# Health education and awareness about diabetic retinopathy among patients attending diabetic clinics in tertiary and regional hospitals in Tanzania

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# **ABSTRACT**

**Objetive:** To assess the level of diabetes education, diabetes eye-care delivery knowledge and awareness about diabetic retinopathy among patients attending diabetes clinics in selected regional and tertiary hospitals in Tanzania.

**Materials and Methods:** A cross-sectional study was conducted in 6 regional and all 4 zonal tertiary referral hospitals in Tanzania. A semi-structured questionnaire was administered to about 413 systematically sampled patients to explore their demographics, diabetes health education, awareness about diabetic retinopathy and eye-care, and challenges encountered when accessing diabetic eye care services.

**Results:** A total of 413 patients were recruited. Seventy one (8.6%) patients were type-1, and 336 (81.3%) type-2. Two hundred and fifty five (61.8%) had diabetes for 1-10 years. Three hundred and twenty two (77.9%) had received diabetes education. Receiving diabetes education was significantly associated with level of education (p<0.0001), residential region (p<0.0001) and occupational status (p<0.007). Nurses and doctors were the leading providers of diabetes education reported by 243 (75.5%) and 196 (47.5%) patients. Radio, television, brochures/posters, relatives and friends were the least mentioned sources of diabetes education. Education messages delivered were diabetic diet (390, 94.4%); control of: blood sugar (226, 54.7%), blood-pressure (49, 12%); eye-care (62, 15%), feet-care (62,15%) and 45 (11%) exercise. Twenty four (5.8%) patients were aware about the need for yearly eye examination. One hundred and twenty three (29.8%) had previous eye examination. Shortage of staff in facilities providing diabetes-care; inadequate drugs and equipment for monitoring blood sugar were the main challenges.

**Conclusions and recommendations:** Although diabetes education is provided to most patients attending diabetes clinics in Tanzania, patients have limited awareness about diabetic complications in particular diabetic retinopathy including the need for yearly eye examination which would make strategies to implement health promotion and prevention of diabetic retinopathy blindness difficulty. Strategies to improve diabetes education are required.

Key words: Diabetes mellitus, Diabetic retinopathy, Diabetes education, Eye-care, Tanzania

# **INTRODUCTION**

The number of people affected by diabetes mellitus is increasing worldwide due to several factors which include rapid population growth, aging, urbanization, and increasing prevalence of obesity and physical inactivity. In Tanzania the same factors have been documented to contribute to a local increase in the number of people with diabetes<sup>1</sup>.

World-wide, the magnitude of patients with diabetes has been estimated to increase from 171 million in the year 2000 to 366 by the year 2030, with most of this increase expected to occur in developing countries<sup>2</sup>. The increase in diabetes will have a corresponding increase in complications associated

with diabetes including retinopathy, cardiovascular diseases, nephropathy and foot ulcers.

Few studies have been published on diabetes in sub-Saharan Africa. However these studies show an increase in prevalence with time. For instance the prevalence of diabetes mellitus in Tanzania in 1989 was found to be 0.87% and that of impaired glucose tolerance to be 7-8% among 6299 Africans aged 15 years and above living in six villages in Tanzania³. There are also marked differences in the country between the rates of diabetes prevalence among different communities, with the highest prevalence being among the ethnic Indian population. In addition a population-based survey in 1996 and 1997 of 770 adults (aged ≥ 15 years) revealed a higher prevalence

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of diabetes, Impaired Fasting Glucose (IFG), overweight, obesity, and physical inactivity especially among women in the urban areas<sup>1</sup>. A study in Northern Tanzania in 2014 reported an overall prevalence of 11.9% among 76 T2DM4. A report on a review of diabetic complications in sub-Saharan Africa noted a varying prevalence of specific complications ranging from less than 10% to over 80% in some countries: foot ulcers 4-19%, peripheral neuropathy 4 to 84%, peripheral vascular disease 3-79%, gangrenous foot ulcers 0.6–69%, and foot amputation rates 0.3–45%. Diabetes causes visual impairment through early onset cataract and diabetic retinopathy. Cataract and diabetic retinopathy are the second and sixth leading causes of visual impairment<sup>6</sup>. A recent study in Tanzania reported a prevalence of 27.9%, 19.1% and 2.9% for background, pre-proliferative and proliferative diabetic retinopathy respectively in Kilimanjaro region<sup>7</sup>.

