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RESEARCH ARTICLE

Challenges Contributing to Loss to Follow-up as Experienced by Glaucoma Patients in the Vhembe District of Limpopo Province, South Africa

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Abstract:

Background:

Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively, could lead to blindness of many people worldwide. Non-adherence to medical treatments typically lead to burdensome consequences such as progressive visual loss and disabilities. Fortunately, literature reveals that with timed appropriate treatment, such blindness can be prevented. Thus, patients' adherence to follow-up plays an important role in maintaining vision. However, glaucoma patients in Vhembe District still miss their follow-up appointments.

Objective:

This study sought to explore factors contributing to loss to follow-up as experienced by glaucoma patients in South Africa.

Methods:

Qualitative, explorative, and descriptive research designs, using qualitative methodology, were adopted. The population consisted of glaucoma patients who had been on antiglaucoma medications for three years and above. The purposive sampling method was used to select 18 participants for the study. Data were collected using a semi-structured interview using an interview guide. Participants were between the ages of 24 and 80 years. Tesch's eight steps of qualitative data analysis were used. Measures to ensure trustworthiness and ethical issues were observed.

Results:

The study findings revealed that some of the patients did not understand glaucoma disease and the importance of follow-up. Financial constraints, traditional/religious belief, shortage of medications, and negative staff attitude were the most cited barriers contributing to loss to follow-up.

Conclusion:

Follow up adherence amongst glaucoma patients was negatively influenced by low disease knowledge. Therefore an improvement in patient education, transportation services, and clinic efficiency may strengthen follow-up visits.

Keywords: Adherence, Appointment follow-up, Glaucoma follow-up, Glaucoma patients, Financial constraints, Shortage of medications.

Article History

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1. INTRODUCTION

Glaucoma is a serious and irreversibly blinding condition of public health importance in Africa. The absence of discrete early symptoms makes the condition hard to recognize by patients. Glaucoma is often referred to as the "silent thief of sight" [1]. The current goals of glaucoma management are to avoid glaucomatous and nerve damage, preserve the visual

field, and total quality of life for patients with minimal side effects. The treatment of glaucoma is aimed at the reduction of the intraocular pressure by daily life-long eye drops (medication). Thus, follow-up examinations and judicious selection of treatment is required [2, 3]. People with glaucoma disease often present late for treatment, thus leading to ophthalmologist facing many challenges when managing the disease [4]. Non-adherence to glaucoma treatment resulting in loss to follow-up (LTFU) has been reported in several studies as a global problem [5 - 7]. Medications non-adherence is a serious challenge and is responsible for many patients losing

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vision from glaucoma. Studies conducted in Iran, Ghana, and China indicated that approximately 50% of glaucoma patients fail to adhere to their medications as prescribed or adherence to follow-up visits [8 - 11].

Poor glaucoma adherence has worse outcomes leading to increased healthcare cost and as a result, more follow-up visits, additional medications, more diagnostic tests and also the need for surgery [5, 12]. Patients at high risk for such worsening outcomes are those who believe that they do not need regular follow-up because they take their medications as prescribed and assume they are safe from glaucoma complications. Moreover, most Sub-Saharan African health care facilities (including South Africa) are mostly located far from patients' home. This makes it difficult for patients with limited financial resources to reach the eye clinics/hospitals. Some patients travel long distance to access the clinics/hospitals for their glaucoma medication [1, 13]. Distance to the eye clinics, inadequate public transportation, poor road networks and mountainous areas were cited as the other reasons preventing glaucoma patients from accessing hospitals [14, 2].

The South African Glaucoma Guidelines, which are in line with those of the International Glaucoma Society, recommend that patients with controlled glaucoma should be seen three times per year, while those with uncontrolled and complicated glaucoma should be seen up to six times a year [15 - 17]. Although there are large secondary care facilities in the Vhembe District, only one hospital has an ophthalmologist who can diagnose and treat glaucoma patients. All other primary and secondary health facilities in the district refer all glaucoma cases to one hospital [18]. This explains the challenges patients have in adhering to follow-up protocols. Although poor medication adherence is a major problem in glaucoma management worldwide, particularly in Sub-Saharan Africa, little is known about loss to follow-up (LTFU) among African glaucoma patients [11]. It is against this background that this study explored factors contributing to LTFU as experienced by glaucoma patients in the Vhembe District of Limpopo Province, South Africa.

