BARRIERS TO AN EFFECTIVE DIABETIC RETINOPATHY SERVICE IN IBADAN, NIGERIA (SUB –SAHARAN AFRICA) - A PILOT QUALITATIVE STUDY

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ABSTRACT

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Background: Diabetic retinopathy is an increasing cause of blindness. The prevalence of retinopathy in hospital attending diabetics in Ibadan is reported to be 42 %. This study assessed the barriers identified by patients and service providers to delivering good services for diabetic retinopathy in Ibadan, Nigeria, Sub-Saharan Africa.

Methods: A qualitative survey using non-participatory observation, in-depth interviews (patients and healthcare providers), and focus group discussion for diabetic patients in the eye clinic in University College Hospital, Ibadan was done. Semi-structured interview and topic guides were used to evaluate the barriers to effective service. The participants were selected using a non-probability, purposive sampling strategy. Twenty participants were involved in the pilot study. There were ten in-depth interviews of patients and two focus group discussions of patients (3 in each group). Four healthcare providers were interviewed (a retinal surgeon, a senior registrar, an endocrinologist and a public health nurse).

Results: Lack of awareness that diabetes causes irreversible blindness was identified as a major barrier by both patients and providers. Cost of treatment of diabetes and treatment of retinopathy was also an important barrier. The long waiting time before consultation, staff attitudes to patients and appointment scheduling problems deterred patients from using the service.

Conclusions: More diabetic patients can be encouraged to use eye service by providing more detailed information/counselling and making clinic attendance less costly and more convenient.

Keywords: Barriers, Diabetic retinopathy, Service, Ibadan

INTRODUCTION

There is a global increase in the population of diabetic patient. It is estimated that there will be an increase from 382 million in 2013 to 592 million by 2035.1 The rate of increase of diabetes in Africa over the same period is 109% (the highest in the world) from 20 million to 41 million. As the diabetes epidemic occurs, there is an imminent increase in visual loss from diabetic retinopathy in the Sub-Saharan Africa.² There is the problem of poor patient attendance at clinics, nonexistent or inadequate referral systems from primary to secondary care and from medical departments to ophthalmic service, poor record keeping, non-existent systematic screening programs, little access to imaging technology including fluorescein angiography and optical coherence tomography, lack of treatment infrastructure including lasers and laser maintenance and lack of national policies and low government priority.3 All these act as barriers to management of diabetes and diabetic retinopathy in Sub-Saharan Africa. In Indonesia and China, barriers to diabetic retinopathy services include lack of (health) education on need for eve care, asymptomatic nature of diabetic retinopathy and non-referral by physicians.^{4,5} In developed countries like UK and USA,^{6,7} barriers identified include fear of laser treatment or surgery, lack of awareness that diabetic retinopathy can be asymptomatic and lead to blindness as well as the cost of attending clinic.

Diabetic retinopathy services commenced fully in Ibadan (University College Hospital) in 2008 after a retinal fellow was trained in India and with the availability of an argon laser machine and a vitrectomy machine (both donated to the hospital). The proportion of diabetics with retinopathy in the clinic was 42.1% which is higher than other centres in Nigeria.⁸ However, it was observed that 57% of diabetic patients referred from the diabetic clinic complied with eye clinic attendance.⁸

The aim of the study was to determine the awareness of diabetic retinopathy among diabetic patients in the clinic and explore the barriers to the diabetic retinopathy service in the University College Hospital, Ibadan.

METHODOLOGY

This was a qualitative study using a non- probabilistic sampling strategy to select participants in the study. The study was carried out in the Eye clinic, University College Hospital, Ibadan, a tertiary facility. It is the only facility where diabetic retinopathy service is provided in the metropolitan city with a population of 2.72 million.⁹ The study involved a nonparticipatory observation, interviews (patients and providers) and focus group discussions (patients).

