

Prevalence of diabetes distress and cross-cultural reliability of DDS-17 scale in rural Haryana

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ABSTRACT

Background: Diabetes distress associated with diabetes is an important under-appreciated domain of diabetes management. The aim of the study is to assess the prevalence of diabetes distress among T2DM patients in Jhajjar district of Haryana, using widely accepted DDS-17 scale along with testing the scale's reliability through Cronbach's α . **Material and Methods:** This observational study with cross-sectional design was carried out among 503 T2DM patients in district, Jhajjar, Haryana. DDS-17 scale was used for diabetes distress assessment. Data entry and analysis were performed using appropriate software. **Results:** 37.97% subjects had diabetes distress either in moderate (DDS-17 Score ≥ 2) or severe (DDS-17 Score ≥ 3) form. English version of DDS-17 scale showed good internal consistency reliability ($\alpha = 0.79$). **Conclusions:** This study conclusively showed that diabetes distress is very common among T2DM patients as more than one third of the T2DM patients had diabetes distress and diabetes distress scale (DDS-17) is an easy, well-accepted questionnaire with good reliability.

Keywords: Cronbach's α , diabetes distress, DDS-17 scale, reliability, T2DM

Introduction

The prevalence of diabetes mellitus (DM) in India is 8.9% with over 77 million individuals affected by it.^[1] Among those diagnosed with diabetes, around half still do not achieve satisfactory glycemic control, despite being on effective treatments; leading to subsequent complications. One of the most important reasons behind this unsatisfactory glycemic control is diabetic distress. Diabetes distress is the hidden emotional response to living with diabetes, due to the burden of relentless daily self-management, worry of its long-term complications, and poor family and physician support.^[2] Diabetes

distress is associated with adverse medical and psychological outcomes, including suboptimal self-management, elevated HbA1c levels, more frequent severe hypoglycemia, impaired quality of life, microvascular complications, cardiovascular morbidity, and mortality.^[3] Global prevalence of psychosocial problems in diabetic patients are very common affecting as many as 44% of those diagnosed with diabetes. In South India, a prevalence study on 546 type 2 DM cases found 40% prevalence of diabetes distress.^[4]

Diabetes distress has been defined across four broad themes: Emotional distress, Interpersonal distress, Regimen distress, and Physician Distress. Emotional distress is a nonpsychiatric emotional reaction to the onset and course of diabetes. Emotional distress arises due to feeling of fear and anger to DM and its complications. Interpersonal distress is feeling of worry that arises due to lack of support from family and friends. Regimen

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distress is what patients feel when overwhelmed by day-to-day management of their diabetes. It arises due to nonadherence to the therapeutic regimen and by being overwhelmed by self-care demands. Physician distress centers around the treating doctor's unresponsiveness and knowledge about DM along with patient's struggle with healthcare system. It refers to the feeling of worry that the treating doctor does not understand enough about diabetes care and patient's concerns about the disease.

Diabetes distress associated with diabetes is an important under-appreciated domain of diabetes management and is of interest to primary care physicians. The main focus of diabetes management is on lifestyle changes and pharmacotherapy, whereas self-management and self-care behaviors are equally important. Diabetes distress can present itself in many ways; Elevated HbA1c, not attending clinic appointments, less frequent blood glucose monitoring or skipping medication doses, impaired relationships with healthcare professionals, partners, family, or friends. The recognition and understanding of emotional issues by primary care physicians in diabetes care is a crucial step toward endorsing support that is not simply prescriptive, but is person centered and collaborative. This study had assessed prevalence of diabetes distress among T2DM patients in Jhajjar district of Haryana, using widely accepted DDS-17 scale along with testing the scale's internal consistency reliability through Cronbach's α .

Subject and Methods

Study Design and Study Population: This hospital based cross-sectional observational study was conducted in out-patient departments of Community Health Centre (CHC), Dighal, and Sub Divisional Hospital (SDH) Beri of district Jhajjar. All diabetic patients who were attending OPD on the day of visit by the investigator, and fulfilling inclusion criteria were recruited in the study through universal sampling technique.

Inclusion Criteria: Diagnosed with T2DM ≥ 1 year, age above 18 years and given written informed consent.

Exclusion Criteria: Comorbidities present in form of other chronic illness such as cancer, psychiatric diseases, and end-stage diseases.

