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Diabetes distress and associated factors among adults with diabetes mellitus residing in a metropolitan city of India: a community-based study

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Abstract

Background Diabetes distress "*refers to the negative emotional or affective experiences resulting from the challenge of living with the demands of diabetes.*" Despite recommendations to screen for distress at regular intervals, it usually remains undiagnosed. This study aimed to determine the prevalence of diabetes distress among adults living with diabetes, determine the factors associated with distress, the association between selfcare and distress, glycemic control and distress and compare the health-related quality of life among those with and without distress.

Methods This cross-sectional, community-based study was conducted in an urban colony in Delhi, India. The participants were selected using simple random sampling and included adults diagnosed with diabetes mellitus. The sample size calculated was 390. The questionnaire included the Diabetes Distress Scale 17, Diabetes Self-Management Questionnaire and Healthy Days measure. Factors associated with distress were tested using bivariate followed by multivariable logistic regression. Multivariable logistic regression was used to find the association between selfcare and distress and glycemic control and distress. Mean number of unhealthy days and health rating were compared between distressed and non-distressed diabetics using Wilcoxon rank sum test and chi square test respectively.

Results A total of 412 adults were included in the study, of which 35.4% had clinically significant distress. Female sex, low socio-economic status, 1 or more comorbidities, diagnosis of diabetes 10 or more years prior, being on treatment and an unmet need for social support were the factors found to be associated with distress. There was a positive association between physicians contact and distress. Those with poor glycemic control had higher odds of distress. There was a significant difference in the health reported by those with and without distress ($p < 0.001$). Those with distress also suffered from significantly more physically unhealthy days and mentally unhealthy days than those without distress ($p < 0.001$).

Conclusion In this study, more than one in three diabetics were found to be distressed. Healthcare providers should increase their focus on the psychological aspects of diabetes and improve their communication with patients. Diabetes distress needs to be screened for in routine clinical settings and addressed appropriately.

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Keywords Diabetes distress, Associated factors, Selfcare, Glycemic control, Health related quality of life, Urban, India, Community-based, Cross-sectional

Background

The burden of diabetes mellitus (DM) has been increasing globally with the estimated global prevalence in 2021 being 10.5% among adults aged 20–79 years [1]. In 2021, the estimated number of persons with diabetes in India was 74 million, which is 9.6% of the adult population [1].

Apart from the commonly known physical and psychiatric complications of diabetes, studies have found that diabetes can result in psychological symptoms that fester beneath the surface, unrecognized by the health care provider [2]. A study conducted by Beeney L et al. (1996) in Australia found that 60% of people suffered from anxiety, shock denial and anger when diagnosed with diabetes and 23% felt they received inadequate emotional support [3]. Another study in 2007 found that patients wanted a "diabetic holiday" so they could feel better [4].

Diabetes distress (DD) "*refers to the negative emotional or affective experiences resulting from the challenge of living with the demands of diabetes, regardless of the type of diabetes* [5]." The concept first introduced by Polonski et al in 1995 when they developed a scale to measure the psychosocial adjustment specific to diabetes: The Problem Areas in Diabetes Survey (PAID) [6]. Since 1995, various studies on distress have been conducted and another scale called the Diabetes Distress Scale 17 (DDS 17) was developed in 2005 [7].

Distress among diabetics may be caused by many factors. Patients may feel overwhelmed, frustrated, angry or burnt out due to the burden of living with a chronic disease and the demands of self-management. Food restriction, lack of empathy from family members and the approach that healthcare providers use of labelling patients as non-compliant and scaring them about the grim prospects further worsen distress [8]. This emotional distress often remains hidden from the healthcare provider and patient [2], which is concerning since it has been found to be associated with poor glycemic control [9] as well as a worse health related quality of life (HRQOL) [10].

Diabetes distress is amenable to treatment, but if not addressed, it can persist and even worsen the glycaemic control, which can lead to chronic complications [11]. The American Diabetes Association recommends psychosocial care, including screening for diabetes distress at regular intervals, to be integrated with medical care [12]. However, this does not take place in routine settings and diabetes distress usually remains undiagnosed. The psycho-social problems faced by people living with diabetes remain largely unaddressed in today's healthcare setup.

Considering more than 75% of adults with DM live in low and middle income countries [1] where the burden of distress in the community has not been explored extensively, there is scope for further research on the prevalence and determinants of diabetes distress as well as its management, so that it can effectively be addressed.

This study was conducted to determine the prevalence of diabetes distress and its domains and to identify the sociodemographic, self-care and other health related factors associated with diabetes distress among adults living with DM in an urban colony in Delhi. We also assessed the association of glycaemic control status with diabetes distress and its domains and compared the fasting blood sugar (FBS) levels between those with different levels of distress. The HRQOL among those with and without distress was also compared.

Methods

This community-based cross-sectional study was carried out in an urban colony in Delhi, India, where the population predominantly belonged to the lower-middle socio-economic class. This colony was situated around 8 km away from a tertiary care institute, and had been adopted by the Community Medicine department as an urban field practice area since 2002. When conducting the study, the colony had a population of around 38,000 people. Health workers from the community medicine department would make routine house visits and collect health related data from the population which would then be entered in the Health Management Information System (HMIS). The colony had multiple primary care government and private facilities (providing out-patient care) within it, where DM care was provided. The nearest secondary level government hospital was 5 km away and tertiary care set-up was 8 km away.