Diabetic retinopathy is asymptomatic in its early stages and if detected early, enhanced good blood glucose control usually delays the progression. Treatment by laser has been shown to be unequivocally effective in saving sight in those with advanced stages of diabetic retinopathy<sup>8</sup>. However in many low resource countries including Tanzania, services for detection and management of diabetic retinopathy are poorly developed and are only available in urban settings<sup>9</sup>. This shortfall is due to a number of challenges related to inadequate qualified human resources, infrastructure, referral system and diabetes education to the public for preventive strategies<sup>10,11</sup>. Knowledge empowerment of patients is an important part of disease management. Health promotion, service availability, demand creation and awareness of diabetes and its complications by patients with diabetes could help in the prevention, early detection, management, and follow-up care of diabetes complication including retinopathy. Therefore educating patients with diabetes that the condition affects their eyes is an important strategy in prevention of visual loss from Diabetic Retinopathy (DR)<sup>12</sup>. In Tanzania diabetes clinics are established in all tertiary and almost all regional hospitals. A previous study noted that there was no link between the eye and diabetic clinics for easy referral and screening of patients with diabetes<sup>13</sup>. Diabetes education has the potential to bridge this gap by informing patients on the care required for their disease. Currently it is not known whether patients with diabetes have access to diabetes education especially on diabetes complications and in particular education about diabetic retinopathy. Additionally, patient's awareness about diabetes and diabetic retinopathy, and challenges encountered by patients during service delivery have not been assessed.

The aim of the study was to assess the level/magnitude of diabetes education provided at diabetic clinics, diabetes eye care delivery and awareness about diabetes and its complications including diabetic retinopathy among patients attending diabetes clinics in selected regional and tertiary hospitals in Tanzania. Also service access challenges encountered by diabetes patients were explored. It is expected that the findings of this study would inform policy makers especially in the Ministry of Health and Social Welfare and other key stakeholders in management of diabetes to prioritize comprehensive health promotion and preventive community eye health services on diabetes and its complications including diabetic retinopathy.

## **MATERIALS AND METHODS**

*Study design:* This was a hospital based cross sectional descriptive study conducted for a period of 6 months between June and December 2014.

Study setting: The study was conducted in selected hospitals including all 4 major tertiary referral hospitals and 6 regional hospitals one from each of the 6 geographical zones of the country. Data was collected from diabetic clinics of each hospital.

Study population: At each hospital, all adult (>18 years) patients attending the diabetic clinic at each hospital on the day of the study were eligible.

*Inclusion criteria*: Adult patients aged 18 years and above who consented to the study.

Exclusion criteria: Seriously ill patients not able to take the interview.

Sampling and sample size: Consecutive sampling was used. Patients were consecutively recruited as they presented to the diabetic clinics until a total of 41 patients was reached. The estimated sample size was 410 assuming 83% of individuals had ever heard about diabetic retinopathy, and with absolute precision of 4%, 5% significance level and 15% non-response rate.

Data collection: Data was collected by interviewing patients using a semi-structured questionnaire. The questionnaire consisted of demographic data and whether they had ever received diabetes education, what was the source and what was specifically taught (messages) of the diabetes education? Questions to assess patient's knowledge on diabetes/diabetic retinopathy included: types of diabetes, complications of diabetes, timing and frequency of screening for diabetic retinopathy, and whether they were aware of different ways of treatment for diabetic eye disease

including diabetic retinopathy. Patients were also asked whether they had ever been referred for routine eye examination or screened/treated for diabetic eye disease including retinopathy. Lastly, patients were asked about any challenges they encounter while accessing services for diabetes.

Data analysis: Data were analyzed using SPSS version 17 software. Chi squared test and a p<0.05 considered to ascertain whether there was a significant difference between variables.

Ethical issues: This study was approved by the Ethics and Research Committee of Muhimbili University of Health and Allied Sciences. Permission to conduct the study was also sought from hospital directors of the selected hospitals. Written informed consent was obtained from all patients before commencement of the study.

#### **RESULTS**

Four hundred and thirteen patients were recruited for the study and all were included in the analysis. Half of (212, 51.5%) the patients were aged between 41-60 years while 133 (32.3%) were aged less than 40 years. The mean age was 51 years. There were slightly more 233 (56.5%) females.

More than half (233, 56.5%) of patients had completed primary school education, while 81 (19.6%) and 60 (14.6%) had secondary and college education respectively. Fifty four (13.1%) had had no formal education. A third (158, 38.2%) were self-employed, 71 (17.2%) were retired while 97 (23.5%) were not employed. More than a third (102, 35.4%) were or had been professionals before retirement while another third (100, 34.7%) were peasants. The distribution of patients by demographic characteristics is shown in Table 1.

