

Assessment of Illness Experience of Type-2 Diabetic Patients Using Patient-Centered Care at Family Medicine Clinic in a Tertiary Hospital in Southern Nigeria

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ABSTRACT

Background: Type-2 diabetes mellitus (T2DM) is a chronic universal public health problem with high prevalence in Africa. Obstacles towards an enhanced T2DM management may occur during consultation as the physician may not be able to explore beyond the principal complaint of the patient. Effective management of the disease involves patient-physician partnership, including the physician's better understanding of the patients' illness experience.

Methods: A descriptive cross-sectional hospital-based study of 236 T2DM patients. The study was conducted over a 4-month period using consecutive sampling method and interviewer-administered questionnaire. Data was analysed using the SPSS version 23. Descriptive and inferential statistics were applied at 95% confidence interval and p-value of ≤ 0.05 .

Results: Majority (56.8%) of respondents were female. The mean age of all respondents was 54.2 ± 9.4 years. About 51.7% feared taking medication for life, 56.8% believed diabetes was caused by certain foods, 37.7% had impact on household/family duties and 67.0% expected information about diabetes. There was statistically significant association between the various fears of diabetes including impact on household function, and poor glycemic control.

Conclusion: This study showed that Type-2 diabetes patients had different illness experiences and misconceptions that negatively influence adherence to recommended treatments. It further showed that the fears and impact on household functionality of diabetic patients had negative effects on their glycemic control.

Keywords: Type-2 diabetic patients, Illness experience, Patient-centered care, Tertiary health institution, Nigeria.

INTRODUCTION

Type-2 diabetes mellitus (T2DM) is a universal public health problem.¹ It is a major cause of morbidity and mortality the world over and the associated disease burden is felt more in the developing countries.^{2,3} The mortality and disability that result from the disease have major implication for productivity as well as social cost to different families and the communities at large.^{2,4} It is rapidly increasing in the African continent and globally at an alarming rate mostly among urban population principally due to poor lifestyles adopted coupled with patients' poor knowledge of the disease.^{1,4} The increased prevalence of this disease justifies effort

towards effective management with good adherence to recommended treatment modalities. Consequently, the burden of the illness on the patient/family and the healthcare system will be reduced.

Obstacles towards an enhanced T2DM management may occur at the level of the doctor-patient communication as the physician may not be able to explore beyond the chief complaint of the patient. It is recorded that the key obstacle is the physician's ignorance of their patient's illness experience.⁵ The illness experience explores four dimensions of unwellness, namely: fears, ideas about causation, impact on functioning and

expectations (FIFE). Effective T2DM patient care involves attending as much to the illness experience as well as to the disease.

Patient-Centered Care (PCC) which incorporates exploring illness experience and offering health promotion is recommended for effective care of T2DM to improve treatment adherence.⁵ It entails applying a holistic concept to patient's care and recognizing the individual as an integrated biopsychosocial-spiritual being rather than focusing only on the disease.^{5,6} Patient-centered care is quality healthcare achieved through partnership between informed, respected patients with their family, and a coordinated healthcare team.^{5,6} The care is individualized with active participation and commitment of the individual, and decisions to respect patients' wants, needs and preferences.^{5,6} Also, the education and support patients need to make decisions are provided. This PCC approach has been shown to increase patients' and physicians' satisfaction, improve patient's health status, lessen patient's symptom burden, and improve medication adherence.^{5,6}

It was difficult to find any studies that assessed illness experience of T2DM patients in the study area. This study will therefore fill that knowledge gap, generates baseline data for superior study designs, improves quality of life and ultimate survival of patients, as well as policy formulation. This study aimed to assess the illness experience of type-2 diabetic patients using patient-centered approach of care in order to offer them a better management, and positive outcome. The objective of this study was to assess T2DM patients' fears, ideas on causation, impact on function, and expectations with regards to type-2 diabetes mellitus and its management.

METHODS

Study Design

The study was a hospital-based cross-sectional descriptive study of T2DM patients who presented to the Department of Family Medicine at a tertiary hospital for follow-up.

