ORIGINAL RESEARCH

Diabetes-related Distress and Self-care Practices among Patients attending two Secondary Care Hospitals in Lagos - A strategy for tailored Interventions

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ABSTRACT

Background: The challenges of diabetes mellitus are huge. Keeping up with the daily requirements of a life-long chronic illness is rigorous.

Objectives: This study assessed diabetes-related distress and self-care practices and determined the extent to which they impact each other.

Methods: This was a cross-sectional descriptive study carried out among patients attending follow-up diabetic clinic of two secondary health care facilities in Lagos over a three-month period. One hundred and seventy-six type 2 diabetes patients that met the inclusion criteria were consecutively recruited. Patients' diabetes-related distress and self-care practices were assessed using a interviewer-administered questionnaire that incorporated two validated measures - The Diabetes Distress Scale (DDS17) and the Summary of Diabetes Self-care Activities (SDSCA: 11 items). Data were analyzed using descriptive and inferential statistics. P-values of < 0.05 was considered significant.

Results: Of the 176 respondents, 70% were females, 73.9% were 51 years and above and 67% had poor glycaemic control (FBS=135.7 ± 47.48mg/dl). The mean score for Total Diabetes Distress (TDD) is 2.89 ± 0.90. Majority (64%) viewed emotional burden (3.30± 1.38) and regimen-related distress (3.35± 1.45) as moderate distress. Dieting was adequate among respondents with "Special diet" being the most frequently practiced (3.58±1.73 days/week). Dieting is associated with total diabetes distress, emotional burden, regimen-related distress and physician-related distress (<0.001). Regimen-related distress is also associated with glycaemic control (p=0.037).

Conclusion: Diabetes distress and low self-care practices are common and impact each other. Targeted interventions incorporating emotional support and effective communication is critical.

Keywords: Diabetes distress, Emotional Burden, Self-care, Glycemic control

INTRODUCTION

The challenges of diabetes mellitus are huge. Type 2 diabetes patients are often faced with the rigors of keeping up with the daily requirements of a life-long chronic illness. They engage in continuous day-to-day self-care practices like medication taking, self-monitoring of blood glucose level, intake of low saturated fat diet, foot care, and physical activity[1]. These activities are vital for the metabolic control of diabetes, control of complications, and improvement in the quality of life of patients[2], yet they pose significant challenges and place a high demand on both patients and their caregivers. Diabetes daily activities are often viewed as difficult, frustrating due to concerns, worries, and uncertainties regarding the management of diabetes. Numerous studies have shown that although the practices of all or some

important aspects of diabetes self-care are low[3,4], they are associated with distress[5-8]. Diabetes Distress (DD) is a psychosocial symptom of diabetes and often, a hidden emotional burden or worries emanating from different areas related to living with diabetes including, feeling of failure, inadequacy in keeping up with one's treatment regimen, conflict with family or friend, anger and frustration[5,9,10] . Diabetes-related distress is prevalent among sufferers. Its prevalence varies from 18–45% with an incidence of 38–48% over 18 months[11]. Evidence has shown that diabetes-related distress significantly impacts self-care behaviours (medication-taking, diet, exercise), self-efficacy and glycaemic control[5,6,8,9]. Hence, the American Diabetes Association has long stated that diabetes distress should be routinely monitored at initial visits, periodically, especially when there is change in treatment, when targets are not met and at onset of complications, and when identified, there should be referrals for counselling and education to identify areas for further evaluation and treatment[5]. Emotional distress, although considered as a common component of the experience of diabetes, emanates from numerous restrictive lifestyle measures and has long been identified as an area of growing interest for clinicians and researchers[10]. Identifying levels of diabetes distress and self-care activities among patients with type 2 diabetes would help health care providers in targeting appropriate intervention as part of comprehensive diabetes care for improved metabolic control and quality of life. Interventions targeting both distress and self-management has been found to have a far-reaching influence on clinical outcomes compared to an intervention targeting either distress or self-care practices[10].

