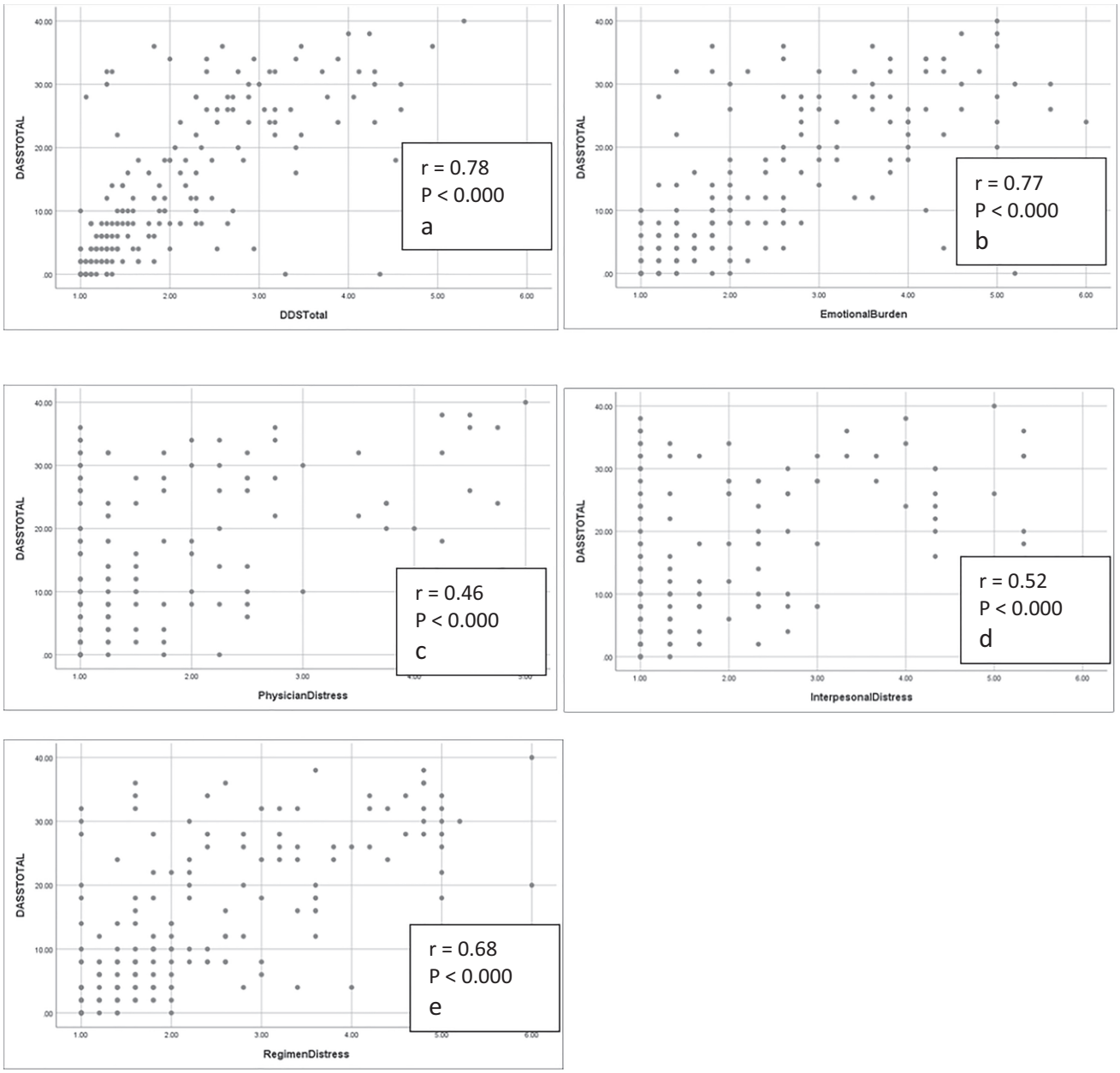

Fig. 3 **a–e** The scatter plots show the correlation between the total score of DDS-17 (H) and the subscales of emotional burden, interpersonal distress, physician distress, and regimen distress with the DASS21 scale

The more the HbA1c, the higher the distress and vice versa (Table 5).

