CHALLENGES IN THE MANAGEMENT OF GLAUCOMA IN A DEVELOPING COUNTRY; A QUALITATIVE STUDY OF PROVIDERS' PERSPECTIVES

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ABSTRACT

BACKGROUND
Glaucoma management is challenging to patients as well as to the eye care providers.The study is aimed at describing the challenges faced by providers using qualitative methods.

METHODS
In-depth interviews were conducted with selected Ophthalmologists and resident doctors in ophthalmology at centres offering medical and surgical glaucoma services in Lagos state, Nigeria, according to established qualitative methods. This was done using semi-structured, open ended questions to explore the providers' perspective on glaucoma burden, challenges in the management, surgery for glaucoma, acceptance of glaucoma surgery by patients, and recommendations for improving glaucoma services. The discussions were recorded with the aid of a micro-cassette recorder. Familiarisation was done to identify key ideas in the data, then, the main themes and sub-themes were identified. Quotes that reflect the themes and sub-themes were then identified in the data.

RESULTS
In-depth interviews were conducted with a total of 11 ophthalmologists and resident doctors in training. Majority were of the opinion that glaucoma is a significant burdenconstituting about 35% of outpatient visits. Identified patient related challenges include; late presentation, lack of glaucoma awareness, delay in referral from optometrists, and poor compliance with medications. Shortages in needed equipment were also identified. Availability, affordability and counterfeiting ofdrugs were the major challenges related to medical treatment. Majority of the participants agreed that surgery should be offered to the patients as soon as the diagnosis of glaucoma is made. However, continuous monitoring of the patient on medical treatment is another line of option for them in early cases; if they are convinced the patients will be compliant. Some respondents considered the current number of glaucoma surgeries as adequate, while somethink otherwise. Reasons put forward for reluctance to offer glaucoma surgery include; late presentation, lack of patient satisfaction, complications of surgery, and negative publicity.

CONCLUSION
Even though the challenges in the management of glaucoma indeveloping countries are many, they are not insurmountable. There is need for concerted and integrated efforts involving all cadres of eye care practitioners, patients, institutions and governments to address this important eye disease. Improved awareness, provision of adequate equipment, availability and affordability of medications, need for training and retraining of eye care providers are all important measures that can lead to better management of the glaucoma patient.

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INTRODUCTION

Glaucoma is a chronic disease characterised by optic neuropathyand visual field defects. It causes gradual, usually painless and initially asymptomatic loss of vision. Glaucoma remains the second commonest cause of blindness and the foremost cause of irreversible blindness worldwide and in Africa. It is responsible for 12.3% of global blindness, this represents about 4.5 million people. Prevalence of glaucoma related blindness was found to be 0.7% in Nigeria, and the second commonest cause of blindness (16.7%) after cataract, in individuals 40 years and above.

The management of glaucoma is aimed at preserving the patient's visual function and quality of life, and this can be achieved through medical, surgicalor laser therapy, all primarily aimed at reducing the intraocular pressure (IOP). These modalities of management are not without challenges, which can be provider or

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patients related. These are especially so, in resource limited economies, where the management of glaucoma can be a very difficult task. Challenges to medical management include availability, affordability, and compliance among others; while surgical treatment is faced with issues such as low glaucoma surgical output, low uptake of surgery by patients, initial high cost, and complications of surgery. Laser treatments are also not generally available or affordable to most patients in poor communities.

This study looks at a relatively less studied aspect of glaucoma management, that involving providers' perspectives using qualitative methods. It is aimed at describing the challenges in the management of glaucoma among eye care surgeons in Lagos state, Nigeria.

METHODS

This study was conducted among ophthalmologists and resident doctors in Lagos State, Nigeria, within selected centres offering comprehensive eye care services. Lagos state is located in the south western part of Nigeria on the narrow coastal flood plain of Bight of Benin, and has a population of 17 million out of a national estimate of 160 million. In the built-up areas of metropolitan Lagos, the average density is over 20,000 persons per sq.km. It is ranked as the fourth in terms of population density worldwide. Regarding eye care, there are two tertiary (government owned) institutions and nine secondary (general) hospitals with medical and surgical eye care.

In-depth interviews were conducted by the principal investigator with selected information rich ophthalmologists and resident doctors in ophthalmology at centres offering medical and surgical glaucoma services in the state. This was done using semi-structured, open ended questions to explore the providers' perspective on glaucoma burden, challenges in the management, surgery for glaucoma, acceptance of glaucoma surgery by patients, and recommendations for improving glaucoma services. The discussions were recorded with the aid of a micro-cassette recorder, after permission from participants. The following steps were taken in data collection and analysis.