Participants included in the study were adults more than 18 years of age with diabetes mellitus, who were diagnosed more than 3 months prior. Subjects with a hearing impairment and unable to converse or those unavailable after two home visits were excluded from the study. The sample size calculated was 390, using the formula $\frac{4pq}{d^2}$, where prevalence (p) was considered to be 42% [13], q was 58% (1-p) and absolute precision (d) 5%. Expecting a non-response and refusal rate of 10%, the final sample size was increased to 433. The study participants were selected using simple random sampling from the sampling frame obtained from the HMIS of the area. The HMIS was a database containing information about socio-demographic characteristics and common health conditions of every individual in the population,

including DM and other common non-communicable diseases.

Clearance from the Institute Ethics Committee for Post Graduate Research, All India Institute of Medical Sciences, New Delhi was obtained. Written informed consent was collected from the participants before including them in the study.

The questionnaire was administered during house visits using Epicollect5. It included questions regarding sociodemographic and health related characteristics, Diabetes Distress Scale 17 (DDS17) [7], Healthy days measures for health related quality of life [14] and Diabetes Self-Management Questionnaire (DSMQ) [15].

Diabetes Distress Scale 17 is a 17 item, self-reported measure containing 4 domains: physician related distress (PRD), emotional burden (EB), interpersonal distress (IPD) and regimen related stress (RRD). Answers are collected on a 6-point Likert scale, ranging from 'not a problem' (1 point) to 'a very serious problem' (6 points) and then averaged for the entire scale and each domain separately. In this study, a score of <2 was considered little or no distress, a score of 2 to 2.9 moderate distress and a score>=3.0 high distress [16].

Healthy Days Measure was developed by the Centers for Disease Control and Prevention [14]. The scale assesses a person's health related quality of life. Unhealthy days are an estimate of the overall number of days during the previous 30 days when the respondents felt that either their physical or mental health was not good [14].

Diabetes Self-Management Questionnaire is a 16 item questionnaire to assess selfcare activities in the past 8 weeks [15]. It consists of 5 subscales: glucose management, dietary control, physical activity, health care use and a sum scale. Answers are collected on a four-point Likert scale (3 - 'applies to me very much' to 0 - 'does not apply to me'). Subscale and total scores ranged from 0 to 10 with higher scores indicating better self-care. To categorize a person as not sufficiently adhering to their self-management regimen: overall and for each subscale separately, a score of 0 or 1 in each question was required [17].

Blood pressure (BP) was measured using a digital BP apparatus (Omron HEM7156). Three blood pressure measurements were taken with 3 min of rest between the readings. The mean of the second and third readings was taken for data analysis. Blood pressure was considered to be controlled if SBP was <130 and DBP was <80 [18].

The following morning, a subsequent visit was made to test the fasting blood sugar using a portable glucometer (SD Biosensor Codefree). A participant was said to have glycemic control if their FBS was <126 mg/dl [18]. Due to logistic reasons, we could not use HbA1c to estimate glycemic control.

Statistical analysis

Data was collected using Epicollect version 5, then extracted on to Microsoft Excel version 2019 and was analysed in Stata version 15. Mean and standard deviation were calculated for continuous variables that were normally distributed. Median and IQR were calculated for continuous variables that did not have a normal distribution. Percentage/proportions were calculated for categorical variables. Prevalence of diabetes distress was reported as a percentage with its 95% confidence interval (CI).

Sociodemographic and health related factors associated with diabetes distress were analysed using bivariate logistic regression. The factors with a p-value of less than 0.20 on bivariate analysis were included in the multivariable regression model. Knowledge of the complications and curability of DM was assessed based on two questions relating to complications and curability of diabetes. Incorrect answers to both the questions was considered as "no knowledge", one correct answer was considered "inadequate knowledge" and correct answers to both questions was considered "adequate knowledge". Social support included tangible (material support like services, financial assistance or goods) and informational (provided by family or friends, example: guidance or information about their similar experiences). The association between selfcare (independent variable) and diabetes distress (outcome variable) was assessed using multivariable logistic regression, after adjusting for confounders: glycemic control, sex, SES, self-reported comorbidities, duration of DM, unmet need of support, knowledge, with the reference category being those with inadequate self-care. Multivariable logistic regression was also used to assess the association between glycemic control (independent variable) with diabetes distress (outcome variable) after adjusting for sex, SES, self-reported comorbidities, duration of diabetes in years, whether the participant was on treatment from government, private or not on treatment, support and knowledge, and the reference category in this case was having adequate glycemic control. Associations were presented as odds ratio with 95% CI. An odds ratio>1 indicates that the variable has a positive association with distress. Kruskal Wallis test was used to compare the median FBS between those with no, moderate and high distress.

In another model, bivariate logistic regression analysis was conducted to estimate the association of diabetes distress with self-reported health. An odds ratio<1 indicated that those with distress were more likely to report poor health (not fair, good very good or excellent health) as compared to those without distress. Between distressed and non-distressed diabetics, one's health rating was compared using the Chi square test and the median

number of unhealthy days (days lost, physical and mental) using the Wilcoxon rank sum test.

