



ORIGINAL ARTICLE

Assessment of Self-care Practices and Role of Diabetes Distress Among Adult Diabetic Patients on Follow-up from North West India

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Abstract

Background: Diabetes Mellitus, a chronic illness, has emerged as a major public health problem on a global scale. The present study assessed self-care practices regarding Diabetes and the role of diabetes distress among adult diabetic patients who were on follow-up. **Material & Methods:** This cross-sectional study with 365 participants was conducted in a tertiary care teaching hospital in Jammu, J&K, India. The study tools included: (a) questionnaire on socio-demographic and clinical details (b) Summary of diabetic self-care activities (SDSCA) measure and (c) Diabetes Distress Scale (DDS). Pearson correlation was applied to find the relationship between variables. The tests of significance used were Chi square/Fisher's exact test. **Results:** The findings revealed that emotional distress was moderate in 43.9% of respondents and most of the participants had little/no distress. Diet and blood sugar testing were the domains of SDSCA, which were found to be associated with diabetes distress. Variables significantly associated with adherence to self-care practices were educational status, Monthly family income, presence of co-morbidities, treatment modality etc. **Conclusion:** This study underscores that the majority of the participants were adherent to medications. The role of sustained self-care education in mitigating diabetes distress can't be more emphasized. Policy makers need to devise interventions like psycho-social support to address diabetes distress and promote sustainable self-care behavior.

Key Words

Diabetes Distress, SDSCA, Diabetic Patients, Follow-up

Introduction

Diabetes mellitus, a silent killer, has become the most challenging disease of the current century. The disease poses a significant challenge to the health care system due to associated high rates of morbidity and mortality. The goal of diabetes management is to achieve optimal glycemic control and prevent complications.^[1]

Diabetes distress (DD) is a negative emotional experience that is mainly due to social and financial effects in diabetic patients. High levels of diabetes distress result

in adverse glycemic control, treatment adherence, and self-management practices.^[2,3] Adherence to self-care activities is both complex and challenging since all of the care is the sole responsibility of the patients.^[4] Poor adherence to medications and self-care behaviors usually results in uncontrolled diabetes, which later on progresses to diabetic complications.^[5] In the context of diabetes self-care, factors like socio-cultural and economic issues, ambiguous medical advice, high care costs and cultural

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differences present unique challenges.^[6] Stress inducing factors like patient provider communication, unrealistic expectation and self-management burdens “all contribute to diabetes distress. This distress has a bearing on problem-solving medication adherence and glucose monitoring thus resulting in poor glycemic control.

During the review of the literature, it was found that there were few studies regarding the assessment of self-care practices and the role of diabetes distress among adult diabetic patients on follow-up in this part of India. So, the authors conducted the present study to fill the research gap in investigating the connection between diabetes distress and self-care practices.

Objectives

Primary: To evaluate the self-care practices and its associated factors in adult Type 2 Diabetes mellitus patients.

Secondary: To assess correlation between various domains of diabetes self-management and diabetes distress.

Methodology

This cross-sectional study was conducted among the diagnosed patients of type 2 Diabetes Mellitus, attending the tertiary-care Centre in the Jammu division of UT of J&K. The study was conducted w.e.f. 1st October 2023 to 31st July 2024. Permission was taken from the Institutional Ethics Committee of GMC Jammu vide IEC no. IEC/GMCJ/2023/1465 dated 21-09-2023.

Inclusion Criteria:

- (a) Patients diagnosed with Type 2 diabetes Mellitus who were on treatment for at least 1 year
- (b) Those aged 15 years and above
- (c) And who were willing to participate in the study

Exclusion Criteria:

1. Pregnant women.
2. Lactating mothers.
3. Newly diagnosed diabetics (less than 1 year of duration of diagnosis)
4. Patients who did not provide Informed Written Consent for the study.
5. Those patients who were previously diagnosed with a psychiatric disorder, dementia or those who were on psychotropic medication that impaired their memory or cognition.

Sample size Determination

The sample size was calculated using an expected prevalence of 37% for overall diabetes self-care activities derived from a study^[7]. The calculation was performed at a 95% confidence level with a relative error of 15% and a design effect of 1. Based on this, the minimum required sample size was calculated to be 302 participants.

To account for non-response rate of 20%, the sample size was calculated to be 362. The final sample size was rounded off to 365 participants, which constituted the sample size included for data analysis.

