INTERVENTION STRATEGIES TO STRENGHTHEN EYE CARE FOLLOW-UP AMONG GLAUCOMA PATIENTS IN SELECTED DISTRICT HOSPITALS OF LIMPOPO PROVINCE SOUTH AFRICA.

BY

SHONISANI ELIZABETH TSHIVHASE

STUDENT NO: 11523912

A thesis submitted in fulfilment of the requirement for the degree:

Doctor of Philosophy in Public Health

UNIVERSITY OF VENDA

FUCULTY OF HEALTH

SCIENCES

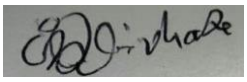
DEPARTMENT OF PUBLIC HEALTH

Promoter	*Co-Promoters*
Prof T G TSHITANGANO	**SENIOR PROF L B KHOZA**

MAY 2021

DECLARATION

I, Shonisani Elizabeth Tshivhase, hereby declare that this thesis titled ***Intervention Strategies to strengthen eye care follow-up among glaucoma patients in selected District Hospitals of Limpopo Province, South Africa*** for the Doctor of Philosophy degree in Public Health at the University of Venda hereby submitted by me, has not previously for any other degree at this university or any other institution. This is an original work, the materials used during preparing this thesis have all been acknowledged by way of referencing.

Student  Date 202/05/20

DEDICATIONS

“You Are Never Too Old To Set Another Goal or To Dream a New Dream.”- C.S. Lewis

I dedicate this study to:

My three lovely beautiful girls, ***Lindelani, Munangiwa and Mashudu****, for their understanding, when Mummy cannot afford to be with them at home all the time,and in memory and honour of my late loving husband,* ***Mashudu Michael Tshivhase (****1959-2012). This is a way of celebrating your life, kindness and support throughout my journey. I will forever cherish those memories. Lastly, I wish to convey a special thanks to my late Father* ***Johannes Khangale*** *and my Mother Vho-****Tshinakaho Avheani*** *for the person that I am.NDI A LIVHUWA.*

ACKNOWLEDGMENT

My deepest gratitude goes to:

God Almighty. I thank you for your care, guidance and protection that sustained and supported me through in difficult circumstances. My sincere appreciation and gratitude for keeping me in Your shadow and enabled me to progress this far: I am immensely blessed.

My Promoters, Senior **Prof LB Khoza** and **Prof T G Tshitangano** for their guidance, encouragement, support and contribution to the success of this study. Their timely counsels and speedy review and corrections of my documents have assisted me a great deal to complete the study on time. Their selfless and sacrificial efforts spurred me on during the difficult moments of the study.

To my friend and mentor, **Ntsieni Mashau.** If I think about a good friend and a sister, your name is always first on the list. You have always been there be it times of joy or despair. I sincerely appreciate your generosity, love and support. Thank you for being such a wonderful friend, but most of all, I thank you for being you.

To **Vho-Pat Avhapfani Ndou**.Vho vha muthusi wa maimo ubva tshe lwendo lwa thoma u swika mafheleloni alwo.A vha ntshileli.

To **Tinotenda Murwira*:*** This success would not have been possible without the significant role you played.

To **The Research and Publication Committee (RPC**) of the University of Venda, for funding the study.

To My study participants who participated in my study. It is impossible to ignore your tremendous cooperation and humble willingness in doing all you could to assist me to conduct this study. I thank you for your time and your effort, NDI A LIVHUWA !

Lastly, those that are not mentioned or those that I have omitted may I take this opportunity to recognise all that played a role in the successful completion of this thesis.

CONTENTS

INTRODUCTION

Aim and outline of the thesis

AIM AND OUTLINE OF THE THESIS

There is a challenge in keeping glaucoma patients within the health care system. To engage the patient, there should be counselling to enhance their understanding of the disease and encourage the participation of the patient in their choice of therapy and compliance with treatment. The ease of financing mechanisms for their treatment is also important. Additional efforts should be geared towards providing a pleasant hospital experience so that follow-up visits would entail a one-stop-shop (Sawesi et al,2016). Therefore, eye care providers working together with the glaucoma patients may enhance better treatment outcomes in South Africa (Cook,2009; Abdull, Chandler & Gilbert, 2016). Many factors influence glaucoma loss to follow up. A better understanding of the relationships between glaucoma knowledge and patient-reported problems in using glaucoma medication revealed opportunities for intervention that may improve patients 'clinical outcomes (Reponen, 2016.The current study seeks to develop a strategy to strengthen eye care follow-up among glaucoma patients in Limpopo province, South Africa.

Chapter 1 introduces the thesis, presenting a theoretical background, theoretical health models, the problem statement, purpose and objectives of the study, definition and operational concepts of the study. It also contains the significance and conclusion of the study.

Chapter 2 is a systematic literature review that analyses the intervention strategies to ensure that glaucoma patients remain in care. The study was published as an article titled "***Systematic Literature Review on strengthening Eye Care Follow-Up among Glaucoma Patients in Limpopo Province"*** in The Open Public Health Journal (2020). The chapter established that various techniques have been employed globally to design and evaluate several interventions to improve glaucoma adherence with diverse accomplishments. The reviewed studies showed that educational interventions are a common strategy that led to significant improvement in medication adherence. The purpose of the systematic literature review was to analyse intervention strategies used to ensure that glaucoma patients remain in care within the health care facilities.

In **Chapter 3** A survey was conducted to increase the understanding of the reasons for loss to follow-up among 429 glaucoma patients. This study has been published as ***"Loss to follow-up amongst glaucoma patients in selected hospitals of the Limpopo Province, South Africa"*** in the journal African Vision and Eye Health (AVEH) (2020). The purpose of the study was to identify behavioural determinants contributing to loss to follow-up amongst glaucoma patients. The study was conducted in fundamentally different settings in Vhembe District: a general regional hospital, district hospitals, and a specialized ophthalmic hospital.

The study findings revealed that non-adherence to scheduled follow-up appointments among glaucoma patients in rural hospitals was still prevalent. However, factors varied due to every person's unique experience. Forgetfulness and financial difficulties were indicated as some of the barriers contributing to glaucoma medication non-adherence.