The diabetic patients were identified from the new patients' register, surgeon record book and laser register. This was done for the years 2011-2013. The initial plan was to pick patients systematically as they came to the clinic, but this was not feasible because of a nationwide doctors' industrial action during the data collection in July/August, 2014. The phone numbers of patients were retrieved from the medical records. The patients were called on phone and invited to be part of the study. Patients were selected to achieve an equal distribution of age, gender and clinical diagnosis. Patients who had not accessed the service early or regularly and subsequently lost significant vision from diabetic retinopathy (DR) were considered to be "information rich plus". Patients with severe DR/ proliferative diabetic retinopathy that required treatment and had not experienced sight loss that had presented earlier and accessed the service were identified and considered as 'information rich'. Patients with diabetic retinopathy of lesser severity compared with the two categories above were identified and included. Patients who had accessed the DR services within the last 2 years were included in the study. This was to avoid recall bias. Patient who were less than eighteen years or too unwell to participate were excluded. This was because of ethical issues about giving consent and to reduce stress respectively.

Ten patients were involved in the in-depth interviews while 6 patients were involved in two Focus Grouped Discussions (FGD). The FGD were organised separately for males and females with each group having 3 people each. This was because of cultural reasons (so the women could freely express themselves and not feel intimidated by the presence of the men). Four providers were interviewed on the study. Semistructured topic guides were used for the interviews and focus discussions. The participants were allowed to use their preferred language (English or Yoruba) during the interviews and discussions.

The summary of the participants is shown in fig 1 below.

Committee and the University of Ibadan/University College Hospital Institutional Review Board. Information sheet and informed consent sheet were given to all participants. Confidentiality of patients was maintained during the interviews and group discussions. Patients were identified by coded numbers which was used in the result. Participants' anonymity was respected. The code identifier and names were kept in a password encrypted document known only to the researcher. The recording was done with an encrypted digital Dictaphone and was transcribed. The recording in Yoruba was transcribed and translated to English. The language for analysis was English. The data was analysed by familiarising with the raw data through reading the transcription many times. Key issues, concepts and themes were identified from the transcripts. Thematic framework was used. The codes identified were arranged using the NVIVO 10 software. The interpretation of the results was then done.

RESULTS

The mean age of the patients was 64.9 ± 5.58 years (Range: 57 - 73 years) and all had type 2 diabetes. There were 6 males and 10 females, giving a male female ratio of 1:1.6. About 62.5 % of the patients had diabetes for 10 years or more. Fourteen (43.8%) patients had at least secondary school education, while 2 (12.5%) had primary or no formal education. Eight (50%) patients had non proliferative diabetic retinopathy while the remaining 8 (50%) had proliferative type.

Health information on diabetic retinopathy:

Concerning awareness of diabetic retinopathy among the diabetic patients, the information was obtained majorly from diabetic clinics, support group meetings, books and/or internet. The effect of diabetes on the eyes was usually disseminated via health talk in the eye clinic. The health talk was that diabetes affect the eyes generally, specifics on how it does was not explained. The patients were not usually aware that diabetes can result to irreversible blindness if not promptly treated. *I was first told about it in endocrinology clinic. Nobody talked on eye and diabetes in eye clinic, just eye generally. (P6)*

...... I didn't mention about Diabetic Association of Nigeria. They ask questions, share ideas and experiences, so that helps with diabetic education. (Pro2)

....There is a book on diabetes, I usually read it. It was in the book I saw the different disease that diabetes cause to the body, the eyes etc...(Focus group1)

..... Through the internet, from our doctors, from the labs, they will let us know what the sugar level is (Focus group2)

Ethical approval was obtained from the London School of Hygiene and Tropical Medicine Ethics Some patients became aware of the effect of diabetic retinopathy after their eyes were affected and they became blind or partially sighted.

I don't know because it is strange to me. I have not seen anyone who had diabetesand that it affected the eyes until it happened to me. (Focus group 2)

I don't think that it affects the eyes until it affected my eyes (P8)

The barriers were grouped under enabling/disabling factors, hospital barriers and beliefs.

1. Enabling/disabling factors

(a) Societal Norms

These include family influence, community and societal influence.

The patients felt they became a burden to their children so they don't sometimes want to ask for help. It is more likely that the diabetic retinopathy patient had no carer to assist. This acted as a disabling factor in the use of the services for those dependent on their children.