Study Setting

The study was carried out at the Family Medicine Clinic, University of Calabar Teaching Hospital (UCTH) of the Niger Delta Region of Southern Nigeria.

Study Population and Sample Size

The study population consisted of adult type-2 diabetic patients receiving treatment at the

Family Medicine Clinic, UCTH. All those who met the inclusion criteria (T2DM patients 18 years and older who had been on medication for at least 6 months, and consented to participate in the study) were recruited in the study after being duly informed of the aim of the research. Patients who were critically ill or had diabetic crisis at presentation were excluded. Those with other comorbid ailments, including history of use of drugs that could affect glucose tolerance were also excluded, as well as pregnant women. Patients were approached as they waited to be consulted by the doctor.

The sample size (nf) was calculated using Leslie Kish single proportion formula, for a study of population less than 10,000.⁷

Where:

$$nf = \frac{n}{1 + \frac{(n-1)}{N}}$$

and N=the estimate of the population size

n = the desired sample size for population more than 10,000. This was calculated using the formula below:⁷

$$n = \frac{z^2 pq}{d^2}$$

Where z = the standard normal deviate usually set at 1.96 and corresponds to the 95% confidence interval.

In the absence of any similar study in this environment, p was set at 50%.⁷

d= degree of accuracy desired usually set at 0.05

The calculated sample size came to 236.

Consecutive sampling method was used in recruiting the participants. All eligible patients who met the inclusion criteria were selected for the study.

Data Collection and Data Collection Tool

The questionnaire used for the study was a semi-structured interviewer-administered type. It was validated through test-retest reliability testing using 24 T2DM subjects with similar socio-demographic characteristics in another hospital within the same study area. This yielded a reliability coefficient of 0.8. The response option was based on a 3-point Likert scale ranged from agree, don't know and disagree. The questionnaire comprised 5 sections that assessed the socio-demographic characteristics with glycated haemoglobin levels of the participants, fears, ideas, functions and expectations respectively.

Each participant signed the consent form after an explanation of the study was provided and queries addressed. Data was collected from April 2015 until July 2015. The fieldwork was conducted Monday to Friday during the clinics operating hours from 08:00 to 16:00. Trained research assistants including the researcher collected the data while patients were in the waiting section of the clinic. The independent variables of the study comprised participants' fears, ideas on causation, impact on functioning, and the expectations about T2DM; which were the illness experience. The dependent variable was glycated haemoglobin, the level which was categorised according to American Diabetic Association criteria into <7% and ≥7% for good and poor glycaemic control respectively.³

Data Analysis

After the data had been checked for completeness and accuracy, manually coded data from the participants' questionnaire were entered on a Microsoft Excel spreadsheet. The data were then imported into the statistical package for social sciences (SPSS) software version 23 for data analysis. Descriptive statistics was used to summarise variables with 95% confidence intervals and results were expressed as mean/standard deviation. Chi square test was used to test significant association between categorical variables. Level of statistical significance was set at ap-value of ≤ 0.05.

Ethical consideration

Ethical approval for this study was obtained from the Health Research Ethical Committee of the UCTH, Calabar. All participants were assured of anonymity, and strict confidentiality was maintained during the entire duration of the study. Participants were assured that refusal to participate will not attract penalty. Participants signed the informed consent before participating in the study.

RESULTS

A total of 236 respondents were recruited in the study. The mean age of the respondents was 54.2±9.4 years. The majority 134(56.8%) were females. About 109(46.2%) of the respondents had good glycaemic control.

Fears About Type 2 Diabetes Mellitus and its Management

Table 1 showed that majority of the respondents 122(51.7%) expressed fear of taking anti-diabetic medication for life followed by fear of side effects of medications 118(50.0%), fear of developing complication 92(39.0%), and that of changing lifestyle 88(37.3%). The least proportion were afraid of death from diabetes 79(33.5%). Majority mentioned diet modification (80.7%), death of relation (47.7%), eye complication (39.2%), cost of medication (54.2%) and dizziness (37.5) as the main fear/reasons behind the various fears (Table 2).