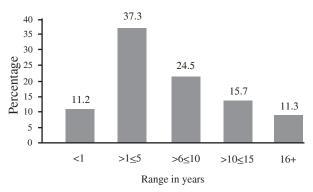
**Table 1:** Demographic characteristics of the study population

Demographic characteristic		No. (%)
Age (years)	<20	7 (1.7)
	21 - 40	60 (14.5)
	41 - 60	213 (51.6)
	>61	133 (32.2)
	Total	413 (100)
Sex	Male	69 (52.7)
	Female	84 (50.9)
	Total	153 (51.7)
Marital status	Married	285 (69.3)
	Widowed	77 (18.5)
	Separated	17 (4.3)
	Single	33 (7.9)
	Total	413 (100)
Education level	Primary	218 (52.7)
	Secondary education	81 (9.6)
	College education	60 (14.6)
	No formal education	54 (13.1)
	Total	413 (100)
Occupation	Self employed	158 (38.2)
	Employed	81 (19.6)
	Retired	71 (17.2)
	Student	6 (1.6)
	None	97 (23.5)
	Total	413 (100)
Type of work	Professional	102 (35.4)
	Peasant/Farmer	100 (34.7)
	Small scale business	64 (22.2)
	Manual laborer	14 (4.9)
	Business	8 (2.8)
	Total	288 (100)

Regarding residential region most (81.4%) patients were residing within regional municipals or peri-urban

districts. Only 77(18.6%) were residing in districts that were away from the tertiary or regional hospitals under the study.

The duration of diabetes for most (154, 37.3%) patients was between 1-5 years. Forty seven (11.3%) patients had diabetes for more than 15 years as shown in Figure 1.



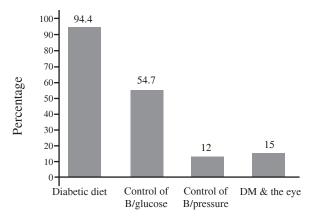
**Figure 1:** Duration of diabetes among the study population (n=413)

Majority (322, 77.9%) of patients had received education on diabetes while 81 (19.6%) had not received any. Having received health education on diabetes was significantly associated with patients level of education (p<0.0001  $\chi^2$ =24.8) residential region (p=0.0001,  $\chi^2$ =53.8) and occupational status. Retired patients were more likely (p<0.007  $\chi^2$ =14.07), to have received health education on diabetes than employed or those without a job. The regions Morogoro, Kilimanjaro and Dar es Salaam had the highest proportion (92-96%) of respondents who reported to have had received health education on diabetes while the two regions of Kagera (67%) and Kigoma (55%) had fewer respondents.

The study revealed that diabetic patients' education was conducted as health talks to a group of patients attending the diabetic clinic twice a week for 30 minutes to one hour by a health-care provider- usually a nurse. Doctors provided diabetes education during consultation with patients. Nurses were reported to give health education by a higher proportion (243, 75.5%) of patients than doctors (196, 47.5%). Mass media including radio and television, brochures/posters and relatives/friends were the least sources of health education messages as mentioned by 6.2%, 6.0% and 2.9% of patients respectively. Retired patients and current professionals were more likely (p<0.007,  $\chi^2$ =16.01) to receive diabetes education from brochures than peasants and laborers.

The commonest health education messages taught to diabetic patients included: Importance and the adherence to diabetic diet (390, 94.4%), followed

by the need for good blood sugar control (226, 54.7%), good blood pressure control (49, 12%); education on prevention of eye complications reported by 62 (15%), the need for regular physical exercise reported by 45 (11%) and education on foot care by 62 (15%), as presented in Figure 2.

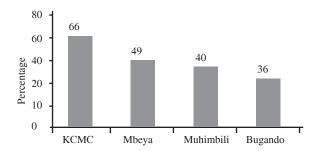


**Figure 2:** Diabetes education messages as reported by patients

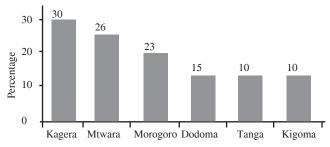
Regarding whether the patients knew about the type of diabetes they had, many (83.6%) did not know whether they had type 1 or type 2. However, the review of records showed that majority of patients (81.3%) had type 2 diabetes while (18.6%) had type 1 diabetes. Most patients (284, 68.8%) knew that their eyes may be affected by diabetes and an even higher proportion 319 (77.2%) of them mentioned low vision and blindness as complications of diabetes. Other organs mentioned by patients to be affected by diabetes were the feet by (191, 46.9%) of patients, the kidneys by 121 (29.3%), the nerves (89, 21.5%), and the heart by 96 (25.3%). This knowledge about diabetes and the eye was significantly associated with region of residency whereby Kilimanjaro region for instance had a higher proportion (32, 75%) of patients who knew that their eyes could be affected by diabetes compared to Kigoma (13, 31%) (p<0.001,  $\chi^2$ = 52.94). It was not associated with gender or duration of diabetes.