Most glaucoma patients did not know that glaucoma needed regular follow-ups like any other chronic disease such as diabetes and hypertension. This was attributed to the fact that glaucoma is asymptomatic. Other patients held traditional or religious beliefs which assumed that glaucoma is caused by witchcraft or evil spirits. Detailed information from patients who were identified as glaucoma loss to follow-up was gathered and it forms part of Chapter four.

Chapter four: This forms part of the qualitative study. The material of this chapter was subsequently published as an article titled "***Challenges Contributing to Loss to Follow-up as Experienced by Glaucoma Patients in the Vhembe District of Limpopo Province, South Africa"*** in The Open Public Health Journal (2020). This study sought to explore factors contributing to loss to follow-up as experienced by glaucoma patients in South Africa. The key findings from the qualitative study were mostly system-related factors such as the negative attitude of the hospital workers, shortage of glaucoma medications, long waiting time, and long queues. The problem of poor communication between patients and health care providers was also highlighted. Other findings revealed by patients that contribute to glaucoma LTFU are lack of escort and family support, difficulty in getting time off, and the issue of stigma and discrimination. Similar findings were experienced by other patients who suffered from other chronic diseases like HIV and AIDS and those attending maternal health.

Chapter five introduces the proposed strategies to strengthen eye care follow-up which were developed after the analyses and interpretation of the three chapters (chapters 2-4) that revealed knowledge gaps. The development of proposed strategies was guided by various theories. The most used theories are the Health Belief Model (HBM); Social Cognitive Theory (SCT); Information Motivation Behavior Skill Model (IMB) and the Social Action Theory (SAT). The selected theories have positive health benefits and have the potential to improve medication adherence. The chapter to be submitted as a proposed strategy to strengthen eye care follow-up among glaucoma patients in a peer reviewed journals.

Chapter five(a) forms part of the proposed strategies to strengthen eye care follow-up.The material of this chapter was published as an article titled**"*Application of an information-motivation-behavioural skills model to strengthen eye care follow-up amongst glaucoma patients"*** in the in the journal African Vision and Eye Health (AVEH) (2021).The study sought to investigate how the application of IMBSM can strengthen eye care follow-up

of glaucoma in Limpopo province South Africa.The key findings from the proposed strategy was that non-adherence limits the potential of successful treatments to improve patients' health and quality of life. The study also revealed that strategies to improve adherence to glaucoma medication are likely to be effective when they include multiple components such as educating the patient and their family members. Therefore, these findings suggest that the application of the IMBSM might improve glaucoma patients' adherence.

Chapter six is a compilation of general discussion which includes empirical findings of the summary of the research findings, strengths and limitations and recommendation to the study. It also reveals the conclusions based on the study findings as well as recommendations for further research works. The following recommendations were made: the patients and family members and community health workers; Primary Health Care(PHC) and eye care health practitioners (ECHP); the Department of Health (DOH); and recommendations for further research and lastly the conclusion of the study.

ANNEXURES: The section included all the annexures such as questionnaire for all glaucoma patients, interview guide for patients who are lost to follow-up, ethical clearance from research and innovation committee, permission letters from the Provincial and district department of health and permission letters from the hospitals. Besides, proofreading and editing letters are also included.

References

Sawesi, S., Rashrash, M., Phalakornkule, K., Carpenter, J.S. and Jones, J.F., 2016. The impact of information technology on patient engagement and health behavior change: a systematic review of the literature. JMIR medical informatics, 4(1), p. e1.

Abdull, M.M., Chandler, C., and Gilbert, C., 2016. Glaucoma, “the silent thief of sight”: patients’ perspectives and health seeking behaviour in Bauchi, northern Nigeria. BMC ophthalmology, 16(1), p.44.

Cook, C., 2009. Glaucoma in Africa: size of the problem and possible solutions. Journal of glaucoma, 18(2), pp.124-128.

Reponen, E., 2016. Preoperative risk-assessment methods, short-term outcome, and patient satisfaction in elective cranial neurosurgery. Dissertationes Scholae Doctoralis Ad Sanitatem Investigandam Universitatis Helsinkiensis.

CHAPTER 1

Theoretical background,theoretical health models and problem statement.

THEORETICAL BACKGROUND

Glaucoma is a group of eye diseases that damage the optic nerve connecting the eye to the brain (Zhao, Fu, Li & Lou, 2015). It is associated with increased intraocular pressure (IOP). Glaucoma remains asymptomatic until it is at an advanced stage when there is vision loss. The vision loss that occurs in glaucoma cannot be reversed. However, with the use of glaucoma lifelong treatment and surgery, visual loss can be slowed down or halted over time (Eissa, Hussein, Habib & El Sayed, 2016). This theoretical background further discusses the global estimates of glaucoma and glaucoma management; management and treatment of glaucoma; barriers and ensuring patient adherence; theoretical health models and frameworks; strategies used to strengthen glaucoma follow up: global perspectives; problem statement; purpose and objectives of the study, definitions, and operationalized concepts significance and conclusion.

Global estimates of glaucoma and glaucoma management

Glaucoma is a serious worldwide public health challenge. It is the second leading cause of irreversible blindness after cataract (Zhao, Fu, Li & Lou, 2015). The number of people affected by glaucoma worldwide is estimated at 66.8 million, with 8.4 million already blind (Schellack, Schellack, Bezuidenhout, Malan & de Klerk,2017; Zhao *et al,* 2015). It was estimated that there were going to be 80 million people affected by glaucoma globally by 2020 and up to 111.8 million in 2040 (Schellack et al, 2017; Zhao *et al,* 2015). The global burden of glaucoma increased from 62 percent to 83 percent between 1990 to 2010. One out of 15 people who became blind and one out of 45 of the visually impaired in 2010 was due to glaucoma (Bourne, Taylor, Fleximan, *et al*,2016). Several studies indicate that Africa and Asia are the most affected by glaucoma than the rest of the world (Tham, *et al,* 2014; Chan, Li, Tham, *et al,*2016). However, glaucoma is not a problem of the developing countries alone, developed countries such as those in Europe and Australia, also find glaucoma as their leading cause of irreversible blindness. An estimated 12 million (2.2%) of European populations above forty years are affected by glaucoma while two percent of the Australians who are above fifty years are affected (Bourne, Taylor, Flaxman*., et al,*2016; Chan et al, 2016). Asians have the largest number of 21.82 million (27.4 %) of glaucoma cases in the world (Zhao *et al,* 2015).