Results

A total of 412 participants were included in this study. The mean (SD) age of the participants was 59 (10.9) years and the median (IQR) duration of diabetes was 8 years (5-12.5). The sociodemographic, health related and treatment related profile of the study participants is described in Table 1. Almost 60% of the participants were illiterate and around 70% were married at the time. Homemakers consisted 35% of the participants and around 60% of the participants belonged to the lower class according to modified Kuppuswamy scale [19]. The median (IQR) fasting blood sugar was 149 mg/dl (120 – 204). 84% of the participants were taking medicines for DM prescribed by a healthcare provider. Insulin alone was prescribed for 2% of the participants, insulin and oral hypoglycaemics were prescribed for 5% and 77% of the participants were prescribed only oral hypoglycaemic tablets. The most common medicine prescribed was metformin, followed by sulfonylureas. Other classes of drugs prescribed were SGLT-2 inhibitors, meglitinides, DPP-4 inhibitors, alpha-glucosidase inhibitors and thiazolidinediones. 3%

Table 1 Sociodemographic, health related and treatment related profile of the study participants

Sociodemographic variables (*N* = 412)		***N* (%)**
Sex	Male	152 (36.9)
	Female	260 (63.1)
Age in years	< 50	83 (20.1)
	50–59	117 (28.4)
	60–69	128 (31.1)
	70+	84 (20.4)
Health related characteristics (*N* = 412)		
Self-reported comorbidities*¶	No comorbidity	134 (32.5)
	HTN	217 (52.7)
	Others	204 (49.5)
Duration of Diabetes	< 1 year	4 (1.0)
	1 to < 5 years	91 (22.1)
	5 to < 10 years	131 (31.8)
	10 to < 20 years	148 (35.9)
	≥ 20 years	38 (9.2)
Knowledge about DM complications and treatment (assessed based on two questions)	Adequate Present (2/2)	218 (52.9)
	Intermediate (1/2)	159 (38.6)
	Absent (0/2)	35 (8.5)
Medicine adherence in the past 7 days (*N* = 399; excludes those who have been prescribed only non-pharmaceutical management)	Not Adherent (< 80%)	93 (23.3)
	Adherent (> 80%)	306 (76.7)
Blood pressure (Control: SBP < 130mmHg & DBP < 80mmHg)	Controlled	109 (26.5)
	Raised	303 (73.5)
Diabetes status as assessed by fasting blood sugar (Control: <126 mg/dl)	Controlled	129 (31.3)
	Uncontrolled	283 (68.7)
Treatment related characteristics		
Presently on treatment from a healthcare provider (*N* = 412)	Prescribed medications and non-pharmaceutical management	345 (83.7)
	Only prescribed non-pharmaceutical management	13 (3.2)
	No	54 (13.1)
Presently on anti-glycemic medication (*N* = 412)	Yes	381 (92.5)
	No	31 (7.5)
Medicine adherence in the past 7 days (*N* = 399; excludes those who have been prescribed only non-pharmaceutical management)	Not Adherent (< 80%)	93 (23.3)
	Adherent (>= 80%)	306 (76.7)
Insulin use (*N* = 412)	Yes	30 (7.3)
	No	382 (92.7)
Polypharmacy (*N* = 412)	Yes (taking ≥ 5 NCD medications daily)	113 (27.4)
	No	299 (72.6)

* Multiple answers are possible

¶ Other comorbidities: hypothyroidism, coronary artery disease, stroke, neuropathy, chronic respiratory disease, chronic kidney disease, retinopathy, diabetic foot, gall stones, benign prostatic hyperplasia, depression, fibroid, hyperthyroidism, arrythmia, piles, polio, epilepsy, tuberculosis, valve replacement, liver disease, cancer

of the participants were only advised non-pharmaceutical management by their healthcare providers. Of the 54 participants who were not on treatment prescribed by a healthcare provider, 66.7% were on self or pharmacy prescribed medicines, 29.6% were not consulting a provider and were not taking any medication and 3.7% were consulting a healthcare provider but were not taking the medicines prescribed. Around 71% (283) of the participants reported taking their medicines regularly every day. Out of the 358 participants who sought treatment, the private sector was being utilized more than the government sector (53% vs. 47% respectively). Almost 30% of the participants had not visited a doctor in the past 6 months. There was an unmet need for social support among 12.4% of the participants. From the 230 participants who felt that they received support, the most common primary giver was their child (41.3%) followed by their spouse (39.6%).

It was observed that about two-thirds (64.6%) of the study subjects had little or no diabetes distress. Moderate distress was present in 26.5%, while high distress was present among 8.9% of the participants (Table 2). The median (IQR) score of diabetes distress among the study participants was 1.5 (1.1– 2.3). The median (IQR) score of physician related distress and interpersonal distress was 1 (1–1), for emotional burden it was 2.2 (1.2–3.8) and regimen related distress it was 1 (1-1.8).

Using multivariable regression, we found female sex, belonging to the lower socioeconomic status as per modified Kuppuswamy scale, having self-reported comorbidities, being diagnosed with diabetes 10 or more years ago, being on treatment from a private or government hospital as compared to not being on treatment and having an unmet need for social support to be significantly associated with diabetes distress (Table 3).

As per the diabetes self-management questionnaire, adequate self-care was seen in 97.1% (400) of the participants (Table 4). The median (IQR) DSMQ total score was 8.7 (6.9–9.7). The median (IQR) scores for the domains dietary control, glucose management, physical activity and physicians contact were 9.2 (7.5–10), 10 (8.3–10), 10 (7.8–10) and 8.9 (4.4–10) respectively.

When determining the association between self-care (including its domains) and distress, after adjusting for confounders (glycemic control, sex, SES, self-reported comorbidities, duration of DM, unmet need of support, knowledge), it was found that those who had adequate contact with their physicians had 85% higher odds of distress as compared to those who had inadequate contact with physicians (Table 4).