A small proportion of diabetic patients interviewed (24, 5.8%) correctly knew that they needed to be routinely screened for diabetic eye disease annually. About 13 (3.1%) patients thought they should be screened only when they have poor vision. Majority (376, 91%) did not know the timing and frequency of being screened for diabetic eye disease. About a third (124, 30.1%) of all patients had at least once been referred for eye examination. Eighty one (65.3%) of the referred patients were referred from the diabetes clinics while 15 (12%) were from

other clinics and only 3 (2.4%) from optometrists. Referral for eye examination was associated with level of hospital whereby higher proportions of respondents attending tertiary hospitals had been referred for eye examination compared to regional hospitals as shown in Figures 3 and 4.



**Figure 3:** Proportion of patients referred for eye examination from tertiary hospitals



**Figure 4:** Proportion of patients referred for eye examination by regional hospitals

Of those examined, 83 (66.9%) were seen at the eye clinic because they had complained of poor vision while 13 (10.5%) were seen after diagnosis of diabetes. Of those screened about 28.8%, 29.7% and 34% were screened for 6 months, one year and 2 years prior to the study respectively.

Only 125 (30.2%) patients were aware of availability for treatment of diabetic eye disease while more than half of the patients 288 (69.7%) were not aware. Seventy (17%) of all patients only had been referred for treatment of diabetic eye diseases including diabetic retinopathy, out of these, 41(58.6%) were referred for treatment from eye clinics because of poor vision.

Of those referred for treatment, 24 (34.3%) were referred to Kilimanjaro Christian Medical Centre, 19 (27%) to Comprehensive Community Based Rehabilitation in Tanzania Hospital and 10 (14.3%) to Muhimbili National Hospital. Fifty three (75.7%) of them got treatment including: surgery for cataract (9, 12.8%), laser (10, 15.7%), investigations (31, 44.2%), surgery for glaucoma (4, 5.7%) and retinal surgery (1, 1.4%).

Challenges encountered by diabetes patients when accessing diabetes care: Inadequate number of staff at the diabetic clinics was reported by many patients as the leading challenge. Patients reported that they

had to travel long distances and had to wait for a long time to be attended due to shortage of staff. Availability of drugs in some clinics was reported as constant problem. It was reported that in some clinics, drugs for control of diabetes were not enough to last patients until the next appointment usually after every three months. Most patients felt they could not afford to buy drugs from pharmacies outside the hospitals.

Unavailability of blood and urine glucose measuring equipment and strips at the diabetic clinics was another reported problem. In some clinics, patients were using the general laboratories for blood glucose examination whenever the same examinations could not be done at the diabetic clinic, mainly due to depletion of gluco -strips or urine strips or defective glucometers. This also contributed to patients spending long hours for the services and sometimes they could not wait any longer as they were afraid of becoming hypoglycemic.

# **DISCUSSION**

The study was conducted to assess the levels of diabetes patients' education on diabetes and their level of awareness about diabetes eye care delivery in Tanzania. The study has shown that diabetes education is routinely provided at the diabetic clinics. The nursing staff were reported by many patients as the main diabetes education providers while mass media and written educational materials were reported as the least sources of diabetes education. Diabetes education messages were not comprehensive as they concentrated mostly on dietary control of blood glucose leaving out the various complications of diabetes including diabetic retinopathy. There is need for eye specialists to train nurses in the diabetic clinics on diabetic eye diseases.

The messages also did not inform patients about primary prevention of diabetic complications and how to find out if complications have occurred. This finding indicates that until now, diabetes clinics are an important source of diabetes education in the country. Strengthening health education provision in diabetes clinics is a strategy that may be used to increase patients' knowledge about diabetes. Health personnel providing diabetes education must be knowledgeable enough to provide comprehensive and structured messages on diabetes. This finding also reflects that patients had not been exposed to other sources (eg television and radio spots, brochures and posters) of diabetes education other than diabetes clinic staff. Observation in diabetes clinics showed a few educational materials displayed on the walls. Lack of other sources of diabetes education like mass media can limit access of the general public to diabetes education because only patients suffering from diabetes will have access to diabetes education in diabetes clinics.