Masoud, Nov and Pikkel (2013) reported an estimated 60 000 people having glaucoma in Israel between 2006 and 2008. The United States of America (USA) is no exception. About 3 million people in the USA were expected to be affected by glaucoma by the year 2020. African American people are between six to eight times more affected than Caucasians in the USA as reported by Dreer, Owsley, Campbell, Gao, Wood, and Girkin (2016). Glaucoma

is more prevalent in developing countries than in developed countries. Literature indicate that glaucoma is one of the most neglected and underreported diseases in Africa (De-Gaulle and Dako-Gyeke (2016). Ghana has the second-highest rate of glaucoma cases in the world and the highest in West Africa. People who are at risk of developing glaucoma, are those of African origin, who are forty years (8.5%) and above. Nigeria has 5.02 percent, while South Africa reported between 4.5 percent and 5.3 percent among the same age group (Abdull, Gilbert & Evans, 2015; Lubuschagne,2017; Ocansey, Kyei, Gyedu, & Awuah,2014; Chassid, Epstein, Sharabi-Nov & Pikkel,2018). The estimated prevalence of glaucoma in South Africa is about five to seven percent in the black population and three to five percent in the white population, with almost 200 000 people affected (Tham, Li, Wong, *et al*,2014; Schellack *et al.*2017).

Some of the glaucoma patients are at risk of developing visual impairment, blindness, and disability. This is life-limiting as those affected are unable to live independently. They may resign from their jobs, stop driving and depend on others because of their visual impairment (Eissa, Husseinn, Habib, Yasmin & Sayed, 2016). Non-adherence to medication and inadequate follow up are thought to be the contributing factors to visual impairment and blindness even in countries like South Africa.

However, for patients with persistent high IOP or progression, visual loss occurs despite the use of glaucoma medications. Through regular follow-ups, the monitoring of glaucoma progression is necessary to reduce the IOP and maintain vision (Fudemberg, Lee, Waisbourd, Murphy, Dai, Leiby & Hark, 2016). Poor adherence with glaucoma medication remains a primary treatment challenge worldwide. About 12% of glaucoma patients were reported to have missed their recommended follow-up visits in the USA, between 2006 and 2008 (Glanz, Beck, Bund, Primo, Lynn, Cleveland, Wold, & Echt, 2012).

Despite the availability of effective topical glaucoma treatment, most African Americans (53.4%) fail to adhere to their treatment unlike the Caucasians (71.2%) (Dreer, et al, 2016). Similarly, Fundemberg *et al* (2016) revealed that only half of the patients with glaucoma are adherent to their follow-up recommendations given by their opthalmologist, while another half becomes lost to follow up. The findings were congruent with those from a study conducted in Ethiopia by Movahedinejad and Adb-Hajbaghery (2016) and Tamrat, Gessesse, and Gelaw (2012) who indicated that 66-67% of the patients were not adhering to their glaucoma treatment. The adherence rate for patients receiving chronic glaucoma treatment is between 43% and 78% worldwide, while other studies reported that 10-30% of glaucoma patients often omit their prescribed doses (Olthoff, Hoevenaars, Webers, Schouten & Borne, 2009). Only an adherence rate of 80% is acceptable. Several authors

have indicated that non-compliance is a significant factor of blindness resulting from glaucoma among Arab populations in Israel (Masoud, Sharabi-Nov & Pikkel, 2013; Chassid, Epstein, Sharabi-Nov & Pikkel, 2018).

Hussein, Eissa, and Kader (2015) indicated that adherence to glaucoma treatment was difficult to measure as most patients gave false information whenever asked by the health care providers. Barriers to glaucoma treatment adherence are similar worldwide; forgetfulness, high cost of glaucoma medication and clinic distance, and problems with eye drop administration are the most cited in Africa (Olthoff et al 2009; Dreer et al, 2016). Lack of understanding of the importance of follow up (46.3%), and unawareness of appointment schedule (30.9%) were cited as the reasons for follow up discontinuation in some studies (Kim, Jeoung & Park, 2016). The awareness level of glaucoma in developed countries such as Australia is higher than in African countries (Ocansey, Kyei, Gyedu & Awuah 2014).

Studies conducted in countries such as South Western Ethiopia and India concur with those conducted in Australia regarding factors contributing to poor follow up (De-Gaulle & Dako-Gyeke, 2016). Rotchford and Johnson (2002) indicated socio-economic issues, lack of formal education, race (black versus white), and access to health care as factors contributing to loss to follow–up in South Africa. While others believe that follow-up is less important if one is using glaucoma medication (Robin & Gover, 2011).

South African glaucoma patients face the same glaucoma treatment challenges as any other African countries such as Ghana and Nigeria. In these countries, most of the patients come from rural areas. Compliance remains poor as they do not have regular access to health care (Welsh, 2016). Patients present very late for consultation when the disease has progressed to an extent that medication can no longer preserve their vision. In contrast, a gap exists regarding glaucoma services between sub-Saharan Africa and European countries. In most European countries, glaucoma services are more advanced than in sub-Saharan Africa since they offer free screening for all patients (De-Gaulle & Dako-Gyeke, 2016). In sub-Saharan Africa, there is one ophthalmologist for every one million African people, whereas in Europe one ophthalmologist sees 10000 people per annum (De-Gaulle & Dako-Gyeke, 2016). 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 (Abu Hussein, Eissa, Abdel-Kader,2015; Eshun, 2015; Masoumpour, 2019).