1. Data from the micro cassette voice recorder was transcribed manually and paged.
2. Familiarisation and reflection to identify key ideas in the data.
3. Main themes and sub-themes were identified from the data in conjunction with the research questions.
4. Coding was done; derived from cadre, gender, interview number, and page of the transcript. For example CO/M/O7/25 represents; consultant ophthalmologist, male, interview 7, on transcript page 25.
5. Quotes that reflect the themes and sub-themes were identified.
6. Interpretation of the findings was done.
7. Write up.

Ethical clearance was obtained from the ethics committee of the London School of Hygiene and Tropical Medicine (LSHTM) and Lagos State University Teaching Hospital(LASUTH). Approvals were also obtained from the Lagos State Health service Commission. All participants consented to the study.

Results

In-depth interviews were conducted with a total of 11 ophthalmologists and resident doctors in training. The summary of cadre and gender is shown in Table 1.

Table 1. Characteristics of selected ophthalmologists and resident doctors

Cadre	Male	Female	Total
Ophthalmologist	2	5	7
Ophthalmologist in training	4	0	4
Total	**6**	**5**	**11**

The themes and sub-themes identified were;

1. The glaucoma "burden"
2. Challenges in management

a. Patient related
   - i. Late presentation
   - ii. Lack of awareness of the populace
   - iii. Delay in referral
   - iv. Poor compliance with medical treatment

b. Equipment related

c. Treatment related

i. Medical treatment
   1. Cost of drugs
   2. Availability of drugs
   3. Compliance with drops

ii. Surgical treatment
   1. Views on surgery as a first line of management.
   2. Adequacy of current number of glaucoma surgeries
   3. Patients' acceptance of surgery
   4. Surgeons' offer of surgery

The glaucoma "burden"

This relates to the proportion of glaucoma visits among patients usually seen in the outpatient department

(OPD). Majority of the participants stated that glaucoma is quite an important problem, and that glaucoma patients constitute a significant percentage of the total patients that visit the OPD. Estimated proportions range from 20 –50%. Below are some of the quotes that reflect this idea.

"Well, glaucoma is, ... of all the patients that we see in this centre, maybe about 30 percent (%), 20 – 30percent are glaucoma patients." (CO / F / 07 / 26)

"Well, as regards the volume of work, volume of patients that I see, I'll say glaucoma accounts for like 50% of the patients that I see." (CO / M / 08 / 34)

"I think up to, ...between 30 and 40% of the patients that come here are glaucoma patients."(SR / M / 11 / 47)

Challenges in management

Patient related – These include the following

1. Late presentation – This was seen as a major challenge in the management of glaucoma. Majority of the participants said a lot of their patients present late, when most of the visual function is already severely affected, and this frequently causes a management dilemma.

"Many of our patients don't come to clinic on time, so we find that we are getting mostly moderate to severe glaucoma when they come for the first time. So, that is a big challenge in the management of glaucoma."(CO / F / 01 / 01)

"And patients...., most of the time by the time they get to us they are almost blind."(CO / M / 09 / 34)

2. Lack of awareness of the condition in the populace – There is generally poor awareness of the condition called glaucoma in the community. Educating the patients about their diagnosis is also a challenge, as some of them are not able to understand the chronic and lifelong nature of the disease. This is evidenced by the following quotes.

"The challenge starts from actually convincing the patient about the condition glaucoma itself. It's more or less like a mystery. No appropriate local word to really drive home the point. Sometimes you want to tell them; maybe I can speak a little bit of Yoruba that we say..... That er...., "ki ni yen, aisan yen, ishan to connecti....., to gbe information lati oju lo si opolo, lo ma a affect" (Translation - "That thing, that disease, the nerve connecting....., that carries information from the eye to the brain, that is what its affects."). Sometimes they don't really understand."(SR / M / 10 / 40)

"Some of them don't understand the disease, and they think that er..... perhaps glaucoma is malaria, when you use drugs, it is once and for all."(CO / M / 09 / 34)

3. Delay in referral – The late presentation of some patients was linked to delay in referring these patient to the ophthalmologist for detailed examination. This was attributed to other professionals in the field of ophthalmology, especially the optometrists. Participants stated that these cadre of workers just give glasses, when most of these patients presents with presbyopic symptoms, whereas this may be the only opportunity to screening these patients for glaucoma.