2. METHODS

A qualitative, explorative, descriptive research design was used to explore the views of LTFU glaucoma patients at the selected health care facilities in the Vhembe District.

2.1. Study Setting

The study was conducted in selected hospitals of Vhembe District, a largely rural district municipality within the Limpopo Province of South Africa. Limpopo is one of the nine provinces of South Africa located in the northern most part of the country. The province shares borders with Zimbabwe on the northern side, Botswana on the west, and Mozambique in the east.

2.2. Study Population and Sampling

The population of the study were all glaucoma patients who had been under glaucoma care in Vhembe District hospitals of Limpopo Province. The target population consisted of LTFU glaucoma patients who were between the ages of

24-80years, who had been using anti-glaucomatous treatment (AGT) for more than three years. The inclusion criterion was that participants should have had sufficient experiences of living with glaucoma. The four hospitals were purposefully selected because their follow-up registers showed a high number of glaucoma LTFU. The researchers had a target of 24 participants, with six participants from each hospital. Despite reaching the saturation point at participant no 8, the researchers continued to conduct interviews until participants number 18. This helped researchers obtain detailed patients' experiences regarding glaucoma eye care services in different hospital settings.

2.3. Data Collection

Data was collected through a semi-structured interview using an interview guide from 18 glaucoma patients who met the inclusion criteria. The participants were interviewed in their language of choice (Tshivenda or Xitsonga) in line with the tradition of Phenomenology [19]. A central question was asked to all participants, "**What challenges led to your LTFU in accessing glaucoma follow up care?**" However, other questions were asked and probes were used to verify or clarify the responses. The interview schedule was semi-structured and allowed the LTFU glaucoma patients to speak freely about the challenges that made them drop out of care. The interviews were conducted in private rooms, and lasted for 30-45 minutes. Field notes were taken and a voice recorder was used to record all the interview sessions. Verbal informed consent was obtained from all participants before starting with the interview. This was done because most participants had a poor vision, which limited their ability to read.

2.4. Data Analysis

Data were analyzed using the eight steps of Tesch's open coding method for qualitative research as outlined in Creswell [20]. The researchers got a sense of the whole by reading all the verbatim transcriptions and similar topics that emerged were grouped together and clustered separately. The researchers summarized the topics that emerged as codes. These codes were written next to the appropriate segments of the transcription. The researchers developed themes and sub-themes from the coded data and the related texts and shortened the total list by grouping topics that relate to one another to generate a sense of the final themes and sub-themes.

2.5. Data Quality

The researchers adopted the contracts of Lincoln and Guba to ensure trustworthiness. Credibility was established through audiotapes verified to confirm accurate transcription and field notes made during the interviews. Credibility was also promoted through direct quotes from the participants. Transferability was verified using adequate descriptive comments so that readers could assess the applicability of the findings in other settings. Confirmability was dealt with by contacting two participants to represent other patients in confirming whether themes accurately captured what participants' had said. Dependability was achieved by asking two independent researchers to review the transcripts and develop themes. The themes were compared and differences

Table 1. Themes and sub-themes reflecting the challenges experienced by LTFU glaucoma patients during follow-up visits at the hospitals/clinics and suggestions made by the patients themselves.

Main-theme	Sub-themes
1. Challenges experienced by glaucoma patients during glaucoma follow-up visits.	1.1.Lack of understanding the need for chronic therapy 1.2.Financial constraints 1.3. Patients' beliefs 1.4. Existing negative attitude of health care providers leading to LTFU. 1.5 Difficulty getting time off to attend appointments/shortage of medications.
2.Suggestions made by glaucoma patients for overcoming barriers contributing to LTFU.	2.1 A need for more education and counseling on glaucoma disease and the importance of follow-up. 2.2.Glaucoma eye care services to be provided in Primary Health Care facilities. 2.3.Create transportation services, such as mobile clinics.

were discussed until a consensus was reached [21].