.....I am not supposed to put my burden on the children. Or is it the money I collect for pension that is not even enough? That is the problem that we are facing. (P10)

Another challenge is that many people with retinopathy don't seem to have people who will help them, carers, I don't know why they have that kind of history, and nobody lives with them, nobody directly responsible. (Pro2)

(b) Use of Traditional Medicine

Those who want to seek help in the clinic are advised on alternative medicine which may make the glycaemic control worse. This was raised by more than a third of the participants-the focus groups and a provider. *The herbal drugs that we were trying then didn't work.* ... *(Focus group2)*

...cultural beliefs in the sense that people want to use alternative therapy...... So they want to use alternative therapy until you discover that your medicine is not being use or they are using something else in addition to it that is making the glycaemic control poor. (Pro2)

(c) Cost and Finances

This involved the cost of treatment of diabetes itself, cost of treatment for diabetic retinopathy - laser treatment, surgical treatment (Anti -VEFGF injections and vitrectomy).

The patients were burdened with the cost of treating the diabetes that they seem not to have extra money to pay for consultation fees in the eye clinic. When consultation fees were paid, they may not be able to afford the necessary eye treatment.

Some drugs I am expected to buy I don't have money to buy it. Even for the diabetes treatment, I can't afford it. My blood glucose is sometimes high before I start to use drugs. (P10) It is not small money that is spent on diabetes. There is a type of food one has to eat. ... There is the drug to use....And it is compulsory, we like it or not to attend clinic. (Focus group1) Most of these patients cannot afford both the cost of their treatment and the cost of follow up in hospitals so they tend to either default on their medications and in doing that worsen their diabetes. And that also with no clinical evaluation, they tend to progress which will tip them into retinopathy. (Pro1)

.. Unfortunately, those with severe form are the ones that don't even have money, retired people, no money (Pro3)

The consultation fees and fees for lasers and injections were viewed by patients as being too high for them to afford, though the patient knew that it was less than the charges in the private hospitals.

...... The treatment of the eyes is expensive. How they can reduce the price of treatment or subsidize the price especially the people with diabetes and eye problem. For example, the laser costed N10, 000 (£35) for one eye. I did it twice per each eye. I paid N40, 000 (£140) for the two eyes. The money is too much, if they can reduce it for diabetic patients. (P5)

.....have wanted to come for follow up, but when I come to UCH, I would be asked to pay again. That I should pay again which I have done three times, so that these eyes will not get worse... (P10)

When I compared it with what we pay outside, UCH is better. (Focus group2)

Most patients...may not be able to afford some procedures ... and this would hinder them in having access to care. (Pro1)

The healthcare provider felt that the cost of treatment for laser in the hospital is the cheapest in the country. However, the healthcare provider agreed that diabetic treatment should be subsidized or even given free to those who can't afford it. The patients also requested for review of prices.

..... Even when the laser was working, our laser happens to be the cheapest in the country; we charge N10, 000 $(\pounds, 35)$ per session. (Pro3)

I think that diabetic care should be subsidized. For some, it should actually be free. But sometimes people don't appreciate when something is completely free. (Pro2)

The reduction in charges will make it easy for us. ... The government help people with HIV, they should also help the people with diabetes. Diabetes is even worse than HIV. (Focus group1)

(d) Lack of Awareness of Health Insurance

The entire patients involved paid out of pocket and none was on the National Health Insurance Scheme (NHIS). This was because most of them were not aware that health insurance covers consultation fees and drug treatment. However, those aware had logistics problems in processing registration of the scheme. *I am not aware of health insurance (focus group2)* I knew about it but I didn't fill the form. I didn't want them to remove anything from the salary again. We believed they are looking for ways out to make money into their pocket. (P10) Yes, I knew about NHIS. My children are trying to help me concerning this, they have paid, but still my name is yet to come out. (Focus group1)

(e) Transport and Distance

This is a major concern for patients with severe visual impairment. They have difficulties in getting to the clinic if they have to take public transport. Those with mobility problems and poor sight, find accessibility to the clinic very difficult because they have no mobility support after arriving in the hospital.