Studies measuring the prevalence of diabetes-related distress and the associated factors including self-care practices in Nigeria are few. Ascertaining the extent of interaction between diabetes-related distress and self-care practices is crucial in a resource-limited country where the major part of care is undertaken by patients. We, therefore, hypothesized that some socio-demographic factors and diabetes distress would be associated with self-care practices among ambulatory type 2 diabetes patients.

METHODS

A cross-sectional descriptive study was carried out among patients with type 2 diabetes attending two secondary care hospitals in Lagos over a period of 3 months. These hospitals offer care to type 2 diabetes patients and indigenes of the surrounding communities based on referral from primary healthcare centres and also render services to staff and employees of Lagos State Government. Approval to carry out this study was obtained in 2015 (HSC378/VOL IV/46) from the Health Service Commission of the Lagos State Ministry of Health, Lagos.

A pretested questionnaire was used to collect information on demographic and clinical data (8 items) including age, marital status, level of education, disease duration, history of smoking and occupation. Information on self-care practices was collected using the Revised Summary of Diabetes Self-Care Activities by Toobert *et al.* [1], a scale that measures diabetes regimen in domains of general diet (2 items), specific diet (3 items), exercise (2 items), and foot care (2 items). Responses in each subscale were based on a 7-days/week which ranged from 0 to 7 days. A score of less than three (<3) was considered as inadequate (low self-care), while a score of more than or equal to three (≥3) was considered as adequate (good self-care). Diabetes- related distress was measured using the Diabetes Distress Scale (DDS17) developed by Polonsky et al, with Cronbach $\alpha > 0.87$[10] and identified by the American diabetes association in 2016 as one of the validated measures for the evaluation of psychosocial constructs in clinical settings[6]. Responses were scored on a 6-

point Likert scale from (1 = not a problem, 2 = slight problem, 3 = moderate problem, 4 = somewhat serious problem, 5 = serious problem and 6 = very serious problem). Accordingly, the minimum and the maximum of the scores in the scale were 17 and 114, respectively. The total score of DDS-17 was calculated by summing the 17 items' results and dividing the total by 17. The four domains of DDS; emotional burden, physician-related distress, regimen-related distress, and interpersonal distress were assessed. Each domain was scored separately by dividing the sum of its item scores by the number of the items in each subscale. A mean item score of ≥ 3 is considered moderate distress worthy of clinical attention while a mean score < 3 is considered as no or low distress. Convenience sampling was employed for this study as patients were consecutively approached and recruited. Glycaemic control was determined using fasting blood sugar (FBS) measured in the morning of the clinic. Glycaemic control was classified as good (FBS < than 110 mg/dl) and poor (FBS > than 110 mg/dl) according to the Consensus Statement on Guidelines for Glycaemic Control provided by the American College of Endocrinology[12]. Participants were eligible to take part in the study if they were on follow-up visits at the two secondary hospitals, were at least 18 years old and above and gave an informed consent. Patients with Type 1 diabetes, gestational diabetes, physical or cognitive impairments and patients unwilling to participate were excluded from the study. The purpose of the study was explained to each participant and the questionnaires administered to all consenting patients with Type 2 diabetes patients that met the inclusion criteria. Ninety-six patients were recruited from the first clinic and eighty patients from the second clinic. It took participants who could fill out the questionnaire between 8-10 minutes and about 10-20 minutes for those who required assistance. Data generated from the questionnaire were analyzed using SPSS 17.0 for windows Evaluation version (SPSS Inc., Chicago, USA). Descriptive statistics were used to assess patients' socio demographic and disease-related information.

The data were described by using frequencies, percentages, and mean ± standard deviation (continuous variables). Student's t-test was used for comparing means of continuous variables, while categorical variables were compared using chi squared test (χ^2). P-value of <0.05 was considered as statistically significant.