There was a significant difference in the median FBS values of those with high DDS scores as compared to those with no or moderate distress. Similarly, there was a significant difference in the median FBS values of those with high regimen related scores as compared to those with no or moderate regimen related distress and the median FBS values of those with no emotional burden was significantly lower than those with moderate or high emotional burden (Fig. 1).

Legend: (a) Diabetes distress overall, (b) Regimen related distress, (c) Physician related distress, (d) Interpersonal distress and (e) Emotional burden,

Each figure depicts Kruskal Walis test comparing the median fasting blood sugar levels among patients with no, moderate and high distress.

It was found that those who had poor glycemic control had higher odds of having diabetes distress, regimen related distress and emotional burden, as compared to those who had adequate glycemic control, after controlling for the following confounders: sex, SES, self-reported

Table 2 Prevalence of diabetes distress and its domains as per Diabetes Distress Scale 17 (*N* = 412)

Distress		Prevalence: *N*	Prevalence% (95% CI)
Diabetes distress	Little or no distress (< 2)	266	64.6 (59.8–69.1)
	Moderate distress (2-2.9)	109	26.5 (22.4–30.9)
	High distress (≥ 3)	37	8.9 (6.6–12.2)
Domain of distress		**Prevalence: N**	**Prevalence% (95% CI)**
Physician associated distress	Little or no distress (< 2)	359	87.1 (83.5–90.1)
	Moderate distress (2-2.9)	27	6.6 (4.5–9.4)
	High distress (≥ 3)	26	6.3 (4.3–9.1)
Interpersonal stress	Little or no distress (< 2)	343	83.3 (79.31–86.6)
	Moderate distress (2-2.9)	18	4.3 (2.7–6.8)
	High distress (≥ 3)	51	12.4 (9.5–15.9)
Emotional burden	Little or no distress (< 2)	181	43.9 (39.2–48.8)
	Moderate distress (2-2.9)	67	16.3 (13.0-20.2)
	High distress (≥ 3)	164	39.8 (35.2–44.6)
Regimenrelated distress	Little or no distress (< 2)	336	81.5 (77.5–85.0)
	Moderate distress (2-2.9)	51	12.4 (9.5–15.9)
	High distress (≥ 3)	25	6.1 (4.1–8.8)

Table 3 Factors associated with diabetes distress among the study participants (*N* = 412)

Sociodemographic and health related characteristics		Distress present (*N* = 146)	cOR (95% CI)	*p*- value	aOR (95% CI)	*p*- value
Sex	Male (%)	36 (23.7)	1	< 0.001	**1**	**0.044**
	Female (%)	110 (42.3)	2.36 (1.51–3.70)		**1.68 (1.01–2.78)**	
Age (years)	Mean (SD)	59 (10.9)	1.00 (0.98–1.02)	0.961		
Education*	Illiterate/ less than primary school (%)	98 (40.0)	1	0.019		
	Primary school or higher (%)	48 (28.7)	0.61 (0.40–0.92)			
Marital Status	Married presently (%)	97 (33.2)	1	0.143	1	0.071
	Separated/divorced/ widowed/not married (%)	49 (40.8)	1.39 (0.90–2.15)		0.60 (0.35–1.04)	
Employment Status*	Employed (%)	33 (27.5)	1	0.032		
	Not employed (%)	113 (38.7)	1.66 (1.05–2.65)			
Socioeconomic Status¶	Lower class (%)	97 (39.3)	1	0.047	**1**	**0.041**
	Middle/ upper (%)	49 (29.7)	0.65 (0.43–0.99)		**0.59 (0.36–0.98)**	
Self-reported comorbidities	Yes (%)	113 (40.7)	1	0.002	**1**	**0.012**
	No (%)	33 (24.6)	0.48 (0.30–0.76)		**0.52 (0.31–0.86)**	
Known case of hypertension	No (%)	67 (34.4)	1	0.665		
	Yes (%)	79 (36.4)	1.09 (0.73–1.64)			
Duration of DM	< 5 years (%)	27 (28.4)	1		**1**	
	5 - <10 years (%)	38 (29.0)	1.03 (0.57–1.85)	0.923	1.05 (0.54–2.04)	0.895
	10 + years (%)	81 (43.6)	1.94 (1.14–3.30)	0.014	**2.28 (1.23–4.25)**	**< 0.001**
Place where the treatment was prescribed	Private (%)	66 (34.9)	1		**1**	
	Government (%)	68 (40.2)	1.25 (0.81–1.93)	0.300	1.09 (0.68–1.76)	0.717
	Not on treatment (%)	12 (22.2)	0.53 (0.26–1.08)	0.081	**0.42 (0.19–0.94)**	**0.035**
Level of health facility where the treatment was prescribed (*N* = 358, includes only those on treatment)	Primary care level (%)	90 (39.5)	1	0.290		
	Secondary or tertiary (%)	44 (33.9)	0.78 (0.50–1.23)			
Insulin use	No (%)	133 (34.8)	1	0.350		
	Yes (%)	13 (43.3)	1.43 (0.67–3.04)			
Polypharmacy (≥ 5 NCD medicines/day)	No (%)	103 (34.5)	1	0.495		
	Yes (%)	43 (38.1)	1.17 (0.75–1.83)			
Social support (tangible and informational)	No unmet need (%)	107 (29.6)	1	< 0.001	**1**	**< 0.001**
	Unmet need (%)	39 (76.5)	7.71 (3.89–15.31)		**7.99 (3.74–17.10)**	
Knowledge regarding complications and curability of diabetes	None (Score 0/2) (%)	18 (51.4)	1	0.042	1	0.095
	Some (Score 1/2 or 2/2) (%)	128 (34.0)	0.49 (0.24–0.97)		0.50 (0.22–1.13)	