...it is the walking that is difficult for me. I don't yet have the stamina to walk. I have to walk with the help of walking stick. No good transportation when I get to the hospital (Focus group1)

Patients living far usually were held up in traffic jams when they enter the city and had to wake up very early in the morning or sometimes sleep overnight in the city to make clinic appointment.

... I want to tell the doctor today that if I have another appointment it should not be on Monday because on Monday from Lagos to this place I find it very difficult. Mostly on Monday, rushing before 5.30am, one find it difficult to get transport because on Monday many buses have left the park. (P9)

(f) Escort

Patients with severe visual impairment missed their clinic appointments if there was no one to escort them to the clinic. This was because of difficulties encountered from leaving their homes to the eye clinic like crossing roads, entering the public transport. Some of the patients had to ask neighbours or their children to accompany them so as to make the appointment. This will incur indirect costs on the strained finances.

.....it is good to come with someone because of not seeing really. The child that comes with me has gone to school, he is doing promotional exam. ... He missed school on such days I had appointment. (Focus group1)

.... I won't be able to come. I can't even cross the road alone myself. (P4)

I cannot cross the road. When I want to go out, my children have to hold me to lead me on. The grandchild with me is coming here for the first time. (P10)

2. Hospital Barriers

These are barriers encountered by the patients in the hospitals. The patients and providers agreed that this is a major problem after the issue of cost is solved.

(i) Long Waiting Time

There were complaints of the long waiting time that it took to see the doctors despite coming early (in the morning).

The first time we came our time was wasted. From morning that we came, we left in the evening around 5pm. We left late..... (P3)

I could come in the morning and leave by 4pm at times. The last time I came from Oshogho. I got here around 9.09am and left by 6pm. (Focus group1)

....for those that can come, when they get here before they see a doctor is another major barrier. They come in the morning and leave late because the volume of patients is too much for doctors to handle. (Pro3)

The clinic has tried some modalities to help reduce waiting time

What we have done recently is to cut down the number of patients we see. If you don't have appointment and is not an emergency, we won't see you. We stagger appointments so that the retinal clinic could be finished by 2.00pm. (Pro3)

(ii) Appointment Scheduling

The clinic appointments were fine by the patients except those who come from outside the city. They have problems when given appointments on Mondays because of difficulty in getting public transport and traffic jams in the city.

....I wanted to tell the doctor today next appointment should not be on Monday ...May be another weekday will be better. (P9)

Those who are attending the diabetic clinic in UCH are afraid Monday appointments will clash with their eye clinic appointments and therefore prefer other day appointment.

.... But I am thinking this might happen because Monday is my endocrinology clinic and I come usually before on Wednesday, but now I am given Monday appointments. (P6)

Patients sometimes have difficulties in changing their appointment time if missed and may have emotional disturbance because of this.

When I came back to take another appointment date, the way the man shun me off; I felt like crying [tears almost drop from my eyes]. (Focus group1)

.. In the office where they issue card, the man there should at me. I was even pleading with him; he was shouling at me that the doctors will complain. (P1)

(iii) Health Worker's Attitude

The attitudes of some health workers were viewed to be harsh and disrespectful by the patients though some changes have been noticed. This was the view of half of the participants. The patients believed that change is necessary, only that they don't have a choice of where to go for the services.

The nurses have changed just a little. They are harsh to people, they shout and abuse one. Like as we sat down here for a while now, they can come and shout - move/ adjust. They should talk to us politely and recognise that we are decent people. We, the sick people that come to the hospital, are not really happy coming here. (Focus group1)

...the staffs are doing very well. Unlike before, they are harsh. It appears they have changed the people here.. (P6)

(iv) Poor Hospital Record Keeping

The case records at times are missing and patients had to wait for a long time for the case records to be found. This results in delay in seeing the doctors. At times, the case records were not found and temporary case records were opened. This further delayed the patients because a thorough check had to be made again. This made patients very agitated and worried. *Another thing is the file you just mentioned. Sometimes they look for my case note for a long time.. They will look for it, look for it in many departments and it will not be found. (Focus group1)*