Management and treatment of glaucoma

The philosophy of glaucoma management is to preserve the visual function and quality of life (QOL) of the individual (Skalicky, Goldberg & McCluskey, 2012; Sgaramella, Nota, Carrieri, Soresi, & Sato, 2017). Vision lost as results of glaucoma cannot be recovered. The primary goal of glaucoma management is to prevent progressive vision loss, visual disability, and blindness by lowering IOP. (Tamrat, Gessesse & Gelaw, 2015; Khodake, Jambhrunkar, Kataria, *et al*,2019). The aim is not mainly to treat the intraocular pressure, optic disc, or visual field, but to treat the patient to provide maximum benefits with minimal side effects and patient compliance (Onofrey, 2016; Konstas, Kahook, Araie, *et al,* 2018). Therefore, IOP reduction by medical, laser, or surgical therapies remain the only clinically proven treatment of Glaucoma (Butt, Ayub & Ali, 2016).

Also, the lowering of IOP was the only proven intervention strategy to prevent loss of vision as stipulated by the International Council of Ophthalmology (ICO) Guidelines (2016) and Pfeiffer, Garcia-Feijoo, Martinez-de-la-Casa *et al* (2015). Also, IOP is the only known modifiable risk factor that can be easily monitored by eye care professionals such as the ophthalmic nurses, ophthalmologist and optometrist (Harasymowycz, Birt, Gooi, Heckler, Hutnik, Jinapriya, Shuba, Yan &Day, *2016*; Konstas *et al*, 2018)

Additionally, the ophthalmologist should strive to maintain the IOP in a stable range to prevent further damage to the optic nerve. Reducing IOP might require aggressive treatment and frequent change of therapy. However, factors such as the stage of the disease, patient risk factors, life expectancy, and social circumstances should be taken into consideration when setting for the IOP target. The initial IOP target for a patient who is at an early stage should be at least 25% and 30%, for both patients with moderate and advanced glaucoma disease (Harasymwycz et al,2016). Furthermore, glaucoma might continue to progress despite treatment even when the IOP level is ranging within the target limit of 22mmHg. So, relying on tonometry alone for glaucoma follow-up is not sufficient (Hollo & Hommer,2016; Prum, Lim, Mansberger, *et al*, 2016).

Most glaucoma patients often require lifelong treatment and follow up care to preserve vision. Medical therapy is the cornerstone of disease management for most glaucoma patients. There are several options for successfully managing glaucoma. The initial treatment is usually drug therapy followed by laser therapy and then incisional surgery. All methods are effective in reducing IOP and preserving sight, but not all treatments work equally well for every glaucoma patients (Robin & Grove, 2011; Butt et al, 2016; Sena & Lindsley, 2017). Therefore, the basic principles of glaucoma management should be considered such as patient education and counselling on compliance; setting IOP target at

less than 22mmHg; choice of medical therapy; side-effects and compliance and lastly, the follow-up that varies from 3-4 months (Parikh et al 2008; Denniston & Murray, 2014).

Medical therapy (Topical drug therapy)

Medical therapy remains the most common initial method of lowering IOP unless contraindicated. Guidelines for glaucoma treatment advise to always start the treatment with eye drops since they are systematically well tolerated (Vieira, Guedes, Vieira &Guides, 2015; Harasymwycz et al, 2016).The first-line of topical therapies for glaucoma includes, (1) Prostaglandin analog which is used as the initial treatment as it is more effective and has few ocular adverse effects, (2) the second line of treatment are the Beta-blockers (alpha agonist) and carbonic anhydrase inhibitors.

These may cause ocular irritation since they require to be used twice or three times daily, and (3) lastly, is Para sympathomimetic (miotic) agents which is the third line of treatment. Miotic agents are only reserved for patients who do not respond to other topical antiglaucoma medications (Li, Lindsley, Rouse, *et al,* 2016; Gizzard, Konstantakopoulou, Garway-Heath, *et al* 2019). Besides, topical drug therapies reduce the production of aqueous humour and enhance the flow of aqueous humour. The selection of the initial drug depends on the target IOP while factors such as efficacy, compliance, safety, persistence, and affordability should be kept in mind when prescribing glaucoma treatment (Ang, Tham & Sng, 2019; Chen, Samadi & Quérat, 2019).

Laser therapy

An alternative treatment is the laser trabeculoplasty. It is mostly used in patients for whom medical therapy fails to adequately reduce IOP. Laser therapy can reduce the IOP from 20% to 30% for most glaucoma patients. Trabeculoplasty is frequently used for open-angle glaucoma as it facilitates drainage and further lowers the IOP (Law & Li,2013; Aptel, Denis, Rouland, Renard & Bron,2016; Gizzard et al.,2019).

Incisional surgery

Incisional surgery is an effective way of lowering IOP. Incisional surgery is the last option to be considered when medication and laser therapy fail to reduce IOP. Trabeculectomy remains the most commonly performed incisional surgery for glaucoma (Law & Li, 2013; Gizzard et al., 2019) as it can normalize the pressure for a period without the use of medications. But it is rarely chosen because of its complications (Parkish et al 2008, Wong, Lee, Choy, Chan & Lai, 2015; Ang et al., 2019.).

Traditional method

Traditional medicine refers to health practices, approaches, knowledge and beliefs incorporating plant, animal, and mineral-based medicines, spiritual therapies, and manual techniques. Traditional medicine is beneficial in treating, diagnosing, and preventing illness or maintaining the wellbeing of an individual. Similarly, traditional eye medicine (TEM) are biologically based practices or therapies that are applied or instilled in the eye. They can be administered orally to achieve the desired ocular therapy (Kayoma & Ukponmwan, 2017).

Traditional healers are the first point of contact for primary health care in sub-Saharan Africa (Maragesi, Kauke, Kagashe&kaali,2016; Tabi, Powell &Hodnicki,2006). The use of TEM is a common practice since people often consult traditional healers before presenting to the hospital. Furthermore, traditional eye medication is commonly used in different countries although products differ from healer to healer. The traditional healers prefer the use of concoctions that cause pain and irritation as they are perceived as being strong. Traditional medicine practitioners are the ones that prescribe traditional eye medication (Maragesi, Kauke, Kagashe&Kaali,2016; Kayoma & Ukponmwan, 2017). It is part of a self-medication practice. Harmless eye practices may be in the form of spells by traditional healers or face washing with water while harmful eye medication includes instillation of alcohol, herbal extracts, breastmilk, donkey or cow dung, human sputum, urine, and bird's faeces. Harmful practices may cause ocular morbidity (Kayoma & Ukponmwan, 2017).