* Education and employment status were not included in multivariable regression due to their inclusion in socioeconomic status which was included in the model

¶ As per modified Kuppuswamy scale: lower and upper lower class have been clubbed to form lower class and upper class, upper middle and lower middle have been clubbed to form middle/ upper classl

Table 4 Prevalence of adequate selfcare and the association of selfcare with diabetes distress and its domains

Self-care and its domains as per Diabetes Self-Management Questionnaire		Number ($N=412$) (%)	cOR (CI)	*p* value	aOR**	CI	*p* value
Self-care	Inadequate	12 (2.9)	1 (ref)		1 (ref)		
	Adequate	400 (97.1)	2.81 (0.61–13.01)	0.186	3.45	0.58–20.50	0.174
Dietary control	Inadequate	22 (5.3)	1 (ref)		1 (ref)		
	Adequate	390 (94.7)	1.19 (0.47–2.98)	0.716	1.10	0.40–2.99	0.854
Glucose management (401)*	Inadequate	37 (9.2)	1 (ref)		1 (ref)		
	Adequate	364 (90.8)	2.56 (1.09–5.98)	0.030	2.28	0.88–5.94	0.091
Physical activity[¶] (326)	Inadequate	25 (7.7)	1 (ref)		1 (ref)		
	Adequate	301 (92.3)	1.90 (0.69–5.22)	0.212	1.35	0.46–3.97	0.582
Physician contact	**Inadequate**	92 (22.3)	**1** (ref)		**1** (ref)		
	Adequate	320 (77.7)	**1.75 (1.04–2.93)**	**0.035**	**1.85**	**1.04–3.31**	**0.038**

*Only includes those on medications or those advised to self-monitor their blood sugar

[¶] Excludes those unable to exercise

** Confounders adjusted for: glycemic control status, sex, SES, self-reported comorbidities, duration of DM, unmet need of support, knowledge

comorbidities, duration of diabetes in years, whether the participant was on treatment from government, private or not on treatment, support and knowledge (Table 5).

A significant difference was found between the self-rated health of those with and without distress using the chi square test, with 43.1% (63) of those with distress claiming they had poor health in general versus only 7.5% (20) of those without distress. On the other hand, more participants without distress claimed to have excellent health in general compared to those with distress (6.4% vs. 1.4%). Those with distress had lesser chances (OR 0.11, CI: 0.06–0.19, $p<0.001$) of reporting fair or better health as compared to those with no distress.

When the median number of days of poor physical health in the past month were compared between those with and without distress (7 vs. 0 respectively) using Wilcoxon rank sum test, a significant difference was found ($p<0.001$). Similar results were found for median number of days of poor mental health in the past month (15 vs. 0; $p<0.001$) and number of days lost in the past month due to poor physical and mental health (5 vs. 0; $p<0.001$) (Fig. 2).

Discussion

In our study, using the Diabetes Distress Scale 17, the prevalence of clinically significant distress was found to be 35.4%. Multiple studies have been conducted across the world where the prevalence of distress has been found to vary from 7 to 87.6%. Reasons for this variation could be attributed to contextual factors, individual factors of the sample included as well as differences in the study designs. The prevalence of distress in our study parallels previous results in India and globally [13, 20, 21]. Only two other community-based studies conducted in India could be found which measured the prevalence of distress. One was conducted in rural areas of Punjab where the prevalence of distress among type 2 diabetics was found to be 100%, which was hypothesized by the authors to be due to the participants living in a "rural area which has restricted access to good quality DM related care and a lower level of education" [22]. The other study was conducted in urban and rural areas of Punjab where the prevalence was found to be 18%. This study excluded type 1 diabetics as well as those suffering from any mental illness [9].

Our finding that over one-third of individuals experience distress due to diabetes underscores the importance of incorporating screening and management of this condition into routine healthcare. In a resource limited setting, screening may be targeted to those found to be at a higher risk of experiencing distress. In this study, factors found to be associated with distress were female sex, lower SES, having at least one comorbidity, having DM for more than 10 years, being on treatment from a private or government hospital as compared to not being on treatment and having an unmet need for social support. However, some factors which were found to be significantly associated with distress in other studies conducted in India and globally were not significant in our study, such as age, use of insulin, marital status, seeking care in a government facility, seeking care in a secondary or tertiary care set up and less education related to diabetes mellitus. This may be due to the low prevalence of these factors found in our study participants (example: the prevalence of insulin use among the participants was