After she had her operation, they didn't know where the case note was. One hour was used to retrieve the case note from the ward. (P5)

..... It seems to be a tall order to get record of diabetic patients, case note get missing.... What happens to our own case notes and record keeping? In the clinic you keep seeing temporary case notes because the records are missing. (Pro 2)

(v) Equipment Malfunction

The laser machine has been non-functional for about one year now. This has made patients unable to have treatment and they have to be referred outside the hospital for treatment.

.....laser was donated to UCH and, we were using it.It broke down, we called the engineers who came to repair it. It has broken down again; but when the engineers sent their bill; the hospital felt the money was too much. Since 8 months to one year now, we have not done any laser treatment. We are reviewing the patients and referring those that need laser. (Pro3)

He said he wants to use laser for me for the left eye, but the laser machine was not working. I was then referred to Lagos. (P10)

The attempts at convincing the hospital management to repair the laser machine had not been fruitful because of the cost involved. However, the Ophthalmological Society of Nigeria was planning to organize a repair workshop for all ophthalmic equipment in the country before the annual conference slated for August in Ibadan. However, the workshop was recently cancelled because the engineers were advised by their embassy against travelling to Nigeria due to the Ebola scare.

(vi) Power Failure

Lack of constant electricity was viewed by the provider as a cause of delay in giving optimum care to the patient because of delays caused. This resulted in long waiting time and increased cost of treatment.



Figure 1: Summary of participants in the study

(vii) Lack of Clarity of Information

The patients were more anxious when no one informs them about what is happening and the possibility of their being seen when the clinic is almost ending.

3. Belief

Curative Expectations

The expectation of patients with diabetic retinopathy and poor vision is very high. They believe that when they reach the hospital all their problems will be solved and vision will be back to before.

... I thought that there will be a way out that the eyes that is not seeing will see again. (Focus group2)

.....our expectation when we come to the eye clinic is "that miracle will happen", ...we must see clearly. (Focus group1)

Patients usually come late and their expectations are quite high. (Pro1)

When the expectations were not met, they were not willing to continue care. Patients wondered if there were no drug or eye drops that can be prescribed or spectacles to correct the problem.

I don't think I can be coming here without any good result. I expected a good result at my initial coming. That's why I have being here many times. (P10)

The expectation is that if eyes cannot see well/read well, one should be given appropriate spectacles to correct the defect. (Focus group2)

DISCUSSION

Many of the patients had an erroneous belief that diabetic retinopathy is symptomatic and this will give them sign to seek care. Lack of knowledge of the asymptomatic nature of diabetic retinopathy makes patient present mostly when symptoms develop.¹⁰ Patients sometimes refuse referral from the physician for eye check because they have no visual complaints. The belief that only when there is pain or reduction in vision or need for glasses is when eye check is necessary need to be cleared among diabetic patients in the locality. Patients with diabetes need to be aware of the importance of regular annual retinal examination and eye check-up.

The health education about diabetic retinopathy appeared to be learnt mainly in the diabetic clinic. Little education was given in the eye clinic except by the doctors who have limited time to counsel the patients due to the volume of work and patients they have to see. Schoenfeld et al found that where complications of diabetic retinopathy are explained to patients, services were more utilised.¹¹ Other authors found similar results.^{4,6,12} The education in the eye clinic should include explanation of what diabetic retinopathy is, its symptoms and effects with the use of poster pictures. If possible, patients' fundus photos could be used to harness compliance to diabetic care, treatment and response during one on one review. The health talk should be more detailed on the effect of diabetes on the eyes and the likelihood of it resulting in irreversible blindness if not given proper care.^{5,7}

The participants in this study believed they could get more information and education on diabetes and retinopathy from the internet apart from the doctors and nurses. This could be due to the tertiary education status of majority of the participants and that the study site is an urban centre.