RESULTS

Table 1 represents the demographic and clinical characteristics of the respondents. Of the 176 respondents, 69.9% were females, 73.9% were 51 years and above, 58.5% were married, 19.3% had at least a primary education, and 40.3% had type 2 diabetes for more than 5 years. About 67% of the respondents had poor glycaemic control with mean fasting blood glucose of 135.7 ± 47.48mg/dl. The study findings revealed that more than half of the respondents (55.1%) had moderate total Diabetes Distress (TDD) with a mean score of 2.89 ± 0.90. Majority of the respondents viewed emotional burden (3.30± 1.38) and regimen-related distress (3.35± 1.45) as moderate distress. Physician-related distress (2.34 ±0.97) and interpersonal distress (2.18 ± 0.99) were low among the respondents. (Table II).

Respondents had adequate self-care in the area of choosing of diet (3.17 ± 1.75 days/week). Been on "Special diet" with a mean score of 3.58 ± 1.73 days/week was the most frequent practiced self-care, while foot monitoring was the least practiced by the respondents (1.63±1.97 days/week) (Table III).

This study also revealed that maintaining an adequate diet was significantly associated with total diabetes distress (p<0.001), emotional burden (p<0.001), regimen distress (p<0.001) and Physician-related distress (p<0.001). Emotional burden

affected engagement in exercise (p<0.001), choosing diet (p<0.001), self-blood glucose testing (p<0.001) and foot care (p<0.001) (Table IV).

Table I: Demographic and Clinical Characteristics of Respondents

Demographic Variables	Frequency (%)
Age (years)	
20 -50	46 (26.1)
≥51	130 (73.9)
Gender	
Male	53 (26.1)
Female	123 (69.9)
Marital Status	
Single	8 (4.5)
Married	103 (58.5)
Divorced	15 (8.5)
Widow/Widower	50 (28.4)
Educational Level	
Primary	34 (19.3)
Secondary	58 (33.0)
Tertiary	52 (29.5)
No formal education	32 (18.2)
Occupation	
Unemployed	29 (16.5)
Employed	40 (22.7)
Retired	64 (36.4)
Self-employed	43(24.4)
Co-morbidities	
Atherosclerosis	1 (0.6)
Dyslipidemia	3 (1.7)
Hypertension	96 (54.5)
Others	15(14.3)
None	47(26.5)
Duration of illness	
< 1 year	29(16.5)
1-5 years	76(43.2)
> 5 years	71(40.3)
Glycemic Control	
FBS < 110mg/dl (good glycemic control)	58 (33.0)
FBS > 110mg/dl (poor glycemic control)	118 (76.0)
Mean ± SD (FBS)	135.7 ± 47.5 mg /dl

***FBS = Fasting Blood Sugar*

DISCUSSION

This study revealed that more than half of the study population had moderate diabetes-related distress worthy of clinical attention. This high level of distress is expected in a resource limited nation where out of pocket payment is huge and the model of care is fragmented, all serving as major contributors of frustration and distress. In Nigeria, sources of distress abound as lack of co-payments/health insurance and fragmented health care system further complicates management of a chronic, self-managed illness. Similar to the findings of this study is a previous one carried out in Malaysia where about 49% of the participants were found to have moderate distress arising due to diabetes (Chew *et al*., 2016). Other similar studies done in the US identified high diabetes distress in about half (51%) of the study participants[8]. Some other studies recorded a low level of distress in 25% and 26% of the study patients in Saudi Arabia and Bangladesh respectively[14,15]. Hence, diabetes related distress is common among people with type 2 diabetes although the level of distress may vary. The variations noted between the different studies may be attributed to the type of distress measuring scale used and the cut-off points for distress classification employed. A more recent classification/ cut off point by Fisher *et al* has been used in diabetes populations due to its ease of administration and greater specificity[8].

This study revealed that majority of the respondents viewed emotional burden followed by regimen-related distress as moderate distress that may require medical intervention. Physician-related distress and interpersonal distress were rated as no or low level of distress. In line with these findings are other studies that rated 'Emotional Burden' as a major contributor to moderate stress experienced by the study participants[13,14,15].