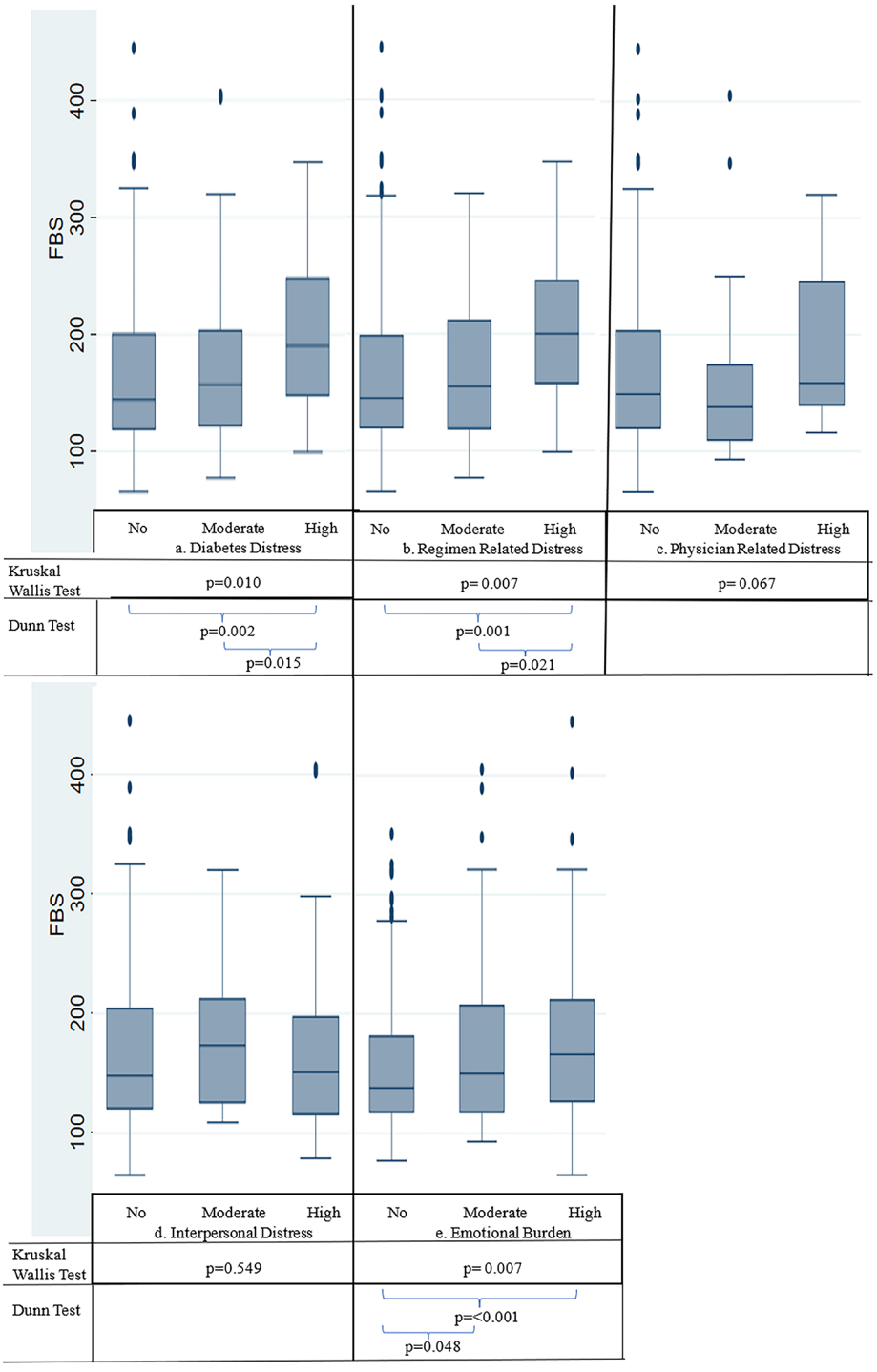

Fig. 1 Box plot depicting FBS of participants with no, moderate and high distress and their comparison(*N* = 412)

only 7.28%) causing the study to be inadequately powered to determine an association with the given sample size.

Varying results have been found in studies conducted across the globe for the association between self-care and distress, ranging from a positive association to a negative association to no association. A positive association may be explained with the health belief model [23] which suggests that the perceived threat of an illness, along with the perception of increased seriousness and one's susceptibility to the threat can increase the motivation to act to counter the threat and increase healthy behaviour. In contrast, feeling unsupported and burnt out would lead

Table 5 Association of glycemic control with diabetes distress and its domains using multivariable logistic regression (*N* = 412)

Diabetes distress	Glycemic control	cOR (CI)	aOR* (CI)	*p* value
Diabetes distress	Present	1 (ref)	1 (ref)	0.014
	Absent	1.56 (0.99–2.44)	**1.89 (1.14–3.14)**	
Domains of diabetes distress				
Regimen related distress	Present	1 (ref)	1 (ref)	0.037
	Absent	1.74 (0.97–3.12)	**1.90 (1.04–3.49)**	
Physician related distress	Present	1 (ref)	1 (ref)	0.322
	Absent	1.31 (0.69–2.51)	1.42 (0.71–2.87)	
Interpersonal distress	Present	1 (ref)	1 (ref)	0.385
	Absent	1.14 (0.65–2.01)	1.45 (0.63–3.33)	
Emotional Burden	Present	1 (ref)	1 (ref)	0.021
	Absent	1.53 (1.01–2.33)	**1.72 (1.09–2.74)**	

*Confounders adjusted for: sex, SES, self-reported comorbidities, duration of diabetes in years, whether the participant was on treatment from government, private or not on treatment, support and knowledge