Sample Size: Taking prevalence of psychosocial problems in T2DM patients as 27%, relative error (l) as 15%, and using the formula sample size = $4pq/l^2$,^[5]

where $p = 27\%$

$q = 73(100-27)$

$l = 4.05 (27*15/100)$

Thus, sample size comes out to be 480 ($73*27*4/4.05^2$), which was rounded off to 500.

Methodology and Data collection Tool: Informed consent was taken after explaining the purpose and protocol of the study. Data were collected using predesigned, semistructured interview schedule by the investigator himself. Psychosocial problems were assessed based on diabetes distress scale (DDS-17); containing 17 questions that include diabetes-related emotional problems (five questions), physician-related problems (four questions), regimen-related problems (five questions), and interpersonal problems (three questions). Subjects were asked to indicate the degree to which each of the items was causing a problem for them during the past one month, from 1 (not a problem) to 6 (a very serious problem).

Interpretation of scores: The DDS-17 yields a total diabetes distress score plus 4 subscale scores, each addressing a different kind of distress. To score, simply sum the patient's responses to the appropriate items and divide by the number of items in that scale. Current research suggests that a mean item score 2.0–2.9 should be considered “moderate distress,” and a mean item score >3.0 should be considered “high distress.” Current research also indicates that associations between DDS scores and behavioral management and biological variables (e.g., HB A1C) occur with DDS scores of >2.0 .

Ethical Permission: The permission from an institutional ethics committee was obtained before the commencement of the study. The permission for using the tool (DDS-17) had been taken from author. The study has been conducted in accordance with the ethical principles mentioned in the Declaration of Helsinki (2013).

Statistical Analysis: The data were compiled and entered in the MS Excel sheet. Analysis was carried out on IBM SPSS ver. 20 using appropriate statistical tests wherever applicable.

Results

Totally, 503 participants were enrolled in the study; their sociodemographic profile is shown in Table 1.

Among the 503 subjects, there was an almost equal distribution of males and females, i.e., 51.7% and 48.3%, respectively. Most of subjects (63.2%) were in mid-age group (39-60). Educational qualification wise, most of subjects were educated up to primary school level (31%) followed by high school (23.7%) and illiterate (20.1%). Socioeconomic status wise, 21.9% subjects were from middle class, 21% from lower class, 20.5% from upper middle, 19.5% from lower middle class and 17.1% from upper class based on B. G. Prasad socioeconomic scale. 66.4% did not had family history of DM type 2. Most of subjects 94.95% were diagnosed DM type 2 between 1 and 5 years followed by 34.2% between 5 and 20 years. 94.4% subjects were taking oral medications for DM type 2, whereas 59.8% had no complications of DM type 2.

As shown in Table 2 and depicted in Figure 1, 191 (37.97%) subjects had diabetes distress with 95% confidence interval

between 33.15% and 42.85%. Out of the total 191 (38%) subjects who had diabetes distress, 151 (30%) were having moderate distress (score 2.0-2.9 on DDS-17) with 95% confidence interval between 25.5% and 34.5%, whereas 40 (8%) were having high distress (score more than 3.0 on DDS-17) with 95% confidence interval between 5.3% and 10.7%.

Prevalence of emotional distress was 53.95%, physician distress was 39%, regimen distress was 61.2% and interpersonal distress was 47.9%. Diabetes distress is not summing total of these four; they are different kinds contributing to diabetes distress as a whole as shown in Table 3 and depicted in Figure 2.

Binary correlation results showed a very strong, significant positive relationship between DD and all four kinds of diabetes distress. Magnitude of relationship was least with interpersonal distress (0.77) and most with distress due to emotional burden (0.82); although all had strong, positive correlation means as distress due to emotional burden/physician distress/regimen distress/interpersonal distress increased; the study participants' diabetes distress score also increased, whereas intercorrelation between subscales (four kinds) of diabetes distress was <<0.8 (in range of 0.5-0.54), which signifies that there is no problem of multicollinearity; that is, they tap into relatively different areas of diabetes-related distress.