Moreover, the main reason for using TEM is the perceived high cost of eye care services, ignorance, barriers to access to primary eye care, preference, failure of conventional treatment, desire to take control over medical treatment, a communication gap between patients and eye care providers and influence of friends and relatives (Achigbu & Achigbu, 2017). However, the effectiveness of TEM in treating ocular problems has not yet been proven as they often cause harm. According to Durowade et al (2018), they are corrosive and harmful and can damage the eyes with possible glaucomatous changes and lead to blindness.

Additionally, there is another form of traditional eye medicine which is used by the Chinese called Acupuncture. Acupuncture has been used for more than 2000 years for the treatment of various illnesses (Law, Lowe, Law, *et al.,* 2015; Law, Wang & Li, 2020). It is the stimulation methods that include needle insertion, acupressure surface electrical, and lasers stimulation. Law *et al* (2015) and Law *et al* (2020) further reported that acupuncture is associated with increase ocular blood flow, reduction of IOP, and improvement of central vision. Therefore, other glaucoma patients may seek acupuncture treatment as an alternative to their traditional glaucoma management.

Barriers and ensuring patient adherence

Lack of adherence to ocular glaucoma therapy is regarded as a serious contributory factor in the progression of glaucoma. Reported adherence to glaucoma medication varies between five percent (5%) and eighty percent (80%) as most glaucoma patients are unable to take their medication as planned (Richardson et al, 2013; Marshall, Hayslett & Stevens, 2018). Numerous adherence barriers prevent patients from accessing glaucoma treatment such as poor education, lack of motivation, forgetfulness, and age differences. However, some simple changes can be implemented to overcome some of the barriers. For instance, (1) providing a patient with an easy schedule; (2) providing a reminder in the form of a handout that can encourage the patient to use eye drops correctly; (3) maintenance of a medication diary for a highly motivated patient can help the health provider to track persistence over time; (4) Simplification of the treatment regimen; (5) selecting medication with the less complications and ocular side effects; and (6) improving patient-doctor relationship (Newman-Casey, Weizer, Heisler et al., 2013; Nieuwlaat, Wilczynski, Navarro et al.,2014). Saeedi et al (2015) and Harsymowycz et al (2016) report that the use of emails and text message reminders is useful for younger glaucoma patients.

Theoretical health models and frameworks

The proposed study was guided by various models namely: Information Motivation Behaviour Skills (IMB); Social Cognitive Theory (SCT); Social Action Theory (SAT) and Health Belief Model (HBM). The significant theoretical framework IMB is important because it is the foundation from which all knowledge is constructed for the research study. It serves as the structure and support for the rationale of the study, the problem statement, the purpose, and the significance of the study (Bowleg, 2012). It provides the background that supports the investigation and offers a justification for the study of a research problem. Therefore, without the theoretical framework structure, the vision of the study is unclear (Bowleg, 2012). All these models are briefly detailed below and will be discussed in detail in Chapter 5.

Health Belief Model (HBM)

The Health Belief Model attempts to explain and predict health behaviors. This is done by focusing on the attitudes and beliefs of individuals. This model addresses problem behaviors that prompt health concerns like nonadherence to glaucoma medications and the possibility of becoming blind (Croyle, 2005; Cate,2016). The HBM views humans as rational beings who behave in certain ways to minimize what they perceive as threats (for instance, non-adherence to medication), and enhance what is perceived as benefits (for example, adherence to glaucoma medications). According to the Health Belief Model theory, a glaucoma patient will comply with treatment regimen if he/she values his/her current level of

vision and believes that anti-glaucoma medication will prevent further vision loss. This model comprises several interactive states of belief which collectively affect glaucoma adherence. The details of the model and its relevance to the study are fully outlined in Chapter 5.

Social Cognitive Theory (SCT)

Social Cognitive Theory accepts that both the knowledge of health risks and the benefits of treatment are necessary to the patients' performing health behavior. Self-efficacy and outcome expectations are additional self-influences that are needed to achieve changes that will result in the desired health behavior. Self-efficacy means the belief in one's ability to perform a given behavior and is a known predictor of health behavior in patients with chronic medical conditions. It has also been shown to influence adherence to glaucoma medications. An outcome expectation is a belief that behavior will result in a specified outcome, and outcomes can be either positive or negative. The SCT suggests that an individual will choose an action that he or she believes will maximize positive outcomes and minimize negative outcomes (Bandura, 1977; Price & Price, 2009). A detailed application of this model to the study is provided in Chapter 5.

Social Action Theory (SAT)

SAT identifies and eliminates factors that contribute to negative health behaviors detrimental to good health, and introduces positive health behaviors which enhance good health (Reynolds, et al., 2010, Ewart, 2009). SAT further suggests the need to expand individually-focused action state concepts by including interdependence with others as a determinant of continued behavior change. This is explained in detail in Chapter 5.

Information Motivation Behaviour Skills (IMB) Model

Fisher, Amico, Fisher, and Harman (2008) propose an IMB model that speculates that information, motivation, and behavioral skills are principle determinants of health-related behavior (Amico, Toro, Alfonso & Fisher, 2005). In the context of this study, this model holds that glaucoma patients who are well-informed through adherence education, are motivated to act, and possess behavioral skills that enable them to act effectively; will remain in care and adhere to their glaucoma medications. The relevance of the model to the study results will be fully discussed in Chapter 5.

Strategies used to strengthen glaucoma follow up: global perspectives

Researchers have described various strategies to improve patient adherence to glaucoma medication such as educating patients and family, simplifying treatment regimen, involving family and friends, as well as customizing treatment regimen to the patient's lifestyle (Okeke, Guigley, Jampbell, et al, 2009). The use of psychologists, social workers, nurse educators,

and pharmacists may be helpful in improving medication adherence (Morse, 2015). Furthermore, direct and indirect methods have been used in developed countries to monitor glaucoma adherence. These include direct monitoring method or observational methods. such as having a trained observer to observe patients when taking medication and measuring the concentration of the drugs or metabolite in blood or urine. However, Mansberger, Shepler, McClure., *et al* (2013) argue that this method is impractical and intrusive. Indirect methods involve physician-estimated patient compliance, patient self-reporting, evaluating pharmacy refill rates and measuring the amount of medication in the bottle at each visit. This method is suitable for large groups.