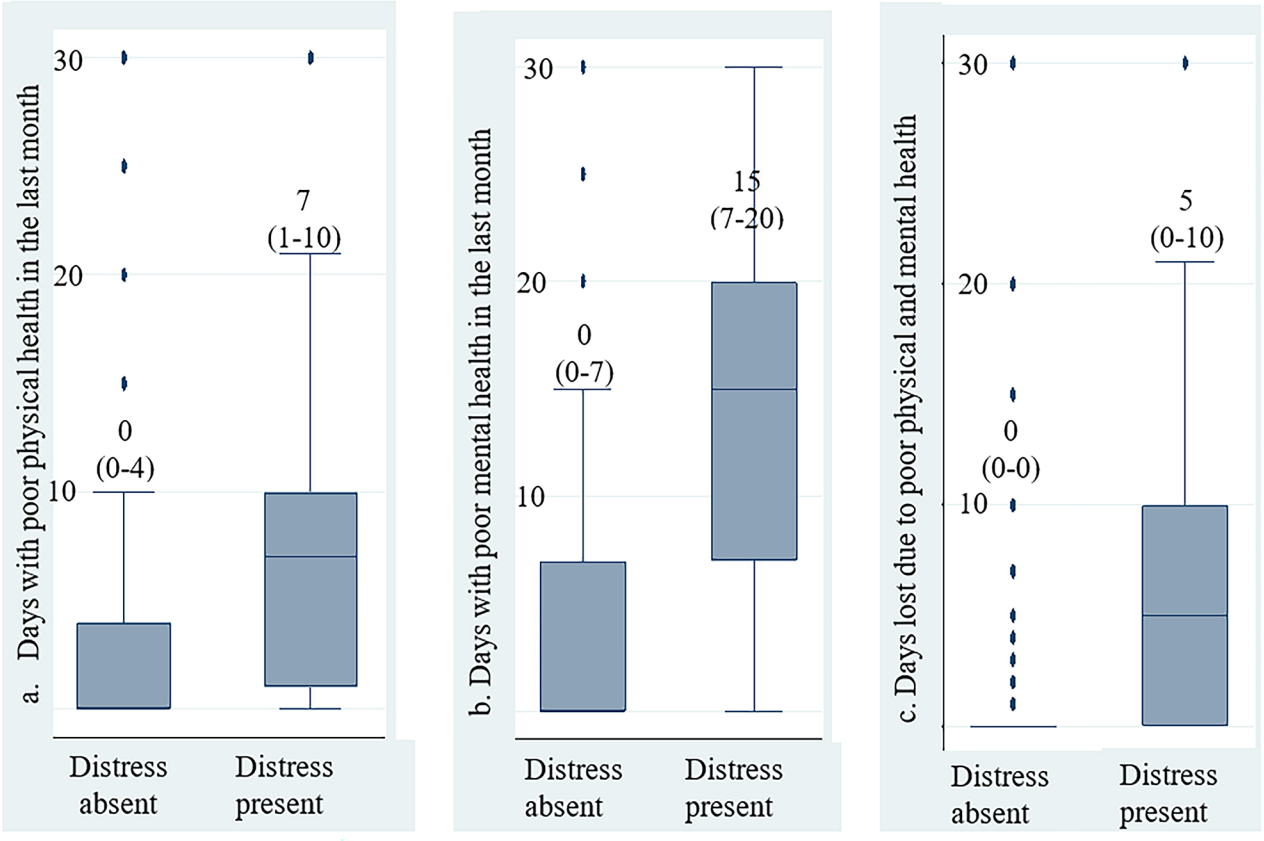

Fig. 2 Box plot depicting median number of unhealthy days experienced by those with and without distress(*N* = 412)

to decreased self-care [5]. It has also been found that some personality variables such as anxiety are negatively associated with healthy behaviour [24]. In our study, self-care was not found to be associated with the presence of distress. Among the domains of selfcare, only those with adequate physician contact had higher odds of having distress compared to those with inadequate physician contact. Given the cross-sectional design of the study, temporality and hence causality between distress and physicians contact could not be determined. However, doctors should keep in mind that their behaviour of labelling a person as non-compliant and scaring them regarding complications may increase distress in patients [8] who have frequent contact with them. The need for doctors to improve their communication and increase their supportive behaviour is evident.

Glycemic control in our study was measured using fasting blood sugar, while most other studies used HbA1c.

However, according to the guidelines published in World Health Organization HEARTS-D, if HbA1c is unavailable, FBS can be used to test for disease control [18]. The Indian Council of Medical Research guidelines too give cutoffs for glycemic targets measured by FBS [25]. Similarly the American Diabetes Association includes fasting capillary glucose as a measure of glycaemic control [26]. FBS as a measure of glycemic control has been previously used in multiple studies. In the UK Prospective Diabetes Study Group multi-centric studies, glycemic targets were set using fasting blood sugar [27, 28]. When assessing the effect of FBS as compared to post-prandial blood sugar on HbA1c, a multinational RCT compared the HbA1c levels between 2 groups: one maintaining fasting glycemic control and the other maintaining post prandial glycemic control and found no difference in the mean HbA1c levels in the two groups [29]. Due to the logistical restrictions, lack of resources and the available evidence mentioned above, FBS was chosen as a measure of glycemic control in our study.

Our study showed that a significantly higher FBS was seen in those with severe distress, severe regimen related distress and moderate and severe emotional burden. In case of a targeted approach to improve glycemic control, management of distress can be directed to these specific groups.