"And also, majority of our patients are being managed by optometrists, unfortunately they sit down on them."(CO / M / 09 / 35)

"Those patients don't come early, they've been seeing optometrists in town, they come very late, CD ratio 0.8, 0.9"(CO / M / 08 / 32)

4. Poor compliance with medical treatment – compliance of patients with medical treatment was observed by participants to be poor.

"Compliance is poor. They only remember to use it when they know they have appointment. They don't usually...., very few of them use it, and by the time they start being compliant it's almost too late."(CO / M / 09 / 35)

"..... you find out that most patients remember to start using their drug when their clinic visit is approaching, and by the time they come, you measure the IOP, it's normal, but they still end up going blind."(SR / M / 11 / 47)

Equipment related– Even though more equipment are available in some institutions compared to others, there is still a general inadequacy in the availability of equipment for the diagnosis and management of glaucoma. Also, the lack of maintenance and frequent break down means that even available equipment may not be functioning when they are needed.

"Pachymeter is not readily available, And ..... perimetry, our FDT, frequency doubling, it has broken down now, for 2 months, we have not been able to fix it."(CO / M / 09 / 34)

"The facilities are not adequate. For example, to check pressure in our clinic we have only one Perkins, so that means we have to shuttle from one room to the other on

a clinic day, you know, to check the pressure for these patients."(CO/F/05/18)

Treatment related

A. Medical treatment – issues that came up in the medical management of glaucoma include the following factors, which have great impact on the compliance of patients.

1. Cost – Drugs are expensive for the average patients to buy because of the high level of poverty.
2. Availability – There are sometimes prolonged periods of scarcity of some drugs.
3. Fake drugs – Due to poor regulations in the country, fake drugs are still common.

"In this environment because of so many factors, drugs are not always readily available, not always authentic, and not cheap. So a lot of patients, if they buy one vial, they may not buy another one, or they will reduce the frequency, you know, they will cut corners, because they can't afford it."(CO/F/06/22)

"And there are occasions like that, when we don't have xalatan, there will be scarcity of xalatan, and the price will go up."(CO/M/09/37)

B. Surgical treatment.-

1. Views on surgery for African patients. – Majority of the participants agreed that surgery should be offered to the patients as soon as the diagnosis of glaucoma is made. However, continuous monitoring of the patient on medical treatment is another line of option for them in early cases, if they are convinced the patients will be compliant.

".....If we see our patients today, we may not see them until 6 months later, and so at first visit, my own practise is to impress it on them that you are going to have surgery."(CO/M/09/37)

"I base my judgment on; one, the stage of the disease, and the particular patient am dealing with. You know, if it's early glaucoma, I probably won't offer surgery if the patient is somebody whom I know can afford the medical therapy, and patient is not somebody I can lose to follow up. I'll just give medical therapy. If the patient is early to moderate stage, and I discover that this is a patient who cannot afford the drugs, of course surgery will be my next option."(CO/F/07/28)

2. Adequacy of current number of glaucoma surgeries – Opinions differ on this subject. Some ophthalmologists believe they are performing quite a lot of glaucoma surgeries in their institution, considering the number of available and willing patients, while some believe the performance of their institution is low.

"Ah....., no, no, no, no, we are not doing enough....., we are really not doing any glaucoma surgery."(SR/M/02/06)

"Trabeculectomy. And that put the residents here at a disadvantage because we don't see more of it, and we are looking forward to seeing more of it."(SR/M/04/15)

"In my unit, I do a lot of glaucoma surgery."(CO/F/06/24)

"In our unit, in this centre, we do a lot of glaucoma surgery."(CO/M/09/38)

3. Patients' acceptance of surgery – A reduction in patients' acceptance of surgery was noted among majority of the participants. Factors that were identified include;
    a. Fear of surgery – There is fear of surgery in general among patients, especially eye surgery. They harbour the fear of going blind after surgery is done.

"Most patients get scared once surgery is mentioned, and because of that they may not even honour their follow up."(SR/M/04/14)

"Some people have a fear and phobia for surgery, you know, which I can understand, because operation of the eye for them is like a major, major thing."(CO/F/06/23)

    b. Negative publicity – Glaucoma surgery is associated with bad publicity and image. Patients have friends and relations that tell them of bad experiences with glaucoma surgery, especially loss of vision.