Internal consistency reliability was assessed using Cronbach's α to determine whether all items on the multi-item scale measured the same concept. DDS-17 scale showed good internal consistency

Table 1: Sociodemographic profiles of study participants			
Variables	Categories	Frequency	Percentage
Sex	Male	260	51.7
	Female	243	48.3
Age	18-39	84	16.7
	39-60	318	63.2
	Above 60	101	20.1
Educational Qualifications	Illiterate	92	18.3
	Primary	156	31
	Middle school	89	17.7
	High school	119	23.7
Socioeconomic Status	Graduate and above	47	9.3
	Upper	86	17.1
	Upper middle	103	20.5
	Middle	110	21.9
	Lower middle	98	19.5
Family history of type 2 DM	Lower	106	21
	Yes	169	33.6
Duration of type 2 DM	No	334	66.4
	1-5	249	49.5
	5-20	172	34.2
Treatment modality	>20	82	16.3
	Oral	475	94.4
Complications of type 2 DM	Insulin	28	5.6
	Yes	202	40.2
	No	301	59.8

reliability ($\alpha = 0.79$). Four subscales, ED, RD, PD, and ID, were having Cronbach's α value; 0.42, 0.38, 0.48, and 0.55, respectively, as depicted in Table 4.

Table 5 shows and Figure 3 depicts that all 17 questions were positively correlated with DDS-17 scale, which was statistically significant. Four-item questions 7, 8, 10, and 12 had low correlation (<0.4); rest all items had moderate correlation. Deletion of any item resulted in almost similar Cronbach's α suggesting their attribution to scale.

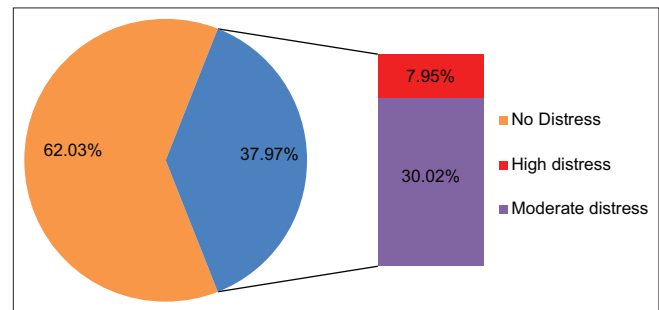


Figure 1: Bar of Pie diagram showing clinically significant diabetes distress categorized in moderate and high distress among the study participants

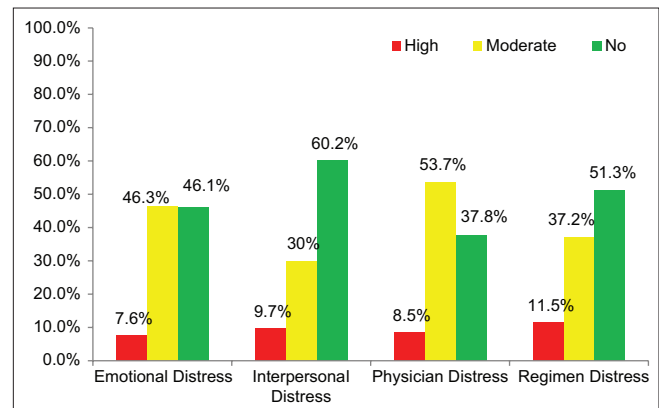


Figure 2: Vertical cluster bar diagram showing prevalence of different kinds of diabetes distress in grades

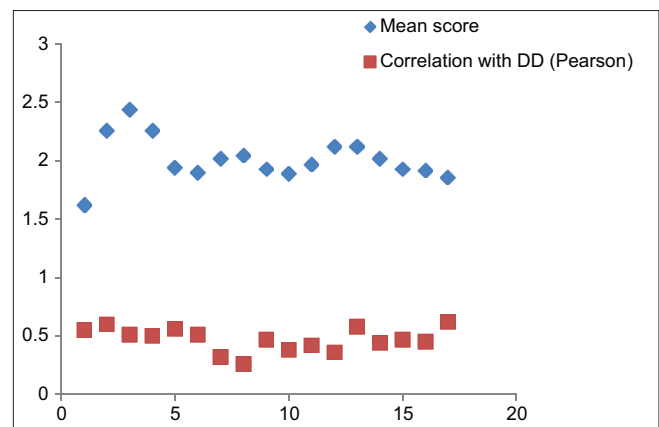


Figure 3: Scatter plot of individual item mean score and correlation with diabetes distress

Discussion

Prevalence of diabetes distress

In the present study, prevalence of diabetes distress was 38% including 30% moderate distress and 8% high distress. Similar findings were observed in other various studies across India such as Patra S *et al.*^[6] (Bhuvneshwar), 42% diabetes distress, and Hemavathi P *et al.*^[7] (Chennai) study, 39%. These similar findings indicate high prevalence of psychosocial problems among T2DM patients. In various other studies performed in other countries, results have been similar such as Geleta B *et al.*^[8] (Ethiopia) study found 36.8% diabetes distress among T2DM patients including 32.4% moderate distress and 4.4% high distress. In contrast to the present study, some studies reported lower prevalence of diabetes distress such as Ratnesh K *et al.*^[9] (Bengaluru) found