There are multiple reasons linking poor glycemic control with distress. Poor disease control may cause one to get distressed, perhaps because of the fear of complications or their self-care efforts being in vain. This was seen in a longitudinal study where an individual's perceived glucose control was negatively associated with distress at the subsequent visit [30]. On the other hand, distress has been found to increase the fasting blood sugar due to the release of stress hormones which leads to insulin resistance in the long run. Thus poor glycaemic control and distress form a vicious cycle [31]. The direction of causality could not be determined from this study. It is undetermined whether distress was the cause of poor glycemic control due to the release of stress hormones or if poor glycemic control was the reason for distress, or both. Most other studies found similar results in the relationship between glycemic control and distress [9, 16].

Health related quality of life refers to those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment [32]. It has been found that having DM causes medical and psychological burdens on the individual, leading to distress, which may worsen the individual's perceived well-being, thus worsening the HRQOL [2]. Our study found that those with distress reported worse health in general and had a greater number of unhealthy days as compared to those with no distress. This finding is uniform across all the studies which associate distress with HRQOL [10], which is another reason why distress is a cause for concern and requires urgent addressal.

The causes of diabetes distress are multifactorial with scope for further exploration. After one is diagnosed with diabetes, distress may be attributed to the constant worry of the self-care needed to control the glycemic status, along with the fear, anxiety, anger and burn-out experienced by the individual due to living with diabetes [2]. Distress has also been found to occur due to the stress of high blood sugar and the fear of developing complications; having to live with complications once they develop; poor consultation by doctors and perceived difficulty in navigating the healthcare system; low self-efficacy felt and due to the social context in which people with DM live [2, 5, 33, 34]. A person's perception of poor consultations and inattention from physicians has been found to increase distress since the individual's concerns about diabetes and their low self-confidence in their self-care routine remain unaddressed [35, 36]. Young adults with type 1 DM reported being self-conscious about having diabetes and were worried how others viewed them. This, along with the negative media representation of type 1 diabetes, were other sources of distress for them [34].

While distress and its associated factors have been determined in this study, an ideal study design to understand the causes of distress thoroughly as well as the relationships between distress, self-care and glycemic control would be a longitudinal follow up of persons with diabetes. From the time of diagnosis, they should be screened for distress, adequate self-care and glycemic control at regular intervals and accordingly managed. Qualitative interviews should also be included to further understand the perceived causes for distress and ways individuals deal with it. Different methods to prevent distress, causes and implications of diabetes distress, as well as effective measures to address diabetes distress needs further exploration in an Indian setting.

Strengths and limitations

A major strength was that this was a community-based study. As compared to other studies which were mostly facility based, this study included diabetics from the community who were taking treatment from different providers; it also includes those who were not taking treatment. Hence, our study has a greater scope of generalisability for related populations. Another strength was the low refusal rate in this study. Also, to the best of our knowledge, this was the first study in India which compared HRQOL between those with and without distress.

However, our study had a few limitations. Being a cross-sectional study, temporality could not be established, hence it is difficult to assess the cause-effect relationship. Modified Kuppuswamy scale was used to

measure SES, which includes household income which was self-reported by the participants and so it may not be fully accurate. Due to logistical constraints, HbA1c could not be tested and instead a glucometer was used to measure FBS. Recall bias may affect the reported self-care and HRQOL of the participants since questions were regarding the previous 8 weeks and 30 days respectively. Social desirability bias may be present for the self-care related findings. The questions regarding support and education regarding diabetes complications and curability were not validated.

Conclusion

Diabetes distress was present in 35.4% of people living with diabetes in this urban colony. Female sex, low SES, having one or more comorbidities, diagnosis of diabetes 10 or more years prior, taking treatment from a healthcare facility (either private of government) as compared to not being on treatment and an unmet need for social support were associated with distress. There was a positive association between physician contact and distress. Those with poor glycemic control had higher chances of distress and those with distress had worse physical and mental health related quality of life.

It is recommended that psychosocial care and screening for diabetes distress at regular intervals be integrated with medical care, so that it may be addressed to improve the control status and well-being of the individual. Hence, it is important to identify diabetes distress and address it along with the medical management of diabetes for better outcomes.

Abbreviations

DD	Diabetes distress
DDS	Diabetes Distress Scale
DM	Diabetes mellitus
DSMQ	Diabetes Self-Management Questionnaire
EB	Emotional burden
FBS	Fasting blood sugar
HRQOL	Health related quality of life
IPD	Interpersonal distress
PAID	Problem Areas in Diabetes Survey
PRD	Physician related distress
RRD	Regimen related distress

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Author contributions

All authors were part of the conception and design of the study. AAA collected the data. AAA and BN performed the analysis. All the authors were part of the drafting and editing of the final manuscript. All the authors have read and approved the final copy of the manuscript and have agreed to be accountable for the manuscript.

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Data availability

The dataset supporting the conclusions of this article is available in the Figshare repository, https://figshare.com/articles/dataset/Dataset_for_study_on_diabetes_distress_conducted_in_Delhi/26317126 [https://doi.org/10.6084/m9.figshare.26317126.v4] [37].

Declarations

Ethics approval and consent to participate

Clearance from Institute Ethics Committee for Post Graduate Research, All India Institute of Medical Sciences, New Delhi was obtained (IECPG-46/27.01.2022). Participants were provided with the following information in a language they understood: Expected duration of participation, the benefits for the participants that were to be expected from the research, any risk associated with the study, maintenance of confidentiality of records, freedom of the individual to participate and to withdraw from the study at any time without penalty or loss of benefits to which the participant would otherwise be entitled. Any patient who required management was managed accordingly or referred to an appropriate facility for further evaluation and management. Informed consent was obtained from the participants before administering the questionnaire.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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