Respondents' Ideas about Cause of Type 2 Diabetes Mellitus

Majority 134(56.8%) perceived diabetes is caused by certain food followed by those who believe that diabetes is inherited among family members 95(40.3%), then 33(14.0%) who believe that diabetes is caused by stress (Table 3). Sugary food was predominant (86.9%). Other causes mentioned by participants were spiritual forces (12.0%), alcohol (11.5%) and infections (3.8%).

Impact of Type 2 Diabetes Mellitus on Respondents Daily Functioning

Major impact on function reported by subjects was on household duties 89(37.7%) followed by 82(34.7%) who said diabetes had affected their relationship with people (social life), while 61(25.8%) said diabetes have affected their job (Table 4). Effect on domestic chores (67.8%) and sexual dysfunction (43.3%) were predominant.

Expectations of Type 2 Diabetic Patients from the Physician Regarding Diabetes and its Treatment

Among the respondents, the majority 158(67.0%) expected information regarding diabetes, 17(7.2%) expected that the anti-diabetic medications will cure diabetes, 73(30.9%) expected to be involved in decision-making in the course of management, while 59 (25.0%) expected emotional support (Table 5). Specific information expected were on the cause (95.6%), treatment (95.6%), complication of diabetes (93.7%) and self-care (37.3%).

Table1. Fears about type-2 diabetes among study participants (N=236)

Category of fear	Responses		
	Agree n (%)	Don't know n (%)	Disagree n (%)
Fear of changing lifestyle	88(37.3)	46(19.5)	102(43.2)

Assessment of Illness Experience of Type-2 Diabetic Patients Using Patient-Centered Care at Family Medicine Clinic in a Tertiary Hospital in Southern Nigeria

Fear of death from diabetes	79(33.5)	43(18.2)	114(48.3)
Fear of developing complication	92(39.0)	51(21.6)	93(39.4)
Fear of taking medication for life	122(51.7)	23(9.7)	91(38.6)
Fear of medication side effects	118(50.0)	39(16.5)	79(33.5)

Table 2. Causes of fear about type-2 diabetic among study participants

Cause of fear	Frequency (n)	Percentage (%)
The lifestyles respondents are afraid of changing		
Diet modification	88	80.7
Exercise	21	19.3
Why some respondents are afraid of death		
Relation died of DM	51	47.7
Somebody known to them died of DM	35	32.7
Others*	21	19.6
The complication respondents are afraid of		
Sexual problem	6	3.6
Kidney disease	39	23.5
Eye complication	65	39.2
Hypoglycaemia	29	17.5
Others**	27	16.2
Why respondents are afraid of taking drug for life		
Side effects of drugs	71	40.1
Money to buy drug	96	54.2
Others***	10	5.7
Side effect respondents are afraid of		
Abdominal discomfort	43	17.1
Fainting attacks	46	18.3
Dizziness	94	37.5
Others****	68	27.1
	251	

Multiple response table

Others*- Heard from people and television, read from internet and books, that it kills

Others** -Foot ulcer, limb amputation -

Others*** - Medications damage body organs, medications ruin health in the future, medications are poisons

Others**** -Palpitation, nausea, vomiting, weakness, tiredness, shivering

Table3. Respondents' ideas about cause of diabetes (N=236)

Variable	Agree n (%)	Don't know n (%)	Disagree n (%)
Diabetes is caused by certain food	134(56.8)	83(35.2)	19(8.0)
Diabetes can be caused by stress	33(14.0)	175(74.2)	28(11.8)
Diabetes is inherited among family members	95(40.3)	123(52.1)	18(7.6)

Table4. Effect of type-2 diabetes on respondents' daily activities (N=236)

Variable	Agree n (%)	Don't know n (%)	Disagree n (%)
Diabetes has affected my household duties	89(37.7)	30(12.7)	117(49.6)
Diabetes has affected my job	61(25.8)	42(17.8)	133(56.4)
Diabetes has affected my relationship with people (social life)	82(34.7)	29(12.3)	125(53.0)

Table5. Expectations of type-2 diabetic patients from the physician regarding diabetes and its treatment (N=236)