Key Barriers Identified

Social norms

The patients felt reluctant in asking their children for assistance for the care of the diabetes and treatment needed for retinopathy. This was because they don't want to be a burden. However, if treatment is not sought, dependence is more since their vision and quality of life worsen. Geneau et al found that elderly cataract patients felt embarrassed or ashamed to ask for help from their children/immediate families in East Africa.¹³

Cost and finances

This was a major barrier to the use of the service mentioned by both patients and providers. Costs include the cost of treatment of diabetes itself, the cost of the (strict) diet they had to adhere to as well as cost of eye treatment(s) that is received.

The cost of laser treatment and injections when necessary makes patient delay their care. This results in further deterioration of the situation in the eyes. Cost has been noted to be barrier to diabetic retinopathy care.⁶

Lack of health insurance is a known barrier to eye service uptake.^{10,12} The insurance helps to alleviate the burden from cost of services and treatment. The patients need to be encouraged to register in the National Health Insurance Scheme to ease the burden of care of the disease and eye care.

Waiting time

Long waiting time has made the patients complained and reluctant in coming to the clinic. Patients are even informed from referral clinics/hospitals that the visits might take the whole day. Long waiting time maybe due to the high volume of eye patients to the doctors, incessant power failure and delays from visual testing, eye dilation and case records retrieval. This may make the family or friends who escorted the patients not willing to come again because of opportunity cost of income or time lost.^{7,14,15} The staggered appointment just recently introduced to reduce the waiting time needs to be evaluated to be sure it is working as desired. However, with staggered appointments, the patients would be missing the health talks in the early mornings. Modalities have to be put in place to ensure that health education is an on-going process throughout the patient's experience in the eye clinic. Long waiting time may result in dissatisfaction of the service being rendered.¹⁶

Staff attitudes

Lack of empathy from the health staff in the clinic acted as a barrier while the patients are waiting to see the doctors. Patients felt this was because the clinic is a government facility and people are treated anyhow without sympathy. This resulted in patients' agitation and harsh response to the clinic's health staff. Some other patients tried to be indifferent so that they will not be delayed further. In other research, health staff attitudes to patients have been noted to make patients fearful of attending clinics.^{7,16}

Appointment scheduling/ case records

The appointment scheduling methods has been changed overtime, from the record officers booking patients to the ophthalmic assistants booking beside the doctors. This was to ensure that the quota for each clinic is not exceeded. However, some challenges still exist. Strict adherence to appointment schedules should be encouraged as well as room to accommodate emergencies and genuine concerns.

The missing case records affected the flow of patient care and patient care itself. Patients were worried when their case records were not found and had to explain to the doctor again the complaints in their eyes. Such patients had to be re-examined as new patients. This resulted in further delay and hampered their management. Delays in retrieval of case records added to the waiting time of patients. A possible way round it is to encourage computerization of the patients' record in the hospital.

The study however had some limitations. The qualitative study may have introduced some selection bias in the participants in the study. The small number of participants in the study may make it not generalizable to the whole population of the diabetics in the eye clinic. However, it forms a basis for further work. The doctors' industrial action may have affected the study since more patients could have being recruited especially for the focus group discussion to get more varied opinion of patients if there was no strike. However, effort was made to explore more views from the participants in the study. The researcher was a healthcare provider in the study site. It is possible that the patients being aware of this might not divulge detailed information despite questioning. The translation of the recording from Yoruba to English may have introduced some bias into the study. However, the researcher whose mother tongue is Yoruba did his best to ensure that the translation is literal as heard from the recordings. All the participants had type 2 diabetes. It is possible that the barriers experienced by type 1 diabetic patients might be different. However, the most common type of diabetes in the environment is type 2.

CONCLUSION

In conclusion, this study has created an opportunity for diabetic patients to voice their feelings about the service they receive and aspects for improvement. It has also helped to know the views of the providers. The main barriers identified include waiting time, lack of health education on diabetic retinopathy, cost and finances, staff attitudes and appointment scheduling problems. These appeared to be barriers in other settings. It is hoped that the results of the study will help to provide evidence on the current service and facilitate changes where necessary.

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