Data Collection Tools

- (a) **Socio-demographic questionnaire:** A structured socio-demographic questionnaire was used to collect the basic background information about the participants. It was developed by the investigators and included information such as age, gender, education, occupation etc.
- (b) **Summary of Diabetes Self-care Activities (SDSCA)**^[8]: The SDSCA is a questionnaire of diabetes self-management that assesses the following aspects of the diabetes regimen such as general diet, specific diet, exercise, blood-glucose testing, foot care, and smoking. The responses are typically scored based on number of days (out of last 7 days) that the individual engaged in a particular self-care activity. A score of “1” is given for the presence and “0” for the absence of a component. ‘High’, ‘Moderate’, and ‘Low’ overall SDSCA scores are ‘6-7’, ‘3-5’, and ‘0-2’ respectively.
- (c) **Diabetes Distress Scale (DDS)**^[9]: DDS is a 17-item self-report instrument to assess psychological stress in diabetes. Each item is rated on a 6-point scale from ‘1’ (not a problem) to ‘6’ (a very significant problem). A mean item score of 2.0 – 2.9 is considered moderate distress, and a mean item score of >3.0 is considered as high distress. A mean item score <2 is considered low / no stress.

Method of Data Collection

Each eligible participant was explained in their local dialect by the investigator, about the purpose of the study and was assured that all the information gathered would be kept confidential. Data was collected using predesigned, semi structured questionnaire using interview technique after taking informed written consent.

Data Analysis

All the data collected was compiled and entered into a master chart in the Microsoft Excel spread sheet. SPSS software was used for statistical work. The results were studied in terms of numbers, proportions, means and the transformed score of Diabetes self-care activities were reported as mean $\pm$ standard deviation domain wise. Correlation between domains of diabetes self-management and domains of diabetes distress was calculated (correlation coefficient). Tests of significance applied were chi square/Fisher Exact test to find the

statistical significance of any association. A p value of <0.05 was taken as statistically significant and all p values reported were two-tailed.

Results

A total of 365 patients were interviewed to assess diabetic self-care practices, their associated factors, and the role of diabetes distress in relation to self-care practices. Females constituted 53.7% of the study population, with majority being Hindu (71.2%). Mean age of patients was 49 ± 2.14 years. Almost half of participants (49.5%) had completed higher secondary education. 51.5% were belonging to rural area. Most of the respondents (55.6%) were from nuclear families with majority (55.1%) having a monthly family income ranging from INR 5,000 to 25,000. Most of the participants (54.8%) had diabetes for less than five years. 47.1% had a family history of Diabetes as shown in Table 1.

The study found that poor adherence to self-care practices regarding diabetes was seen in 7.4% of subjects, moderate adherence in 83.6% and excellent adherence in 9% of our study subjects. Table 2 depicts the association of adherence to self-care practices regarding diabetes with socio-demographic and clinical variables. This was evident from the table that adherence to self-care practices was significantly associated with the educational status of participants, monthly family income, modality of treatment for Diabetes, presence of co-morbidities and availability of glucometer at home ($p < 0.05$).

Table 3 shows the distribution of participants according to Diabetes Distress, which reveals that the majority experienced little to no distress in regimen-related, physician-related related and interpersonal Distress. 43.9% of the patents were suffering from a moderate level of emotional distress.

Table 4 reveals the correlation between various domains of Diabetes self-management and different domains of Diabetes Distress. Among the domains of diabetes self-management, dietary adherence shows a small but statistically significant negative correlation with the total diabetes distress score, indicating that greater is the overall distress, poorer is the dietary self-care. Blood sugar testing also shows a significant negative correlation with physician-related distress. However, exercise, foot care, smoking and the total SDSCA score do not show any significant correlations with any domains of diabetes distress.

Discussion

The results of the present study revealed that the mean age of the participants was 48.63 ± 10 years, which was in agreement with the results reported by Kumar S *et al* [10]. However, Afaya RA *et al* [11] in a study from Ghana

reported a higher mean age of 57.5 ± 11.8 years in the respondents. It was found in the current study that 48.5% of the participants were residing in urban areas, which is in contrast to the results reported by Abd El Kader *et al* [12] and Azzam MM *et al* [13]. Where about two third of the respondents were living in urban areas.