Table II: Distribution of Diabetes-related Distress among Respondents

Domains of Diabetes-related Distress	Frequency (%)	Mean Scores
Emotional Burden		
Moderate Distress	113 (64.2)	
Not a Distress	63 (35.8)	3.30± 1.38
Physician-related Distress		
Moderate Distress	41 (23.3)	
Not a Distress	135 (76.7)	2.34 ±0.97
Regimen-related Distress		
Moderate Distress	113 (64.2)	
Not a Distress	63 (35.8)	3.35± 1.45
Interpersonal Distress		
Moderate Distress	41 (23.3)	
Not a Distress	135 (76.7)	2.18 ± 0.99
Total Diabetes Distress		
Moderate Distress	97(55.1)	
No Distress	79 (44.9)	2.89± 0.90

*Domain scores were used to derive the Mean ± SD

Table III: Diabetes Self-Care Activities Mean Scores (Days/week) among Respondents

Summary of Diabetes Self-Care Activities (SDSCA) Domains	Mean Scores (Days/ week)
General Diet	3.17 ± 1.75
Special Diet	3.58 ± 1.73
Exercise	2.60 ± 1.91
Blood Glucose Testing	2.39 ± 1.61
Foot Monitoring	1.63 ± 1.96

Table IV: Association between Self-Care Practices & Diabetes-related Distress

VARIABLES	SELF-CARE ACTIVITIES							
	DIET		**EXERCISE**		**SBST**		**FOOT CARE**	
	Test	*P* Value	Test	*P* Value	Test	*P* Value	Test	*P* Value
TDD	0.361	<0.001*	0.228	0.002*	0.296	<0.001*	0.184	0.015*
EB	0.374	<0.001*	0.319	<0.001*	0.309	<0.001*	0.238	<0.001*
PD	0.312	<0.001*	0.152	0.044	0.049	0.518	0.066	0.387
RD	0.326	<0.001*	0.237	0.002*	0.309	<0.001*	0.295	<0.001*
ID	0.148	0.049	0.094	0.213	0.137	0.070	0.044	0.562

SBST- *Self Blood Sugar testing,* ***TDD-*** *Total Diabetes Distress,* ***EB-*** *Emotional Burden,* ***PD-*** *Physician-related Distress,* ***RD-*** *Regimen-related Distress,* ***ID-*** *Interpersonal Distress.*

** P-values of < 0.05 was considered significant*

** student t Test for test of association*

From this study, the questions for emotional burden domain as determined showed that "*Feeling overwhelmed by the demands of living with diabetes*" was highly rated by study respondents as a major source of distress. This shows that patients often view the on-going demands of diabetes as frustrating, difficult and overwhelming. This perception may increase the risk of distress, poor self-care and poor metabolic control. Patient reassurance and encouragement is paramount at each encounter by healthcare providers. A study by Tol *et al*., found emotional burden prevalent among the participants. However, "*feeling angry, scared and/or depressed when I think about living with diabetes*" was highly rated[13]. From this study, "*Feeling that I am not sticking closely enough to a good meal plan"* and "*not feeling motivated to keep up my diabetes self-management"* were the most prevalent report from regimen-related distress domain. This shows that patients are aware of the role of diet in controlling diabetes and often feel concern when they do not meet up with the demands. They are aware of the need to self-manage their condition, but lack of motivation and low self-efficacy can be a hindrance. Self-efficacy is an important determinant of adherence to treatment regimen and change in self-care behavior[17]. Hence, constant emotional and social support from families and good communication and mutual trust between health care providers and the patients should be promoted which can serve as effective intervention for improved metabolic control. Integrating emotional burden assessment and support into routine visits is paramount. However, this integration can be a source of concern for clinicians that are often time constrained and who may not have received any training on management of stress. Having collaborative care where referrals are made within an integrative system of care will go a long way in identifying distressed patients and offering a specialist care.