Table 2: Prevalence of diabetes distress among study participants

Distress result	Frequency	Percentage	95% C.I.	
			LL	UL
No Distress	312	62.03		
Diabetes distress				
Moderate distress	151	30.02	24.42%	34.58%
High distress	40	7.95	5.3%	10.7%
Clinically significant diabetes distress	191	37.97	33.15%	42.85%

Table 3: Different grades of four kinds of diabetes distress

Kinds of DD	Frequency	Percentage
Emotional distress		
High Emotional distress	38	7.6
Moderate Emotional distress	233	46.3
No Emotional distress	232	46.1
Physician distress		
High Physician distress	49	9.7
Moderate Physician distress	151	30
No Physician distress	303	60.2
Regimen distress		
High Regimen distress	43	8.5
Moderate Regimen distress	270	53.7
No Regimen distress	190	37.8
Interpersonal distress		
High Interpersonal distress	58	11.5
Moderate Interpersonal distress	187	37.2
No Interpersonal distress	258	51.3

Table 4: Internal consistency reliability of DDS-17 and its four subdomains along with their correlation with clinically significant diabetes distress

DD subtypes	Number of items	Mean score (SD)	Cronbach's α	Correlation with DD (Pearson)	P
Diabetes Distress	17	2.01 (0.47)	0.79	1	
Distress due to Emotional Burden	5	2.09 (0.54)	0.42	0.82	P<0.001
Regimen Distress	5	2.08 (0.49)	0.38	0.80	P<0.001
Physician Distress	4	1.86 (0.63)	0.48	0.80	P<0.001
Interpersonal Distress	3	1.97 (0.74)	0.55	0.77	P<0.001

prevalence of diabetes distress 19.6%. The difference may be due to the reason that they had used DDS-17 score 3.0 as cutoff for diabetes distress, whereas the present study and other various studies used standard cutoff mentioned in DDS-17 scale, i.e., DDS score of 2.0 as cutoff for diabetes distress and 3.0 as cutoff for high diabetes distress. In another study, Delahanty L *et al.*^[10] (USA) found prevalence of diabetes distress 28.3% among T2DM patients. The differences may be due to fact that diabetes distress among diabetic patients depends on various factors such as age, education level, SES, and family support of patients along with personal coping ability to stress, which varies among different individuals and different regions.

Prevalence of different kinds of diabetes distress

The four domains of diabetes distress: Emotional distress, physician distress, regimen distress, and interpersonal distress tap around different origin and different domains of distress. Prevalence of regimen distress was 61.2%, emotional distress 53.9%, interpersonal distress 47.9%, and physician distress 39%. We found that all four types had strong, positive correlation with diabetes distress, which means as distress due to emotional burden/physician distress/regimen distress/interpersonal distress increases, study participant's diabetes distress score increased ($P < 0.001$). The four kinds of diabetes distress are determined from four subscales of DDS-17 scale. Similar results were found in Vidya KR *et al.*^[11] (Bangaluru) study, in which prevalence of regimen distress was 62.85%, emotional distress 54%, interpersonal distress 57.6%, and physician distress 56.7%. In another study by Anita D *et al.*^[12] (Indonesia), emotional distress was most prevalent 65.9%, regimen distress was 56.9%, physician distress 54.6%, and interpersonal distress 52.2%. These similar findings indicate towards high prevalence of different kind of diabetes distress. In contrast to present study; Tunsuchart K *et al.* (Thailand) found prevalence of emotional distress 27.1%, physician distress 4.3%, regimen distress 15.4% and interpersonal distress 12.4%. Difference in findings may be due to the fact that in Tunsuchart K *et al.*^[13] study; most of the study subjects were educated (90.8%) and employed (69.7%), and their diabetes distress prevalence was low (9%).