2.6. Ethical Consideration

Permission was obtained from the Limpopo Provincial Health Department and the hospital CEOs before conducting the study. Participants were given sufficient information regarding the purpose of the study. Participants were not coerced into participating but were encouraged. Participants' rights to privacy and confidentiality were observed throughout the study. Ethical clearance SHS/18/PH/35/0111 was obtained from the University of Venda Research Ethics Committee. Informed verbal consent was also obtained from each interviewed participant. Participants were informed that participation was voluntary and that they could freely withdraw at any time and that no rewards were to be given. Codes instead of names were used to ensure anonymity.

3. RESULTS

3.1. Demographic Profile of LTFU Glaucoma Patients

All participants' age ranged from 24 years and above, with the oldest being 80 years old. The patients were mainly female with only eight males. Most participants did not have a formal education. The highest qualification held by two patients was a grade 12 certificate. Concerning employment, only five participants were employed. Most participants stayed more than 15km from the hospitals where glaucoma eye care services are provided.

The findings reflected aspects that could be addressed in order to improve glaucoma follow-up care in different health facilities. The themes and sub-themes are presented below (Table 1).

Theme 3.2: Patients' challenges experienced during glaucoma follow-up visits in the hospital/clinics.

3.1.1. Lack of Understanding the Need for Chronic Therapy

It was revealed during the interview sessions that some patients did not understand glaucoma disease and the importance of follow-up. Patients mentioned that there is no need to continue coming for follow-up because they felt no pain in their eyes. This sentiment was expressed by three participants, as shown in the following extracts:

Participant 7: "I don't feel any pain in my eyes and my vision looks fine. I have been using this treatment for many

years".

Participant 11: "Look at me, my eyes look perfectly well, I don't need any eyedrops".

Participant 13: "Eyedrops did not restore my vision while I was still working. I have lost my job because I can no longer see, I don't need this medication anymore".

3.1.2. Financial Constraints

Lack of money to travel to the hospital was frequently reported as a barrier for LTFU in this study. Most participants said they were unable to attend their regular clinic visits due to a lack of transport money. Most participants stated that they could not travel on their own and, therefore, needed additional transport money for the escort. These views are captured in the following quotes:

Participant 2: "I stay far away from the hospital and I cannot afford to travel to the hospital, that is the main reason I stopped going for my check-up".

Participant 3: "The situation is hard, getting money is a problem, do you think one can stay with that money up to this date? If I had the money, I would have come for my check-up".

Participant 6: "I cannot travel alone, I cannot see. I ask my grandson to accompany me every visit, where I come from is very far, I must hire a car for me and him. For the two of us, I pay R360 for the transport alone. It is too much".

3.1.3. Traditional /Religious Belief

Some participants frequently mentioned traditional eye medicine(TEM) and the use of holy water as barriers for their LTFU. They believed that glaucoma disease is caused by evil spirits or witchcraft. This was confirmed by three participants as follows:

Participant 4: "I am using traditional medications to remove the evil spirit in my eyes; it will cleanse my eyes, then I will be able to see clearly again".

Participant 7: "I stopped going for my follow-up and use holy water after my pastor prayed and told me to stop using glaucoma medications for a while".

Participant 13: "My uncle took me to the traditional healer who is our family member and told me that he can cure my glaucoma completely, provided I stick to his concoctions (mixture of different herbs) because somebody have put some

spells in my eyes so that I cannot work for my family”.