This study findings also show that self-care practices were found inadequate in almost all the domains of exercise, blood glucose testing and foot care. Other studies have shown similar trend[3,4]. Of the four aspects of the recommended diabetes self-care practices assessed, dietary intake was adequately practiced by almost half of the respondents with "specific diet" being the most adhered to. This means that the study respondents considered following diet plan as important in managing their illness, hence engaged in it. On the other hand, regular "exercise", "blood sugar testing" and "foot care" were inadequate as respondents found them difficult to adhere to. Similar to this finding is a study done in Ethiopia where more than half of the respondents (57.7%) followed the recommended dietary intake and only 31.1% had exercise for thirty minutes per day[18]. In contrast, a study done in Bangladesh reported that more than 90% and 70% of the respondents did not follow the dietary advice and foot care respectively[19]. Hence patient's ability to self-care varies depending on their knowledge of the required skills, self-efficacy, health literacy and the extent to which they consider it important[17]. Because self-care is behavioural, patients' view on the relevance of self-care can affect the practice. In this study, diabetes distress affected self-care activities. Maintaining an adequate diet contributed to total diabetes distress, emotional burden, regimen-related distress and physician-related distress. In addition, emotional burden resulted from maintaining healthy diet, exercise and constant self-blood glucose monitoring. This shows that diabetes related distress and self-care practices have a bidirectional relationship; while moderate or high level of distress can lead to reduced motivation to engage in self-management, worries, concerns and uncertainties about one's ability to effectively engage in self-care

can result in distress, thus consideration of these in clinical practice is appropriate.

The fact that this study did not find an association between glycemic control and self-care practices is in contrast with a study where adherence to all or some aspects of self-care practices resulted in adequate metabolic control and improvement in quality of life of patients [1]. In contrast to some similar studies that reported an association between some demographic characteristics of participants including age, educational status, occupation, knowledge level, duration of diabetes and diabetic self-care practices[13,15,20,21], this study found no association between diabetes self-care and the aforementioned demographic characteristics, although this not expected.

Furthermore, choosing a healthy diet, exercising, self-blood testing and foot care contributed significantly to total diabetes distress. Determining the areas or source of patient distress during clinical encounter will assist health care professionals in providing personalized interventions.

Limitations of Study: Sample size used for this study may limit generalization of result findings. Self-report of self-care employed may be prone to social desirability and recall bias

CONCLUSION

This study provided further evidence of low self-care practices and moderate diabetes-related distress among ambulatory type 2 diabetes patient in Nigeria. Emotional burden as a result of complex and often complicated set of activities patients engaged in is prevalent. This underscores the need for healthcare professional to consider comprehensive and continuous evaluation of emotional distress for patients with type 2 Diabetes. Psychosocial and family support are needed to improve patients' motivation, self-confidence, level of involvement in diabetes management and metabolic control. There is need for a paradigm shift from the conventional acute system of care that carters for chronic health challenges to an integrative chronic model of care in order to further reduce the burden associated with the management of diabetes in our nation.

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REFERENCES

1. Toobert DJ, Hampson SE and Glascow RE. The summary of diabetes self-care activities measure: results from 7 studies and a revised scale. Diabetes Care, 2000; 23(7):943-50
2. Shrivastava SR, Shrivastava PS and Ramasamy J. Role of self-care in management of diabetes mellitus. J Diabetes Metab Disord., 2013; 12(14) 1-5
3. Yusuff KB, Obe O and Joseph BY. Adherence to anti-diabetic drug therapy and self-management practices among type-2 diabetics in Nigeria. Pharm World Sci. 2008; 30 (6):876-83.
4. Rajasekharan D, Kulkarni V, Unnikrishnan B, Kumar N, Holla R and Thapar R. Self-care activities among patients with diabetes attending a tertiary care hospital in Mangalore Karnataka, India. Ann Med Health Sci Res. 2015; 5(1):59–64.
5. Young-Hyman D, de Groot M, Hill-Briggs F, Gonzalez JS, Hood K and Peyrot M. Psychosocial care for people with diabetes: a position statement of the American Diabetes Association. Diabetes Care 2016; 39 (12):2126–2140