Variable	Agree n (%)	Don't know n (%)	Disagree n (%)
Expectation of information about diabetes	158(67.0)	44(18.6)	34(14.4)
Expectation that medication cures diabetes	17(7.2)	133(56.4)	86(36.4)
Expectation of shared-decision making	73(30.9)	130(55.1)	33(14.0)
Expectation of emotional support	59(25.0)	141(59.7)	36(15.3)

Relationship between Respondent’s Fears and Impact on Function as Regards Type-2 Diabetes and Glycaemic Control

The fears of; changing lifestyle, diabetes complications, taking anti-diabetic medication for life and medication side effects had a significant association with poor glycaemic control ($p < 0.05$), except for the fear of death ($p > 0.05$) (Table 6). Among the impacts on function, only household duties had a significant association with poor glycaemic control ($p < 0.05$) as shown in table 7.

Table6. Relationship between respondent’s fears about type-2 diabetes and glyatedHb level

Respondent’s fears	Level of glyatedHb			X ²	p - value
	Poor n(%) n=127	Good N(%) n=109 N=236	Total n(%)		
Fear of changing lifestyle					
Agree	64 (72.7)	24 (27.3)	88 (100)	21.044	< 0.005*
Don’t know	17 (37.0)	29 (63.0)	46 (100)		
Disagree	46 (45.1)	56 (54.9)	102 (100)		
Fear of death					
Agree	53 (67.1)	26 (32.9)	79(100)	3.492	0.114*
Don’t know	21 (48.8)	22 (51.2)	43(100)		
Disagree	53 (46.5)	61 (53.5)	114 (100)		
Fear of developing complications					
Agree	71 (77.2)	21 (22.8)	92 (100)	33.682	< 0.005*
Don’t know	22 (43.1)	29 (56.9)	51(100)		
Disagree	34 (36.6)	59 (63.4)	93(100)		
Fear of taking medication for life					
Agree	84 (68.9)	38 (31.1)	122(100)	24.175	< 0.004*
Don’t know	11 (47.8)	12 (52.2)	23(100)		
Disagree	32 (35.2)	59 (64.8)	91(100)		
Fear of medication side effects					
Agree	80(67.8)	38(32.2)	118(100)	30.825	<0.004*
Don’t know	20(51.3)	19(48.7)	39(100)		
Disagree	50(63.3)	29(36.7)	79(100)		

*Significant p – values, X² = chi-square

Table7. Relationship between impact on function and glyatedHb level among respondents

Respondent’s effect on function	Level of glyatedHb			Total (%)	X ²	p - value
	Poor n(%)	Good n (%)	n (%)			
DM affects household duties						
Agree	66(74.2)	23 (25.8)	89(100)	26.846	< 0.001*	
Don’t know	13 (43.3)	17 (56.7)	30(100)			
Disagree	48 (41.0)	69 (59.0)	117(100)			
DM affects job						
Agree	47 (77.0)	14 (23.0)	61(100)	8.287	0.056	
Don’t know	21 (50.0)	21 (50.0)	42(100)			
Disagree	59 (44.4)	74 (55.6)	133(100)			
DM affects social life						
Agree	59 (72.0)	23 (28.0)	82(100)	4.921	0.140	
Don’t know	13 (44.8)	16 (55.2)	29(100)			
Disagree	55 (44.0)	70 (56.0)	125(100)			

*significant p – values, X² = Chi-square

DISCUSSION

This study found that more than half (56.8%) of the participants were females. The female preponderance in this study may be a reflection of the gender profile of T2DM in the study center. This could also be explained from the angle that traditional African men tend to be busier with their jobs to cater for their families than coming to hospital. Similar studies done in Nigeria and Tanzania also reported female preponderance.^{1,4} The mean age in this study (54.2 ± 9.4 years) was in line with report from another study that stated that increasing age is a risk factor for T2DM.² Participants with good glycemic control accounted for 109 (46.2%). This finding was close to a Nepalese study of 56.5%,³ but different from that in Tanzania which was 24.2%.⁴ These discrepancies could be related to differences in methodology, geographical location, socio-economic status and duration of T2DM in the subjects.