Discussion

The mean age and gender distribution of the participants in the study was similar to the DDS-17 original scale (age, 54 vs 56 years, and proportion of male participants, 56.5% vs 52%, respectively) [2]. The proportion of participants educated in high school and above was ~ 80% on both the scales. The mean HbA1c level was 8.5%, similar to that of the DDS-17 (E). Our study reported the maximum proportion of people with emotional burden followed by regimen-related distress. In contrast, the scale validation study for the Asian Pacific Islander population reported regimen-related distress followed by emotional burden [7]. The findings from the Polish version of the scale were similar to our results: the emotional burden preceded the regimen-related distress [5]. Nearly one-fourth of our participants were having emotional and regimen-related distress, whereas it was nearly twice (45%) for the Asian Pacific scale. Other studies conducted in

Table 4 Item statistics for factors 1–4 of the DDS-17 (H) ($n = 200$)

Items	Corrected item-total correlation	Cronbach's alpha after item is deleted
Q1	0.62	0.96
Q2	0.47	0.96
Q3	0.74	0.96
Q4	0.52	0.96
Q5	0.56	0.96
Q6	0.71	0.96
Q7	0.51	0.96
Q8	0.82	0.96
Q9	0.63	0.96
Q10	0.75	0.96
Q11	0.73	0.96
Q12	0.76	0.96
Q13	0.69	0.96
Q14	0.73	0.96
Q15	0.59	0.96
Q16	0.69	0.96
Q17	0.77	0.96
EB (Facor1)	0.90	0.95
IPD (Facor2)	0.80	0.96
PD (Facor3)	0.74	0.96
RD (Facor4)	0.87	0.95

India also found that emotional burden was higher, followed by regimen-related distress among type 2 diabetes mellitus patients [20]. The prevalence of diabetes distress was 18%, similar to our findings [20].

Exploratory factor analysis of our study was not exactly similar to the scale developed by Polonsky et al. [2]. The analysis did not support allocating some items as per the original scale. Though items 1, 3, 6, 8, 10, 11, 12, 14, and 16 loaded on factor 1, meaning items 6, 10, 12, and 16 represent regimen distress, and we aggregated these four together. Items 6, 12, and 16 loaded on one more factor justifying our classification. We aggregated the rest of the items 1, 3, 8, 11, and 14 in emotional burden. Items 7, 13, and 17 loaded in the same factor (interpersonal distress). Item number "7": "feeling that friends or family are not supportive enough for self-care efforts" loaded on two factors. But the meaning of which strongly suggests the problems related to interpersonal relationships rather than regimen-related issues. Items 4, 9, and 15 loaded together (physician distress). Item 2, "Feeling that my doctor doesn't give me clear enough directions on managing my diabetes," did not load on any of the factors based on our cut-off point. On assessing the communality to decide the sufficiency of the variables, we found that factor 2 has an acceptable level of communality (0.51). We have decided not to remove this item and to keep this in factor 3 representing physician-related distress. In the Mexican version of the scale, the author identified a three-factor loading, in which emotional and regimen distress was

Table 5 Association of DDS-17 (H) with characteristics of participants

Characteristics	Little/no distress, *n* (%)	Moderate distress, *n* (%)	High distress, *n* (%)	Chi-square value*	*p* value
Age group(years)					
30–40	15 (57.7)	4 (15.4)	7 (26.9)	14.8	0.14
41–50	27 (54)	13 (26)	10 (20)		
51–60	45 (80.4)	5 (8.9)	6 (10.7)		
61–70	31 (64.6)	11 (22.9)	6 (12.5)		
71–80	5 (50)	3 (30)	2 (20)		
> 80	2 (40)	1 (20)	2 (40)		
Gender					
Male	72 (65.5)	20 (18.2)	18 (16.4)	0.2	0.90
Female	53 (62.4)	17 (20)	15 (17.6)		
HbA1c					
≤ 7	45 (93.8)	3 (6.3)	0	24.9	0.00
> 7	80 (54.4)	34 (23.1)	33 (22.4)		
Education					
Primary	16 (51.6)	11 (35.5)	4 (12.9)	9.2	0.33
High school	32 (61.5)	10 (19.2)	10 (19.2)		
Intermediate	23 (63.9)	6 (16.7)	7 (19.4)		
Graduate	29 (74.4)	4 (10.3)	6 (15.4)		
Postgraduate	10 (76.9)	2 (15.4)	1 (7.7)		