3.1.4. Existing Negative Attitude of Health Care Providers Leading to LTFU

Patients mentioned that they stopped going for their follow-up appointment because of the rude behavior from some of the hospital staff. Patients complained that some hospital staff is not welcoming and treat them as small children during their hospital visits. This was mentioned by three participants, as reflected in the quotation below:

Participant 9: *“Nurses speak to us in a very disrespectful manner, i am not a child, I will rather not visit this hospital again than be treated like a nobody”.*

Participant 3: *“There is that male clerk in the admission office who is rude to most of us, he does not treat me well every time I visit this hospital, particularly if I missed the appointments dates, so I decided to stay at home to avoid him”.*

Participant 16: *“The doctors who work here in this clinic do not really care about us. You find them coming very late after waiting for so long. That female doctor hardly greets us”.*

3.1.5. Difficulty Getting Time off to Attend Appointment/Shortage of Medications

It was revealed during the interviews that glaucoma services are not available in most primary health care facilities in the study area. Glaucoma eye care services are provided in most hospitals that are situated more than 15km away from participants’ homes. Patients further indicated that they stopped going for their follow-up visits because their bosses do not give them time off to collect their glaucoma treatment. Unfortunately, hospital clinics do not operate on weekends and public holidays. Patients also added that they are not given adequate eye drops to last them for 2 to 3 months.

This is supported by the words of two participants below:

Participant 5: *“My eyedrops got finished, then I stopped using it because the staff only provided me with one month eyedrops, they should at least give me for two months, and I cannot come here every time because of the distance, it is winter now, my joints are painful because I have joints pain and I cannot stand for a long time”.*

Participant 14: *“I wait for my son who works in town to drive me. He only gets time off very late when the clinics are closed. It is a problem when I ran out of my eyedrops. Really, I do not know what to do”.*

Participant 15: *“I work on weekdays only and don’t have time to come to the clinic for my medications, I am afraid to ask permission because I am still new in this firm”.*

3.2. Theme: Suggestion Made by Glaucoma Patients Geared Towards Improving Loss to Follow-up and the Strategies that would Assist them to Remain in Care

In order to overcome the challenges experienced by the glaucoma patients, there are several suggestions that they themselves made towards getting rid of some of the negative things they experience. These emerged in the sub-themes below.

3.2.1. Health Education

Patients stated their views on methods that could assist them to attend regular glaucoma follow-up and to remain in care. The outlined methods included health education and incorporating glaucoma eye services into primary health care (that is including mobile clinics). Glaucoma patients felt that they were not well informed about the importance of attending glaucoma eye services and how it operates. They also supposed that health education would enrich them with the knowledge they need to encourage them to re-engage and remain in care. They mentioned that if they were well informed on the advantages of glaucoma adherence and the risks of dropping out of care, they would definitely remain in care.

This was confirmed by the following excerpt:

Participant 1: *“It will be helpful if nurses teach us about glaucoma disease, this will help us and our families to understand the importance of follow-up and medication adherence”.*

Participant 11: *Another patient added: “I think there should be more education in the community to increase glaucoma awareness”.*

3.2.2. A Need for Providing Glaucoma Eye Care Service in the Primary Health Care Setting (Including Mobile Clinic)

Patients emphasized that they would appreciate it if glaucoma eye service could be provided in clinics like other services, such as diabetes and hypertension. This was pointed by one patient who said: *“We need to get our glaucoma medications whilst coming for my diabetes check-up at the same clinic. I should avoid these clinic/hospital visits that are too many”.*

Another patient said: *“I think that collecting glaucoma treatment will save us from transport money and assist in adherence”.*

3.2.3. Providing Medication that will Last for Longer Periods

In all interview sessions conducted, it was clear that patients were not happy about the number of AGT given since they have difficulties taking time off from work, lack of escort, long-distance, transport problems, and clinics that operate during weekdays only. They indicated that it would be helpful if they could be provided with AGT that would last for 2-3 months. This is confirmed by the following excerpts:

This was pointed out by a participant who said: *“I suggest that the doctor should give me enough medications to last for a few months to minimize clinic visits because I can’t visit the clinic alone, I need someone to help me”.*

Another participant said: *“This place is too far, and transport coming to this place is very scarce, I think giving treatment that could last for months will be much better”.*