"…many of them have friends and family members who had advanced or very advanced glaucoma who were operated on and at the end of the day, they were blind. So as a result of this the uptake of surgery is very low."(CO/F/07/26)

    c. No improvement in vision

"Well, from my experience, the major reason is that once you tell the glaucoma patients that; sorry, this surgery is to prolong your vision, it's not going to improve your vision, which we have to emphatically tell them. When you tell them that, they tend not to want to go in for surgery anymore."(CO/F/03/12)

"I mean, telling your patient that is seeing 6/9 that; am going to take you to surgery, after surgery your vision will not improve, it might even drop slightly after surgery, and probably go back to what it was before surgery, and the surgery is for you not to use your drug, but at the same time I can't give you 100% guarantee that you will not use your drug."(SR/M/10/44)

4. Surgeons' reluctance to offer of surgery – Various reasons put forward for reluctance on the part of the ophthalmologist to offer surgery include
    a. Complications of glaucoma surgery – Complications of glaucoma surgery is one of the factors pushing surgeons away from it. It is believed that they are common, persistent, may result to patients needing another surgery, and most especially may precipitate visual loos for the patient.

"….when the complications come up, the patient will keep coming back to you, and most surgeons do not really think it's the best, they don't like it. So, they are no longer eager to offer surgery as a line of treatment for patients with glaucoma."(SR/M/11/49)
"I've met some colleagues who are somewhat afraid of the surgery itself."(CO/M/08/33)

    b. Negative publicity – Participant stated that the bad publicity resulting from poor results due to a glaucoma surgery is a restraint, in the willingness to go all out and offer surgery.

"When any bad thing happens, the patient does not die, just go blind. And then it's your name, that so, so and so did surgery for me and I went blind, which has a negative publicity."(SR/M/11/49)

    c. Late presentation – Because majority of the patients present late, when the glaucoma is very advanced, and a lot of the visual functions is already lost, surgeons are not so eager to perform surgery at this time, because of the possibility of "wipe out syndrome."

"In advanced cases, the surgeon may be afraid that the vision may wipe off completely. And the patient will say that; I was seeing before, and after you did surgery, you made me blind."(SR/M/11/49)

"...patient has been running away, and then it's when the disease is severe, when the disease has progressed to a severe stage, that is when the patient wants surgery. At the end of the day, that patient will end up scandalising you, so you'll rather want to leave the patient alone, and let the patient continue on drops, because the patient did not follow your advice ab-initio."(CO/M/09/36)

    d. Lack of satisfaction – Also, because there is no improvement in the patients' vision, glaucoma surgery is somewhat unrewarding to patients and ophthalmologist alike.

"Glaucoma surgery is a thankless surgery, because there is no obvious improvement in the patients' vision, and patients usually try to relate to what they can feel, that my vision has improved."(SR/M/11/49)
"…glaucoma patients never feel satisfied, they tell you; doctor, my vision has still not improved. Nobody wants to hear that always."(CO/F/03/12)

DISCUSSION

The goal of glaucoma management is to stabilise the patient's visual function and improve the quality of life. Early detection and effective treatment are necessary to prevent loss of vision. It is a lifelong journey and may initially be daunting. Management of glaucoma is associated with a number of peculiar challenges, with far reaching consequences which may determine the eventual visual outcome.

Without any doubt, glaucoma constitutes a significant public health issue, being the second largest cause of blindness after cataract worldwide, and the foremost cause of irreversible blindness.Glaucoma has been estimated to affect about 60.5 million people worldwide, and this has been predicted to increase to nearly 80 million by 2010, POAG is, and will be responsible for more than half of this figure.Prevalence of glaucoma related blindness was found to be 0.7% in Nigeria, and the second commonest cause of blindness (16.7%) after cataract, in individuals 40 years and above. It was also found to represent about one quarter of the overall outpatient department consultations in an hospital based study in Urban Nigeria.This glaucoma burden is reflected in the perception of participants in this study who also agreed that glaucoma patients constitute a significant percentage of all patients seen, with estimates put at 20 – 50%.

Patients' related challenges identified by providers in this study include; lack of awareness of glaucoma in the general population, late presentation, delay in referral from optometrists, and poor compliance with medical treatment given. Glaucoma still remains a mystery, and the concept that it causes irreversible loos of vision is often difficult to comprehend by most patents. Awareness in the general population is low, and there is no local dialect word to define glaucoma. In a hospital based study among newly diagnosed

glaucoma patients, about half of them had never heard of the term glaucoma before. Participants describe the difficulty of even counseling the patients about the exact nature of their eye disease, and recommended that there should be a local word that adequately sums up what glaucoma is. The term 'adakefoju' meaning 'the silent blinder' has been suggested and is currently adopted by the Glaucoma society as the Yoruba term for glaucoma. Increased awareness in the population might also translate into earlier presentation.