Internal consistency reliability of DDS17

In the present study, the overall Cronbach's α for the English version of DDS-17 was 0.79 and deletion of any item (out of 17) resulted in almost similar Cronbach's α , suggesting their attribution to scale. Similar results found in Malaysian English version of DDS-17 reliability study, where Cronbach's α was

Table 5: The psychometric properties of diabetes distress scale

Question	Mean score (SD)	Cronbach α if item deleted	Correlation with Diabetes distress (Pearson's)	P
1. Feeling that my doctor doesn't know enough about diabetes and diabetes care	1.62 (1.07)	0.774	0.55	$P<0.001$
2. Feeling that diabetes is taking up too much of my mental and physical energy every day	2.26 (0.98)	0.770	0.60	$P<0.001$
3. Not feeling confident in my day-to-day ability to manage diabetes	2.44 (1.03)	0.777	0.51	$P<0.001$
4. Feeling angry scared and/or depressed when I think about living with diabetes	2.26 (1.03)	0.778	0.50	$P<0.001$
5. Feeling that my doctor doesn't give me clear enough directions on how to manage my diabetes	1.94 (1.06)	0.773	0.56	$P<0.001$
6. Feeling that I am not testing my blood sugars frequently enough	1.90 (0.94)	0.776	0.51	$P<0.001$
7. Feeling that I will end up with serious long-term complications, no matter what I do	2.02 (0.96)	0.791	0.32	$P<0.001$
8. Feeling that I am often failing with my diabetes routine	2.05 (0.80)	0.793	0.26	$P<0.001$
9. Feeling that friends or family are not supportive enough of self-care efforts (e.g., planning activities that conflict with my schedule, encouraging me to eat the "wrong" foods)	1.93 (0.93)	0.780	0.47	$P<0.001$
10. Feeling that diabetes controls my life.	1.89 (0.93)	0.786	0.38	$P<0.001$
11. Feeling that my doctor doesn't take my concerns seriously enough	1.97 (0.90)	0.784	0.42	$P<0.001$
12. Feeling that I am not sticking closely enough to a good meal plan	2.12 (0.87)	0.787	0.36	$P<0.001$
13. Feeling that friends or family don't appreciate how difficult living with diabetes can be	2.12 (1.05)	0.777	0.58	$P<0.001$
14. Feeling overwhelmed by the demands of living with diabetes.	2.02 (0.99)	0.783	0.44	$P<0.001$
15. Feeling that I don't have a doctor who I can see regularly enough about my diabetes	1.93 (1.00)	0.780	0.47	$P<0.001$
16. Not feeling motivated to keep up my diabetes self-management	1.92 (0.92)	0.781	0.45	$P<0.001$
17. Feeling that friends or family don't give me the emotional support that I would like	1.86 (1.07)	0.767	0.62	$P<0.001$

0.78.^[14] In contrast to our study, in original DDS-17 study by Polonsky *et al.*, it was 0.93.^[15] The difference may be due to difference in sociocultural aspect and higher education status of study participants.

This study conclusively showed that more than one third of the T2DM patients had diabetes distress; the four different kinds of diabetes distress were highly prevalent among T2DM patients too. Hence, to ensure good adherence to diabetic care plans, it is necessary to screen all the patients with T2DM for psychological well-being. Diabetes distress scale (DDS-17) is an easy, well-accepted questionnaire; it identified different aspects of diabetes distress and efficiently quantified them.

There are a few potential limitations of this study. At first, the data reported are cross-sectional, and implications about causation can only be inferred. Second, the study was based on participants' reports of data, and therefore, there may be recall bias. Lastly, the study is restricted to one district Jhajjar; hence, the findings may not be representative of whole state or nation.

Based on findings of this study, we recommend that psychosocial screening of diabetes distress at every level of diabetes care should be performed by primary care physicians and an advocacy program be made available at the community level to improve the awareness level of psychosocial well-being of persons

with diabetes and making lifestyle changes that are slow but continuous, such as increasing physical activity, paying attention to diet, and diligently monitoring blood glucose should be implemented.

Summary of key points

Compliance with medication and health-seeking behavior among diabetics not only depends on the availability and accessibility of health care but also on perceived diabetes distress. DDS-17 is the most common tool to assess the perceived diabetes distress for the holistic management of diabetic patients. This study estimates the burden of diabetes distress among the vulnerable diabetic population of rural Haryana, who might find it difficult to access health care and proves the cross-cultural reliability of the DDS-17 scale in the North Indian state of Haryana.

Ethical policy and Institutional Review board statement

Institutional Ethics Committee Approval: From Biomedical Research and ethics committee, Pt. B.D. Sharma PGIMS Rohtak (BREC/19/154 dated 26.12.19). The study has been conducted in accordance with the ethical principles mentioned in the Declaration of Helsinki (2013).

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Conflicts of interest

There are no conflicts of interest.

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