However, pharmacy refills can be inaccurate for individual patients. Other methods involve utilizing electronic medication monitors like eye drop monitor, measuring clinical response, and using completed patient medication diary (Mansberger et al,2013; Robin &Grover,2011; Osterberg & Blaschke, 2005). However, as Robin and Grove (2011) state, each method has its advantages and disadvantages. There is no consensus regarding the best method for measuring adherence. Some patients were consistently over representing their adherence while ophthalmologists have done a poor job in detecting nonadherence in their patients. Tse, Shah, Jamal and Shaikh (2016) indicated that self-reported estimate of adherence are unreliable as they tend to. overestimate adherence rates (Robin & Grove, 2011; Friedman, Guigley, Gelb, Tan, Margolis, Shah, Kim, Zimmerman & Hahn, 2007). Osterberg and Blaschke (2009) reported improvement in patient medication adherence in five days before and after their appointment with the physician.

Several authors revealed that medication reminders such as telephone, text messages and email improve glaucoma adherence (Boland et al,2014; Pennesi, Weleber, Yang, et al, 2018). Saeedi, Luzuriaga, Ellis, and Robin (2014) argue that email and text messages are useful for younger patients only. Noecker (2019) and Sleath, Blalock, Carpenter, et al (2015) state that another strategy that improves glaucoma medication adherence is a good doctor-patient relationship. The study also mentioned that doctor-patient communication plays a vital role in ensuring glaucoma adherence. Notably, some patients were not willing to reveal their nonadherence for fear of not being good patients by the physicians. Furthermore, some patients become less adherent to their treatment when their scheduled time is still far and extremely adherent to glaucoma regimen in the last five days leading to their appointment day to give a false impression to the physician (Hahn, 2009; Sleath, Blalock, Carpenter al (2015 Noecker, 2019). Also, adherence can be improved when doctors communicate treatment side effects and offer advice regarding ways to avoid them. Noecker (2019) and

Cook, Bremer, Ayala, and Kahook (2010) indicate that another strategy to improve medication adherence is the implementation of adherent assessment interviews.

Though glaucoma is incurable, it is manageable. The primary objective of glaucoma therapy is to prevent progressive vision loss, disability and blindness. Regular monitoring is vital in lowering of IOP and maintaining vision. The American Academy of Ophthalmology (Fudemberg *et al,* 2016) recommends that glaucoma patients be seen by an ophthalmologist at least every 6-12 months for a comprehensive eye examination. Similarly, the South African Glaucoma Guidelines recommend that patients with controlled glaucoma should be seen three times per year; with those with uncontrolled and complicated glaucoma being seen up to six times a year (South African Glaucoma Society, 2006; Michaelov, Armstrong, Nguyen, Instrum, Lam, Denstedt, Hutnik, 2018). In the light of the foregoing discussion, this study developed an intervention strategy to strengthen eye care follow-up among glaucoma patients in selected hospitals of Limpopo Province, South Africa.

Problem Statement

Despite follow-up recommendations by the South African Glaucoma Guidelines, patients on glaucoma treatment in Vhembe District Health Facilities still missed their scheduled appointment between April 2015 and October 2016 (refer to Table 1). The primary researcher noted with concern the difference in numbers between patients who missed their appointments and those who adhered to their treatment schedules. Some missed their scheduled follow-ups by three or four months, others missed their appointment date by up to six to twelve months. Among them were males and females and young and old (Hospitals Eye Clinic Register, 2016). Some patients presented with diminished vision while others were already blind in one or both eyes (Hospitals Eye Clinic Register, 2016). What is more worrying is that their visual acuity was deteriorating every time they visited the eye clinic.

This might affect their everyday life as well as that of their family members. Patients might lose their jobs when their vision deteriorates. Such people might become a burden to the family and government as they will become dependent on the government grant assistance. The country's economy will be negatively affected as these patients might need special training to function independently. Adherence to regular follow-up-medical appointments is critical for effective glaucoma management (Lee, Murakami, Duncan, Kao, Huang, Lin & Singh, 2013; Fudemberg, Lee, Waisbourd, *et al,* 2016). No known study has been done to develop interventions to strengthen eye care follow-up among glaucoma patients in the Limpopo Province, hence this study.

Table 1: Loss to follow up distribution 2015-2016

Vhembe district	Total glaucoma patients	A loss to follow up	Remaining	% of total glaucoma patients by hospital
Hospital A	300	100	200	66.67%
Hospital B	56	25	31	12.44%
Hospital C	44	16	28	9.78%
Hospital D	20	5	15	4.44%
Hospital E	30	12	18	6.67%
Grand Total	**451**	**158**	**292**	100%

Source: Vhembe District - Hospitals Eye Clinic Register (2016)

Purpose and objectives of the study

The purpose of the study was to develop a strategy to strengthen eye care follow-up among glaucoma patients in Limpopo province, South Africa. To meet the study's purpose, objectives were necessary including conducting systematic literature reviews to strengthen eye care follow-up among glaucoma patients, increasing the understanding of the reasons for loss to follow-up among glaucoma patients, exploring factors contributing to loss to follow-up as experienced by glaucoma patients in the rural hospitals. The findings of the current study guided the development of the proposed strategy to strengthen eye care follow-up among glaucoma patients.

Definitions and operationalized concepts

Glaucoma: This is a term used to describe several types of eye conditions that affect the optic nerve, and optic nerve damage is caused by increased pressure to the eye also known as intraocular pressure (Quigley,2011). In this study, glaucoma refers to damage to the optic nerve of the eye due to high intraocular pressure on patients who attend eye clinics in the selected hospitals of Vhembe District.