Delay in referring patients to ophthalmologist on the part of other eye care workers such as optometrists was also identified as one of the factors contributing to late presentation by patients. It is believed that the need for glasses when presbyopia sets in at about 40 years of age is a good opportunity for screening patients for glaucoma, since population based screenings are generally not practicable.Population based studies have shown that a great number of glaucoma patients remain undiagnosed, and late presentation is often prevalent in most developing countries.Patients may present to optometrist because they are more in number and ophthalmologists may be more difficult to see, due to shortages and mal-distribution.There is paucity of data on the ophthalmic practises (apart from refraction) of optometrists in Nigeria, where majority of the practises are unregulated. However, since they represent vital integrated eye care workers, there is a need to work closely together to fight the blinding scourge of glaucoma.

A key element in the VISION 2020; the right to sightprogramme is infrastructural development, and provision of adequate equipment is one of its components. Health care workers (including eye workers) need equipment to be able to deliver effective services. Lack of basic equipment for managing and monitoring glaucoma patients such tonometers, was identified by participants as another major challenge. Similarly, Nigerian studies,have shown that quite a number of equipment needed for the management of glaucoma were either not available, inadequate or not functioning. Availability of appropriate infrastructure and technology has been conservatively estimated at around 50% in many developing countries.There is therefore an urgent need to make availability of equipment for glaucoma care a priority for governments and hospital administrators in Nigeria.

A major challenge in glaucoma care is treatment related; whether medical or surgical, which are primarily targeted at reducing the intraocular pressure (IOP), and maintaining the visual function. Medical treatment is usually the first line of management (even in patients who would eventually have surgery), but challenges in a developing country setting identified by participants in this study include availability, cost, and counterfeit drugs. Middle and low income earners spend a significant proportion of their income on medical therapy.Other problems not peculiar to a developing country setting such as; side effects, multiplicity of drug administration and so on, are also important. All these may lead to poor compliance with adverse effect on IOP control, and consequently the visual function. Investigating compliance directly with patients with a view to determine and solve specific issues affecting compliance might have a positive effect.

Due to the problems associated with medical therapy in a developing economy setting, surgery has been advocated as a first line of management for African patients. Trabeculectomy (with adjuvants) is the most frequently performed glaucoma surgery in Africa, Nigeria and perhaps in the world. However, there is some evidence to suggest that ophthalmologists in Africa may not be performing enough glaucoma surgeries, despite the recommendation of surgery as the first line of treatment. But, this may not be a uniform phenomenon in all African countries or even within countries. This is supported by the divergent opinions of participants in this study; while some agreed that surgery should be offered as early as possible, others consider factors such as severity of the glaucoma and the perceived capacity of the patient to be compliant with medical therapy. Also, some responded that they were quite satisfied with the number of glaucoma surgeries being performed, while others were of the opposite view.

Various reasons may be attributed to this low “glaucoma surgical output.” Surgeon factors include; inadequate number of ophthalmologists, not offering surgery to patients who have the potential to benefit, lack of adequate skill, the challenges of post-operative care, and so on. Patient factors include; fear of surgery, no restoration of vision, possibility of losing remaining vision if surgery fails or is complicated, possible need for repeat surgeries, and initial high cost of the operation. These are some of the factors that reduce patients' acceptance of glaucoma surgery.Surgery acceptance varies across Africa and Nigeria;Quigley et alfound an acceptance rate of 46% in Eastern Africa,68.8% in Southwest, Nigeria,8.2% by Adegbehingbe in another South-western Nigerian study, 32.5% by Omoti et al in Eastern Nigeria, 46.8% by Onyekwe et alalso in Eastern Nigeria, and 48% by Mafwiri et al in Tanzania. There is no doubt that developments of adequate glaucoma surgical skills leading to better outcomes, patient education, development of a standardised protocol for the management of glaucoma in Africans, would lead to

improved acceptance of surgery by patients, and surgical output will also increase. This will in turn boost skill acquisition of ophthalmologists, and the training of resident doctors.

In conclusion, glaucoma represents a major public health burden and even though the challenges of management in developing countries are many, they are not insurmountable. There is need for concerted and integrated efforts involving all cadres of eye care practitioners, patients, institutions and governments to address this important eye disease.

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