Diabetes is predominantly a self-management disease with medication adherence and self-care behaviors among the essential pillars of management. The results have shown that an overwhelming percentage of participants were adherent to medication which is consistent with the

Table 1: Frequency and Percentage Distribution of Participants' Demographics (n=365)

S.No.	Variables	N	%
1	Gender		
	Male	169	46.3
	Female	196	53.7
2	Age (Years)		
	15-30	17	4.7
	30-45	111	30.4
	45-60	176	48.2
	>60	61	16.7
3	Religion		
	Hindu	260	71.2
	Muslim	73	20.0
	Christian	32	8.8
4	Residence		
	Rural	188	51.5
	Urban	177	48.5
5	Literacy		
	Illiterate	21	5.6
	Middle	138	37.9
	Hr. Secondary	182	49.9
	Graduate & above	24	6.6
6	Type of Family		
	Nuclear	203	55.6
	Joint	162	44.2
7	Monthly Family Income (INR)		
	<5000	91	24.9
	5000-25000	201	55.1
	25000-50000	71	19.5
	>50000	2	0.5
8	Duration of Diabetes		
	<5 Years	200	54.8
	=5 Years	165	45.2
9	Family History of Diabetes		
	Present	172	47.1
	Absent	193	52.9

findings reported by Afaya RA *et al* [11] and Abu Sabbah KO. [14] However, contrasting findings were reported from Malaysia [15] and Cameroon [16] where majority of patients were non-adherent to the medication. Financial challenges were cited as the reason for non-adherence in Cameroon.

Among the demographic and clinical variables, the present study revealed that educational status, monthly family income, diabetes treatment modality, having a glucometer and strips at home and presence of co-

**Table 2: Association between Adherence to Self-care Practices Regarding Diabetes with Socio-demographic and Clinical details (n=365).**

S.No.	Variables	POOR ADHERENCE N (%)	MODERATE ADHERENCE N (%)	EXCELLENT ADHERENCE N (%)	TOTAL N (%)	P Value
1	Age Group (Years)					0.0609
	15-30	1(5.95%)	14(82.4%%)	2(11.8%)	17(100%)	
	30-45	3(2.7%)	106(95.4%)	2(1.8%)	111(100)	
	45-60	17(9.7%)	156(88.6%)	3(1.7%)	176(100%)	
	>60	3(5.0%)	57(93.4%)	1(1.7%)	61(100%)	
2	Gender					0.27
	Male	10(4.1%)	140(94.1%)	19(1.8%)	169(100%)	
	Female	17(8.7%)	165(88.7%)	14(2.6%)	196(100%)	
3	Educational status					0.001
	Illiterate	27(22.5%)	87(72.5%)	6(5)	120(100%)	
	Middle	18(17.3%)	74(71.1%)	12(11.5%)	104(100.0%)	
	Higher secondary	15(12.1)	85(69.1%)	23(18.6%)	123(100.0%)	
	Graduate& above	3(16.6%)	6(33.3%)	9(50%)	18(100%)	
4	Monthly family income (INR)					0.000
	<5000	15(16.5%)	73(80.2%)	3(3.3%)	91(100%)	
	5000-25000	9(4.5%)	190(94.5%)	2(1.0%)	201(100%)	
	25000-50000	0(0.0%)	68(95.8%)	3(4.2%)	71(100%)	
	>50000	0(0.0%)	2(100%)	0(0%)	2(100%)	
5	Duration of diabetes (Years)					1.000
	<5yrs	13(6.5%)	183(91.5%)	4(2.0%)	200(100.0%)	
	=5yrs	11(6.7%)	150(90.9%)	4(2.4%)	165(100%)	
6	Diabetes treatment modality					0.004
	Oral	21(7.7%)	251(91.6%)	2(0.7%)	274(100%)	
	Insulin	0(0.0%)	18(85.7%)	3(14.3%)	21(100.0%)	
	Both	3(4.3%)	64(91.4%)	3(4.3%)	70(100.0%)	
7	Having a glucometer and strips at home					0.000
	Yes	4(2.0%)	187(94.4%)	7(3.6%)	198(100.0%)	
	No	20(12.0%)	146(87.4%)	1(0.6%)	167(100.0%)	
8	Presence of Co-Morbidities					0.001
	Yes	20(11.0%)	159(87.8%)	2(1.1%)	181(100.0%)	
	No	4(2.2%)	174(94.6%)	6(3.3%)	184(100.0%)	

morbidity were found to be significantly associated with adherence levels of medication. In contrast to the current results, Afaya RA *et al* [11] observed that age was positively associated with non-adherence to medication with younger patients likely to be more non-adherent compared to older patients aged 70 years and above. Some authors have noted that medication adherence improves with increasing age [17]. In consonance with current results, Afaya RA *et al* [11] underlined that medication adherence has a relationship with the educational level of participants.