Hospital: Is a building where people go for special medical treatment or advice Chenail, 2012; Collins English Dictionary, 2012). In this study, hospital refers to health facilities in the Vhembe District where patients obtain specialist care for their eye-related health problems.

The loss to follow up (LTFU): means not keeping AGT visit appointment for 90 days or longer from the last booked refill appointment date (Makwindi, 2016). In this study, it refers to patients who have defaulted in taking their AGT in hospitals of Vhembe District.

Patient: The term patient refers to a person who is receiving medical treatment especially in a hospital /clinic or a person who receives treatment from a particular doctor (Bunch, 2014).

In this study, the patient refers to a person who has eye problems that require medical care and attends the glaucoma eye clinic.

Strategies: These are plans made to reach a long-term goal (Kaplan & Norton, 2001). In the HBM, the intervention strategy is cued to action (Kasser & Kosma, 2012). In this study, strategies shall refer to intervention plans for prevent loss to follow up amongst glaucoma patients.

Adherence: The term adherence is defined as the degree to which medication-taking behavior corresponds with agreed recommendations from a health care provider (WHO; accessed 2018/02/20). In this study, adherence is when a glaucoma patient is taking the anti-glaucoma medication as advised by a health professional

Factors: One of several things that influence or cause a situation (Longman Dictionary of Contemporary English, accessed 2018/06/02). In this study, factors in HBM are susceptibility, severity, benefit, barriers, and cues that make glaucoma patients not adhere to treatment.

Significance and conclusion

This study is significant because it developed a strategy that may help glaucoma patients to re-engage and to remain in care. The study findings may help to address factors contributing to loss to follow-up care among glaucoma patients on anti-glaucoma treatment (AGT) in the selected health care facilities. The study may also provide health care providers with knowledge about the causes of loss to follow up amongst glaucoma patients. The study may also be beneficial to Vhembe hospitals as the intervention strategies development may reduce LTFU rate and increase the rate of patient's compliance within the district. The developed strategy may also be applied to other chronic conditions like hypertension, diabetes and HIV. The study may benefit many researchers interested in researching related topics. Moreover, policymakers will have data to guide them in developing policies involving the treatment and care of glaucoma patients. The findings from this study may help to address the gap contributing to loss to follow up care of glaucoma patients on AGT in health care facilities. It is also hoped that the government may benefit from this study by having a community that is free from acquiring secondary blindness caused by glaucoma LTFU. Communities and families may also benefit from the proposed strategy. When patients are adherent, they will have positive health outcomes such as controlled IOP which would slow down disease progression and prevent vision loss.

Reference

Abdull, M.M., Chandler, C, and Gilbert, 2016.Glaucoma, "the silent thief of sight": patients' perspectives and health-seeking behavior in Bauchi, Northern Nigeria. *BMC ophthalmology*.16-44.

Abdull, M.M., Gilbert, C.C, and Evans, J. 2015. Primary open-angle glaucoma in northern Nigeria: stage at presentation and acceptance of treatment. *Arch Ophthalmol.*130(10):1252-1258.

Abraham, C. and Sheeran, P. 2014. *The health belief model. In Cambridge Handbook of Psychology, Health and Medicine, Second Edition*. Cambridge University Press. DOI: 10.1017/CBO9780511543579.022.

Abu Hussein, N.B., Eissa, I.M. and Abdel-Kader, A.A., 2015. Analysis of factors affecting patients' compliance to topical antiglaucoma medications in Egypt as a developing country model. *Journal of ophthalmology*.

Achigbu, E.O. and Achigbu, K.I., 2017. Bilateral orbital cellulitis: A case report and management challenges. *Nigerian Journal of Ophthalmology*, 25(1), pp.52-55.

Ang, M., Tham, C.C. and Sng, C.C., 2020. Selective laser trabeculoplasty as the primary treatment for open angle glaucoma: time for change?

Aptel, F., Denis, P., Rouland, J.F., Renard, J.P. and Bron, A., 2016. Multicenter clinical trial of high-intensity focused ultrasound treatment in glaucoma patients without previous filtering surgery. *Acta ophthalmologica*, *94*(5), pp. e268-e277.

Bastawrous, A., Burgess, P.I., Mahdi, A.M., Kyari, F., Burton, M.J. and Kuper, H., 2014. Posterior segment eye disease in sub-Saharan Africa: review of recent population-based studies. *Tropical medicine & international health*, *19*(5), pp.600-609.

Bourne, R.R., Taylor, H.R., Flaxman, S.R., Keeffe, J., Leasher, J., Naidoo, K., Pesudovs, K., White, R.A., Wong, T.Y., Resnikoff, S. and Jonas, J.B., 2016. Number of people blind or visually impaired by glaucoma worldwide and in world regions 1990–2010: a meta-analysis. *PloS one*, 11(10), p. e0162229.

Bowleg, L., 2012. The problem with the phrase women and minorities: intersectionality—an important theoretical framework for public health. *American journal of public health*, 102(7), pp.1267-1273.

Bradford W., Lee, Yohko Murakami, Martin T. Duncan, Andrew A. Kao, Jehn-Yu Huang, Shan Lin, and Kuldev Singh.,2013 Patient-related and system related barriers to glaucoma

follow-up in a county hospital population. *Invest Ophthalmol*;54:6542– 6548. DOI:10.1167/iovs.13-1210

Butt, N.H., Ayub, M.H. and Ali, M.H., 2016. Challenges in the management of glaucoma in developing countries. *Taiwan Journal of Ophthalmology*, 6(3), pp.119-122.

Chan, E.W.E., Li, X., Tham, Y.C., Liao, J., Wong, T.Y., Aung, T. and Cheng, C.Y., 2016. Glaucoma in Asia: regional prevalence variations and future projections. *British Journal of Ophthalmology*, 100(1), pp.78-85.

Chen, E., Samadi, B. and Quérat, L., 2019. Patient Management. In *Medical Treatment of Glaucoma* (pp. 189-216). Springer, Singapore.

Chenail, R.J., 2012. Conducting qualitative data analysis: Reading line-by-line, but analyzing by meaningful qualitative units. *The Qualitative Report*, *17*(1), pp.266-269.