This study revealed that, more than one-third (37.3%) of the respondents had fear of changing their lifestyle. Specifically, fear of dietary restriction ranked highest. Other studies carried out in Greece and Malaysia reported similar finding.^{8,9} Almost one-fifth (19.5%) of the respondents did not know if they fear lifestyle changes while more than two-fifth (43.2%) did not fear lifestyle changes. Family support was crucial in this aspect as family meal was affected by the illness. Patient counseling was crucial to increase adherence to lifestyle modification. More than one-third (33.5%) of the respondents had fear of death from diabetes. Among those who feared death, the majority (47.7%) mentioned death of a relative from diabetes as reason for the fear. The finding in this study is in keeping with the findings from studies conducted in Malaysia and Pakistan where most of the participants in both studies had fear of death from diabetes.^{9,10} In the report from Malaysia, the participants fear was secondary to the fact that diabetes has life threatening complications, while for those in the report from Pakistan, their fear was centered on the disease shortening their lifespan. Close to one-fifth (18.2%) of the participants did not know if they were afraid of death from diabetes while close to half (48.3%) of them were not afraid of death from the disease. Patients need to be adequately educated about diabetes in order to abate this fear of death with the associated psychological problems accompanying such fear.

Almost two-fifth (39.0%) of the respondents feared diabetic (DM) complication. Among those who feared having DM complications, eye complication (33.9%) was the most feared complication. The reason behind this finding was related to past experience the respondents had from people with diabetes. This finding was as reported in the study conducted in Greece earlier cited.⁸ Also, similar finding is documented in a report from Kuwait.¹¹ However, an American study reported that the complication feared most was lower limb amputation,¹² which was secondary to the respondents' misconception about diabetes. More than one-fifth (21.6%) of the respondents did not know if they fear DM complications while almost two-fifth (39.4%) had no fear of the complications.

More than half (51.7%) of the respondents had fear of taking their medication for life. Almost one-tenth (9.7%) did not know if they feared taking their medication for life while close to two-fifth (38.6%) expressed no fear. Among those who expressed fear, the majority (54.2%) mentioned cost of medication as the reason for the fear. There is a dearth of literature on the fear of taking anti-diabetic medication for life to the best of our knowledge. Half of the participants in this study feared side effects of anti-diabetic medication. The side effect mostly mentioned by the participants who expressed fear of medication side effects was dizziness. Dizziness, the most feared side effect among the participants could be related to their past experience in connection with hypoglycaemic or hyperglycaemic incidents. This was also reported in a study from Ethiopia.¹³ About one-sixth (16.5%) did not know if they fear the medication side effects while more than one-third (33.5%) had no fear of such side effects. The fear of taking anti-diabetic medication for life/and the medication side effects may lead to poor/non-adherence to medications which may increase the risk of developing DM complications.

More than half (56.8%) of the respondents perceived certain foods as cause of diabetes of which the majority mentioned sugary food. This is similar to reports from Saudi Arabia and Libya where 62.4% and 35.6% respectively of the participants perceived certain foods as DM cause.^{14,15} More than one-third (35.2%) had no idea about this perceived cause while close to one-twelfth (8.0%) did not accept this idea. More than two-third (40.3%) of the participants

perceived heredity as cause of DM. This finding corroborate that from a Nigerian and Indian studies where 14% and 65.25% of the respondents respectively perceived heredity as DM cause.^{1,16} More than half of the subjects had no idea that DM is inherited while close to one-twelfth (7.6%) did not accept that it is inherited. The perception of almost one-seventh (14.0%) of the respondents was linked to stress. Similar findings were seen in studies done in Libya and Saudi Arabia earlier cited.^{14,15} Almost three-quarters (74.2%) did not know stress as a cause of diabetes while almost one-eighth (11.8%) did not accept that stress causes DM.