4. DISCUSSION

Our study findings reveal that in predominantly rural populations, challenges to follow-up are still reported among patients with chronic diseases such as glaucoma. The study findings add to studies that have been conducted in South

Africa about glaucoma. Notably, no known study has explored the barriers faced by glaucoma patients during their follow-up clinic visit. The current study revealed several findings that are similar to other study findings conducted around the globe (Thompson, Thompson, Young *et al.* [22] Lee *et al.* [23]. The loss to follow-up was influenced by various factors described by the patients themselves that hinder them from remaining in care. Patients felt that some of the barriers are beyond their control. The reasons outlined included lack of glaucoma awareness or understanding of the disease, unsatisfactory staff attitude, traditional/religious beliefs, financial constraints, difficulty getting time off from work to attend appointments, and shortage of medications. Although patients face many barriers that challenge their remaining in care, they nonetheless suggested strategies that might assist them in re-engaging and remaining in care.

The study found a lack of understanding that glaucoma needed frequent follow-ups like any other disease, such as hypertension and diabetes. Therefore, most glaucoma patients were not aware that they should go for their regular follow-ups. Patients stopped using eye drops and follow-up appointment, assuming that their eyes no longer needed medication because they were not experiencing any pain. This was attributed to the fact that glaucoma is asymptomatic (Zhao *et al.* [24]. Furthermore, other glaucoma patients were not aware that glaucoma medication is for life, and such patients can live a quality life with good vision if they adhere to their medications like everyone else. Our study findings concur with those by Dagtekin *et al.* [25], who reported that glaucoma patients were not aware that they needed regular eye examinations. However, Thompson *et al.* [22], reported that there are patients who believed in eyedrops adherence and follow-up clinic appointments even if there is no vision improvement.

The attitude of health care workers has a lot of influence when it comes to attending follow-up among glaucoma patients in most countries. The study established that some patients become lost to follow up due to the negative attitude of healthcare workers. Patients highlighted that health care workers are impolite and disrespectful towards them during their regular visits. Therefore, to avoid such hostility, patients decided to stay at home and stopped going for their follow-up as scheduled. This finding is similar to Bassett, *et al.* [26], who reported that in South Africa, the second most highly perceived barrier was poor service delivery in most health facilities. Also, our study concurs with the findings by Abdul [14] and Wasti [27], who discovered that health system factors, including the relationship with service providers, make it difficult to seek regular follow-ups. Patients in the current study complained about the poor doctor-patient relationship. They further explained that poor communication between them and health providers makes it difficult for them to ask for clarity regarding their eye condition. Similar results were reported by Hann [28] and Morse [29], who showed that good patient-physician communication is an essential element in engaging patients with their care. Consistent study findings disclosed that most patients reported that other clinic nurses were rude and disrespectful, and this discouraged them from going back to the clinic [30]. Parallel results were also confirmed by several authors who agree that good patient provider-relationship is an important motivating factor for follow-up care [31 - 34].

Fewer patients in the study become LTFU because they resort in using traditional eye medications (TEM). They believed that they would be cured by the use of TEM. These patients assumed that glaucoma is caused by witchcraft or evil spirits. Thus, the reasons why they consulted traditional healers and religious prophets for prayers and cleansing. Participants thought the use of TEM or holy water would permanently cure

them of glaucoma. Due to these strong religious and traditional beliefs, such patients drop out of care to seek healing from traditional and faith healers. Some participants indicated that they resort to TEM because of the unavailability of glaucoma medications in the local clinics. These findings are in line with the Ugandan and Nigerian studies, which found that patients had poor access to eye care and their beliefs in divine healing contributed to trusting in TEM and the use of holy water [29, 35, 36].