The current results have elucidated that diet and blood sugar were the variables among the summary of diabetes

self-care activities (SDSCA), which have a significant negative correlation with the total diabetes distress score. These results suggest that higher overall distress may be marginally associated with poor dietary self-care and lower adherence to blood sugar monitoring. Afaya RA *et al* [11] and Mahdilouy P *et al* [18] reported that the number of years in school was significantly associated with patients' frequency of adhering to diet. It is logical to conclude that high literacy levels make people aware of disease complications and decisions to adhere to diabetes self-care activities are better. Abd El Kader *et al* reported a significant relationship between gender and diabetes self-care activity, and it was attributed to participants being

**Table 3: Distribution of Study Participants According to the Score of Diabetes Distress among Different Domains.**

Variables	Diabetes Distress Score		
	Little/no distress	Moderate distress	High distress
	(<2) N (%)	(2-2.9) N (%)	(>3) N (%)
Emotional Distress	172 (47.1)	160 (43.9)	33(9)
Physician Distress	286 (78.4)	75(20.6)	4(1)
Regimen Distress	299 (82)	65 (17.7)	1 (0.3)
Interpersonal Distress	278 (76.2)	78 (21.4)	9 (2.4)

Table 4: Correlation between Various Domains of Diabetes Self-management and Different Domains of Diabetes Distress.

SDSCA	Emotional burden	Physician Related Distress	Regimen Related Distress	Interpersonal Distress	Total Score DDS
	r(p)	r(p)	r(p)	r(p)	r(p)
Diet	-0.103 (0.050)	-0.084(0.109)	-0.064(0.220)	-0.011(0.830)	-0.112 (0.003)
Exercise	-0.028(0.588)	-0.009(0.858)	0.011(0.840)	0.023(0.661)	0.002 (0.974)
Blood Sugar Testing	0.005(0.921)	-0.110(0.036)	-0.019(0.713)	-0.017(0.744)	-0.039 (0.454)
Foot Care	-0.010(0.843)	-0.061(0.247)	-0.005(0.926)	0.008(0.876)	-0.010 (0.849)
Smoking	0.106(0.06)	0.096(0.11)	0.074(0.23)	0.088(0.84)	0.119(0.083)
Total Score SDSCA	-0.006(0.902)	-0.049(0.349)	-0.038(0.467)	-0.015(0.782)	-0.022 (0.672)

urban females for whom self-care activity is an essential component of daily chores.^[12]

When diabetes distress scores were analyzed in the present study, it was found majority had little/no distress, while 43.9% had moderate distress in the emotional domain, and the rest of the three domains had 17-21 % moderate distress. Abd AL Kader^[12] and Hassan AH *et al*^[19] reported high diabetes distress in about one-third of respondents, with the emotional and regimen domain being affected the most. Another study reported that 39% of the study sample had moderate or high levels of diabetic distress, and no correlation was found between any demographic factor and diabetic distress, except for participant age.^[20] Baskaran R *et al* found in their study that 4% of subjects had mild distress, 30% had moderate distress, and 66% experienced severe distress. Medication adherence was observed in 50.2% of subjects, with a significant association between diabetes distress and medication adherence.^[21]

Abd AL Kader ^[12] found a significant relationship

between marital status, place of residence, duration of diabetes, and diabetes distress. If the diabetes duration is short, disease awareness regarding management and complications is likely a bit lower, which may result in high levels of distress.

Nasr R *et al* ^[22] noted that diabetes distress was a key determinant of self-care behaviors, with regimen-related distress emerging as the most reported. It was also reported that emotional burden was positively correlated with self-care adherence, which aligns with results reported by Shreck E *et al*^[23]. Authors also noted that suboptimal self-care practices among respondents with only 1.5 to 2.7 days per week devoted to essential self-care activities. The results found a positive association between physical activity and self-care adherence, thus establishing the role of exercise in diabetes management.

Limitations

Since the design of the study is cross-sectional, no causal association can be inferred. Use of self-report methods to assess adherence to medications is likely to

overestimate or underestimate levels of adherence.

Conclusion

The study reported that key variables which were significantly associated with medical adherence included educational status, monthly family income, treatment modality, having a glucometer, and presence of comorbidities. Among the domains of summary of diabetes self-care activities (SDSCA), diet and blood sugar were found to have a significant negative correlation with the diabetes distress score. The majority of the respondents reported little/no distress, with 43.9% reporting moderate distress in the emotional domain. The results elucidate the role of various social and medical variables in interplay with diabetes distress and self-care behaviors. The policymakers need to look for targeted interventions like counseling for better outcomes. The recommendation from the study would be that routine diabetes care should integrate structured self-care education, psychosocial counseling and regular distress screening, with targeted support for low-income and less-educated patients and improved access to home blood glucose monitoring.

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