*Moderate distress and high distress were merged for chi-square

Wherever the cell value is less than 5, the Fischer exact test was applied

considered a single factor [6]. The scale's Thai and Chinese validation study also condensed the items into three factors only [21, 22]. The Chinese version has eliminated two items (items 12 and 15), and the analysis was performed with the remaining 15 items. The three items of the interpersonal distress domain were loaded on the emotional burden domain in the Bahasa Indonesia version of the scale [10]. In our study, though items of regimen distress fall on two different factors, based on the content and meaning, we have decided to keep it together under regimen-related distress only. The communalities of all variables in our study were > 0.50, which indicates that none of the items was insufficient. The Scree plot test also supported a four-factor solution. We concluded that items of our scale loaded on four factors as those of the original scale. Overall, these four factors determined 65% of variance in all the questions, consistent with the translated Brazilian version (67%) [6].

Our scale had high internal consistency (0.958), similar to the DDS-17 (E). Cronbach's alpha for individual items ranged from 0.955 to 0.959, similar to the English, Chinese, Danish, Brazilian, and Malay scales. The Chile version reported different results in which the value of Cronbach's alpha was 0.62–0.75 [6]. The total distress score, along with the four subscales, had a significant correlation with the DASS 21 total score (convergent validity)—highest correlation with DASS 21 obtained for emotional burden and a moderate correlation for physician and interpersonal distress. The Mexican scale also reported the same trends using the HADS scale (Hospital Anxiety and Depression Scale) but with a moderate correlation with emotional burden and a weaker correlation with interpersonal and physician-related distress. The instrument could differentiate between patients who were clinically different based on the glycemic control status: HbA1c > 7% was positively correlated with DDS-17 (H) version scores. Patients who achieved good glycemic control had little/no diabetes-related distress. This was in accordance with the findings of the Malay version of the scale [23].

Strengths

The forward and backward translation of the scale involved a systematic and rigorous methodology. The study involved patients from the tertiary care center's field practice area, which helped assess the use of the scale in primary care settings. The original scale and most of the other validation studies have not taken into consideration fasting and post-prandial blood sugar, whereas our study assessed the same apart from HbA1C. Also, it is the first attempt to translate and validate the DDS-17 scale in the Hindi language with a systematic methodology.

Limitations

The scale was found to be valid and reliable in type 2 diabetes mellitus patients at the primary care setting only. The scale does not take into account the distress among patients with other types of diabetes. Hence, the scale cannot be generalized to patients with other types of diabetes such as type 1, Maturity Onset Diabetes of the Young (MODY), and gestational diabetes. The second limitation of the study is the difficulty in administering the scale to patients with low literacy levels. The items of the scale demand a relatively higher level of literacy for better comprehension and appropriate response.

Conclusion

The Diabetes Distress Scale 17(H) is valid and reliable among Hindi-speaking Indian type 2 diabetes mellitus patients to assess diabetes-related distress. It is a valid tool for early identification and targeted individual management for type 2 diabetes mellitus patients in primary care settings.

Acknowledgements We thank Mrs. Neera Tiwari, Senior Hindi Officer, AIIMS Rishikesh, and Mr. Pankaj Punjoth, Diabetes educator, AIIMS Rishikesh, for assistance with the translation of the DDS-17 scale.

Author contribution The authors confirms the contribution for the following: study conception and design, data collection, analysis and interpretation of results, and manuscript preparation.

Declarations

Competing interests The authors declare no competing interests.

Ethical clearance Ethical approval was obtained from the Institutional Ethics Committee of AIIMS Rishikesh: AIIMS/IEC/20/362.

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