Lack of finances for transportation was the most mentioned barrier contributing to LTFU in our study. Patients mentioned that they did not have transport money as well as administrative costs that must be paid at the hospital. This is especially the case for patients who are not getting any social grants. Long distance to the health facility also increases the high cost of transport fare. Several authors agree that patients and their escorts become non-adherent because of financial difficulties [37 - 40]. The findings of our study concur with those by Thompson *et al.* [41], who stated that transport and follow-up costs continued to be the contributing factors to LTFU. However, in Philadelphia, Altangerel *et al.* [42] indicated that the rate of glaucoma LTFU remained poor, irrespective of an attempt by the government to reduce transport costs. Parallel results were obtained by Munro *et al.* [43], who revealed that some HIV and TB patients become LTFU regardless of having transport money.

Some patients in the current study indicated that they unwillingly dropped out of care due to difficulties in getting time off from work. By the time they knock off, the clinics are already closed. Furthermore, patients revealed that glaucoma clinics in the study area do not operate over the weekends or public holidays. Also, patients complained that the health care staff refused to give them eye drops that can last longer, for at least 2-3 months. Therefore, some patients are left with no treatment to use. Failure to get enough medications leads to non-adherence, which also limits compliance with follow-up appointments. Similar results were reported by Guigley *et al.* [44] and Thompson *et al.*, [41] in their study. They mentioned that the difficulty of an escort or a patient in receiving time off from work was associated with poor follow-up. These results concur with those by Ankomah, *et al.* [45] and Bogard, *et al.* [46] who reported that failure in getting enough medications and difficulty in taking time off from work are barriers for remaining in care for HIV patients.

When it comes to suggestions regarding strategies that can improve glaucoma follow-up care, health education was highlighted as a major strategy that could retain patients in care. Patients are certain that if equipped with the knowledge, they would be motivated to remain in care because they would understand the importance of attending glaucoma follow up. There are a variety of studies that have found that education is the main intervention that helps in improving glaucoma treatment adherence [47 - 50]. In addition, glaucoma patients in this study suggested that they would appreciate it if glaucoma eye care services can be provided at the primary health care facilities as it would be more accessible to most glaucoma patients, and would help in improving adherence and follow-up. Transport services that can ferry patients from home to the clinic, especially for the visually impaired patients who need an escort, should be provided. Another useful strategy that was not mentioned by the participants in this current study was the use of M-Health. According to most studies in the review, M-health (using electronic interventions such as mobile phone, email, and SMS) was useful in improving glaucoma adherence. The researchers assume that similar M-Health strategies can also have an impact in this study population.

5. LIMITATIONS OF THE STUDY

The study was conducted in selected public hospitals in Vhembe District of Limpopo Province and focused on LTFU glaucoma patients only. Therefore, the results might not be generalized to hospitals in other South African provinces. Other researchers may explore the effectiveness of the findings to assist them in their specific situations.

CONCLUSIONS AND RECOMMENDATIONS

In conclusion, it was found that patients lost to follow-up was a potentially significant problem. Follow up adherence amongst glaucoma patients was negatively influenced by travel cost for the patients/escort from home to the health facilities, difficulty getting time off to attend appointment and shortage of medications, insufficient understanding of glaucoma disease and its treatment and holding to traditional and religious beliefs. LTFU glaucoma patients suggested the following strategies that might help them to remain in care: more education on the serious effects of glaucoma and the importance of follow-up visits, transportation services that bring patients to the clinic and back home, glaucoma eye care services (including the supply of glaucoma medications) provided at the Primary Health Care facilities, affordable transportation like mobile clinics, especially for those patients who rely on escorts due to their poor vision. Future studies are needed to develop interventions that can reduce the identified barriers to follow up.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical clearance was obtained from the Ethics and Research Committee of the University of Venda, South Africa. Ethical clearance certificate no. SHS/18/PH/35/0111 was approved.

HUMAN AND ANIMAL RIGHTS

Not applicable.

CONSENT FOR PUBLICATION

Informed consent was obtained from all participants in the research.

AVAILABILITY OF DATA AND MATERIALS

The data that support the findings of this study are available from the corresponding author, [S.T], upon reasonable request.

FUNDING

None.

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise

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