6. Fisher L, Hessler DM, Polonsky WH and Mullan J. When is diabetes distress clinically meaningful? Establishing cut points for the Diabetes Distress Scale. Diabetes Care. 2012; 35(2):259–264.
7. Ogbera A and Adeyemi-Doro A. Emotional distress is associated with poor self-care in type 2 Diabetes Mellitus. J Diabetes. 2011; 3:348-52.
8. Fisher L, Mullan JT, Arean P, Glasgow RE, Hessler D, Masharani U Diabetes distress but not clinical depression or depressive symptoms is associated with glycaemic control in both cross-sectional and longitudinal analyses. Diabetes Care. 2009; 33(1):23-8
9. Gonzalez JS, Fisher L and Polonsky WH. Depression in diabetes: have we been missing something important? Diabetes Care. 2011; 34(1): 236–239.
10. Polonsky WH, Fisher L, Earles J, Dudl RJ, Lee J and Mullan J. Assessing psychosocial distress in diabetes: Development of the diabetes distress scale. Diabetes Care.2005; 28: 626–31
11. Aikens JE. Prospective associations between emotional distress and poor outcomes in type 2 Diabetes. Diabetes Care 2012; 35: 2472–2478
12. American College of Endocrinology: Consensus Statement on Guidelines for Glycaemic Control. Endocrine Pract. 2002; 8 (Suppl 1): 5-11
13. Tol A, Baghbanian A, Sharifirad G, Shojaeizadeh D, Eslami A, Alhani F and Tehrani M. Assessment of diabetic distress and disease related factors in patients with type 2 diabetes in Isfahan: A way to tailor an effective intervention planning in Isfahan-Iran. J Diabetes Metab Disord. 2012;11(1):20.
14. Majed OA, Abdulmajeed MA, Mohammed AA, Dhifallah MA and Khaled A. Diabetes Related Distress Assessment among Type 2 diabetes Patients. Journal of Diabetes Research. 2017; 1-10
15. Islam MR, Karim MR, Habib SH and Yesmin K. Diabetes distress among type 2 diabetic patients; Int J Med Biomed Res 2013; 2(2):113-124
16. Peyrot M, Rubin RR, Lauritzen T, Snoek FJ, Matthews DR and Skovlund SE. Psychosocial problems and barriers to improved diabetes management: Result of the Cross- National Diabetes Attitude, Wishes and Needs (DAWN) study. Diabet Med. 2005; 22 (1):1379–1385.
17. Allen NA, Fain JA, Braun B and Chipkin SR. Continuous glucose monitoring counselling improves physical activity behaviours of individuals with type 2 diabetes. A randomized clinical trial. Diabetes Res Clin Pract. 2008; 80(3):371–379.
18. Ayele K, Tesfa B, Abebe L, Tilahun T and Girma E. Self-care Behaviour among Patients with Diabetes in Harari, Eastern Ethiopia: The Health Belief Model Perspective. PLoS One. 2012; 7(4).
19. Saleh F, Mumu SJ, Ara F, Begum HA and Ali L. Knowledge and self-care practices regarding diabetes among newly diagnosed type 2 diabetics in Bangladesh: a cross-sectional study; BMC Public Health. 2012; 12 (1112):3-8
20. Amente T, Belachew T, Hailu E and Berhanu N. Self-care Practice and its Predictors Among Adults with Diabetes Mellitus on Follow Up at Nekemte Hospital Diabetic Clinic, West Ethiopia. Wjmms. 2014; 2(3):1-16.
21. Chew BH, Vos R, Mohd-Sidik S, Rutten GE. Diabetes-Related Distress, Depression and Distress-Depression among Adults with Type 2 Diabetes Mellitus in Malaysia. *PLoS One*. 2016; 11(3):1-1