Among the respondents, more than one-third (37.7%) reported having difficulties to carry out their household functions/chores. Similar reports from Lebanon and Brazil recorded that 80% and 50.7% respectively had difficulties carrying out their household functions.^{17,18} Differences in the result may be due to methodology used in each study and the duration of years the participants had lived with diabetes in the different study populations. More than one-eighth (12.7%) of the respondents did not know if their household functions were affected while almost half (49.6%) of the participants' household functions were not affected. Other impaired functions found in this study were on social life in more than one-third (34.7%) and on job in slightly more than one-quarter (25.8%) of the respondents respectively as seen in similar studies carried out in Lebanon and Brazil.^{17,18} More than one-eighth (12.3%) of the respondents did not know if their social function was affected while in more than half (53.0%), their social function was not affected by DM. Also, more than one-sixth (17.8%) did not know if their job were affected by DM while more than half (56.4%) had no effect on their job. These findings show that functional impairment is common in DM patients. It should be routinely inquired during consultation in order to offer a holistic care to such patients.

This study shows that, more than two-third (67.0%) of the respondents expected information about diabetes. Specific information expected were on: cause, treatment and complication of DM including self-management. This finding is in accordance with the finding in another study conducted in America.¹⁹ However, in another similar study done in America, 97% of the subjects expected information on treatment duration.²⁰ Close to one-fifth (18.6%) of the respondents did not

know of any information expectation while close to one-sixth (14.4%) did not expect any information about the disease. A minority (7.2%) of the respondents expected their medications to cure their diabetes. Similar reports from Lagos (Nigeria), America and India recorded 13%, 65% and 56.5% respectively.^{1,16,20} Differences in objective of the study and methodology used in the different studies including health literacy level in the participants could explain these variability. This finding of unrealistic expectation could be addressed through awareness campaign explaining the chronic nature of diabetes. More than half (56.4%) of the respondents did not know if they expect their medication to cure the disease while more than one-third (36.4%) did not expect DM cure by their medication.

In this study, close to one-third (30.9%) of the respondents expected a shared-decision in the management of their disease. This finding was lower than that of a similar American study that recorded 69.4%,¹⁹ which may be due to differences in methodology. More than half (55.1%) of the respondents did not know if to expect shared-decision while about one-seventh (14.0%) did not want shared-decision. One-quarter (25.0%) of the subjects expected emotional support which was similar with a report from Greece.⁸ More than half (59.7%) of the participants did not know if to expect emotional support while close to one-fifth (15.3%) did not want emotional support.

This study depicts that fear of changing lifestyle had a significant association with poor glycemic control. This association was also reported by another study done in Malaysia.²¹ Furthermore, the fears of diabetic complications, taking anti-diabetic medication for life including the medication side effects, had a significant association with poor glycemic control. A study conducted in Germany indicated a significant difference between fear of diabetic complications and poor glycemic control.²² There is paucity of data concerning the association between the fear of taking anti-diabetic medication for life/the medication side effects and glycemic control in our environment.

In this study, it was revealed that impact on household function had significant association with poor glycemic control which is similar to finding in another study done in Egypt,²³ but contradicts that in a study conducted in Sweden where there was no significant association.²⁴ In

the Swedish study, there were significant predictors such as female gender, age of ≥ 65 years and presence of complications in the study participants.

CONCLUSION

The study concluded that diabetic patients have various illness experiences that could influence their treatment adherence and outcome. Consequently, assessing and utilizing patient-centered approach of care is crucial if the goals and targets set for diabetic patients are to be met. Hence, the need to properly educate patients on the nature of the disease, addressing any misconception to ensure life-long treatment adherence.

RECOMMENDATIONS

Physicians should incorporate exploring the illness experience using the patient-centred approach of care to every diabetic patient during consultation to ensure a better management. To the best of the author's knowledge, there is paucity of data regarding the fear of taking anti-diabetic medication for life by T2DM patients. There is also paucity of data about the relationship between; the fear of taking anti-diabetic medication for life/side effect of anti-diabetic medication including fear of death from diabetes and glycaemic control. Higher study design may be employed to explore some of the grey areas.

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AUTHORS' CONTRIBUTIONS

All the authors were responsible for conceptualizing the study. UEA, UNO, PEA, FA, BOO and IGO collected, evaluated and analyzed the data under the supervision of IBO. IBO reviewed and edited the article. All the authors contributed immensely to the manuscript and agreed to the final version.

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Assessment of Illness Experience of Type-2 Diabetic Patients Using Patient-Centered Care at Family Medicine Clinic in a Tertiary Hospital in Southern Nigeria

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