In order to provide diabetes education which will also benefit the general public outside the hospital, alternative ways of providing diabetes education including mass media and educational materials need be employed. Structured diabetes education messages should target to educate diabetes patients and the public on prevention of diabetes, diabetic retinopathy and other complications, early diagnosis of diabetes and diabetic retinopathy and prevention of visual loss from diabetic retinopathy. Messages may include: Healthy diet to prevent obesity, regular exercise, diabetes can cause blindness, the early stages are only detectable by examination of the retina, everyone with diabetes should have an annual retinal exam to allow early diagnosis and treatment of diabetic retinopathy, control of blood pressure is necessary to prevent visual loss from diabetic retinopathy<sup>14</sup>. The regional differences in terms of awareness and referral of patients for tertiary eye examination are probably related to the presence of tertiary eye services for diabetics and an eye screening program in Kilimanjaro region<sup>7</sup> compared to other regions.

The findings in this study show that only 5% knew the type of diabetes they were suffering from. This is in contrast to a similar study in South Africa<sup>15</sup> and Kenya<sup>16</sup> whereby 96% and 90% respectively were aware of the existence of type 1 and 2 diabetes. This is probably related to the level of education of the study population and the level of diabetes education received. In the current study, more than 64% of patients either had no formal education or had primary education only which probably limited their understanding of the disease.

This study also confirms that patients knowledge about diabetes and its complications including diabetic retinopathy among diabetic patients in Tanzania is limited, especially with regard to preventive aspects. This could probably be explained by the fact that education about diabetes complications is not routinely given as the nurses and doctors concentrate mainly on survival skills of managing diabetes at an expense of more advanced education on complications. The fact that most clinics had fewer staff could also explain the lack of detailed diabetes health education. Although majority of the patients knew that diabetes affects the eye and has the potential to cause blindness, they did not know when and how frequently they should be screened for diabetic eye disease. Some of them thought they should be examined only when they developed vision loss.

The most serious ocular complication of diabetes is diabetic retinopathy is usually asymptomatic

until late in the course of the disease. Such lack of knowledge, could lead to blindness in these patients as they will be seen by eye specialists when it is very late. Most patients were also not aware of possibilities for treatment of diabetic eye disease including diabetic retinopathy. Apart from the eye complications, study participants had very limited knowledge of other complications of diabetes. This finding is similar to a study in India<sup>17</sup> where patients had insufficient knowledge on diabetes but contradicts with findings in a study in Kenya<sup>18</sup> which concluded that patients attending Kenyatta National Hospital were generally aware of diabetic retinopathy as a complication of diabetes. Studies have shown that increasing patient's knowledge about a disease and its complications has significant benefits in relation to compliance to and reduction in complications of the disease<sup>19</sup>. There is a definite need to empower patients with the knowledge required to help them obtain maximum benefit from their treatment for diabetes to improve their livelihood.

Lack of knowledge may also translate into poor practice. About 68% had had no previous eye examination while referral for eye examination depended on whether patients complained of poor vision. Such late referrals has implications on the outcome of treatment and quality of life of affected patients.

More than a third of patients who had been screened were lastly screened more than one year to two years prior to the interview reflecting poor follow-up care or lack of awareness about the importance of eye screening. Only 17% had been referred for treatment. This finding is similar to the study in South Africa<sup>14</sup>. Strategies to educate patients with diabetes are likely to change the practice among these patients to enable them to seek for comprehensive care for diabetes including regular examination and screening for diabetic retinopathy. A study in Singapore had demonstrated that diabetes education did change the practice among patients with diabetes towards a more effective self-care<sup>20</sup>.

The challenges reported by patients indicate the need to improve services for patients with diabetes by establishing strategies for continuous supply of equipment for monitoring glycaemia control; training staff in specific management of diabetes and its complications and expansion of clinical care. Increasing the number of trained personnel will enable many district as well as regional hospitals to be staffed with health personnel who are qualified in diabetes management thereby improving access to diabetes care. In the areas studied, patients accessing diabetes services were mainly those residing near the

particular hospitals. Adequate staff will also enable adequate consultation time and provision of health education to patients. Improvement of services for people with diabetes and its complications is an urgent priority for countries in sub-Saharan Africa including Tanzania which should focus on primary prevention of complications<sup>9</sup>.

# **CONCLUSIONS**

Diabetes education is provided by health care providers to most patients attending diabetes clinics in Tanzania. However, diabetes patients have limited awareness about diabetic complications including diabetic retinopathy. Accessing of services by patients is challenged by inadequate facilities and trained staff to provide diabetes services. Efforts to improve services for people with diabetes by training more staff in diabetic management, expanding clinical care and implementing strategies for diabetic education are necessary in order to inform patients and empower them to seek for comprehensive care of diabetes. Referral for eye examination of all diabetic patients is emphasized as an important policy recommendation.

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