Chia-Chien, H & Brian, A., S. (2012). Instrumentation in: *Encyclopaedia of Research Design*. Thousand Oaks: Thousand Oaks: SAGE Publications, Inc. Accessed on 26 may 2017

Chinn, P.L. and Kramer, M.K., 2013. *Integrated Theory & Knowledge Development in Nursing-E-Book*. Elsevier Health Sciences.

Cook, P.F., Schmiege, S.J., Mansberger, S.L., Kammer, J., Fitzgerald, T. and Kahook, M.Y., 2015. Predictors of adherence to glaucoma treatment in a multisite study. *Annals of Behavioral Medicine*, 49(1), pp.29-39.

Curtis, C., Lo, E., Ooi, L., Bennett, L. and Long, J., 2009. Factors affecting compliance with eye drop therapy for glaucoma in a multicultural outpatient setting. *Contemporary nurse*, *31*(2), pp.121-128.

Dako-Gyeke, P., Aikins, M., Aryeetey, R., Mccough, L., & Adongo, P. B. (2013). The influence of socio-cultural interpretations of pregnancy threats on health-seeking behavior among pregnant women in urban Accra, Ghana. *BMC pregnancy and childbirth*, *13*(1), 211.

De-Gaulle, V. F., & Dako-Gyeke, P. 2016. Glaucoma awareness, knowledge, perception of risk and eye screening behavior among residents of Abokobi, Ghana. *BMC ophthalmology*, 16(1), 204.

Denniston, A. and Murray, P. eds., 2014. *Oxford handbook of ophthalmology*. OUP Oxford.

Dreer, L. E., Owsley, C., Campbell, L., Gao, L., Wood, A., & Girkin, C. A. 2016. Feasibility, Patient Acceptability, and Preliminary Efficacy of a Culturally Informed, Health Promotion Program to Improve Glaucoma Medication Adherence Among African Americans: “Glaucoma Management Optimism for African Americans Living with Glaucoma” (GOAL). *Current eye research*, 41(1), 50-58.

Dreer, L.E., Girkin, C. and Mansberger, S.L., 2012. Determinants of medication adherence to topical glaucoma therapy. *Journal of glaucoma*, 21(4), p.234.

Durowade, K.A., Salaudeen, A.G., Akande, T.M., Musa, O.I., Bolarinwa, O.A., Olokoba, L.B., Fasiku, M.M. and Adetokunbo, S., 2018. Traditional eye medication: A rural-urban comparison of use and association with glaucoma among adults in Ilorin-west Local Government Area, North-Central Nigeria. *Journal of Community Medicine and Primary Health Care*, 30(1), pp.86-98.

Ehiemua, U.R.A. 2014. *Reasons for poor adherence to Antiretroviral therapy (ART) by young females 15-24 years HIV/AIDS patients in Oshakati District*. Stellenbosch University

Eissa, I. M., Hussein, N. B. A., Habib, A. E., Yasmin, El Sayed, Y. M.2016. Examining Delay Intervals in the Diagnosis and Treatment of Primary Open Angle Glaucoma in an Egyptian Population and Its Impact on Lifestyle. *Journal of Ophthalmology: 7012826*

Ewart, R., Lausen, H. and Millian, N., 2009. Undisclosed changes in outcomes in randomized controlled trials: an observational study. *The Annals of Family Medicine*, *7*(6), pp.542-546.

Fisher, J.D., Amico, K.R., Fisher, W.A. and Harman, J.J., 2008. The information-motivation-behavioral skills model of antiretroviral adherence and its applications. *Current HIV/AIDS Reports*, 5(4), p.193.

Friedman, David S., Harry A. Quigley, Laurie Gelb, Jason Tan, Jay Margolis, Sonali N. Shah, Elizabeth E. Kim, Thom Zimmerman, and Steven R. Hahn. 2007. "Using pharmacy claims data to study adherence to glaucoma medications: methodology and findings of the Glaucoma Adherence and Persistency Study (GAPS)". *Investigative ophthalmology & visual science* 48 (11): 5052-5057.

Fudemberg, S.J., Lee, B., Waisbourd, M., Murphy, R.A., Dai, Y., Leiby, B.E. and Hark, L.A., 2016. Factors contributing to nonadherence to follow-up appointments in a resident glaucoma clinic versus primary eye care clinic. *Patient preference and adherence*, 10, p.19.

Gizzard, G., Konstantakopoulou, E., Garway-Heath, D., Garg, A., Vickerstaff, V., Hunter, R., Ambler, G., Bunce, C., Wormald, R., Nathwani, N. and Barton, K., 2019. Selective laser trabeculoplasty versus eye drops for first-line treatment of ocular hypertension and glaucoma (LiGHT): a multicentre randomized controlled trial. *The Lancet*, 393(10180), pp.1505-1516.

Glanz, K., Beck, A.D., Bundy, L., Primo, S., Lynn, M.J., Cleveland, J., Wold, J.A. and Echt, K.V., 2012. Impact of a health communication intervention to improve glaucoma treatment adherence: results of the interactive study to increase glaucoma adherence to treatment trial. *Archives of Ophthalmology*, 130(10), pp.1252-1258.

Glaucoma algorithm and guidelines for **glaucoma South African Glaucoma Society 2006.** www.glaucoma.org/news/aging-population-contributes-to-rising accessed on 10 January 2017.

Gogate, P., Deshpande, R., Chelerkar, V., Deshpande, S. and Deshpande, M., 2011. Is glaucoma blindness a disease of deprivation and ignorance? A case–control study for late presentation of glaucoma in India. *Indian Journal of Ophthalmology*, 59(1), p.29.

Greyling, M., 2004. Research at Grass Roots: For the social sciences and human services professions, AS de Vos, (ed), H. Strydom, CB Fouche and CSL Delport: book review. *SA Journal of Industrial Psychology*, *30*(1), p.100.

Hahn, S.R., 2009. Patient-centered communication to assess and enhance patient adherence to glaucoma medication. *Ophthalmology*, 116(11), pp. S37-S42.

Harasymowycz, P., Birt, C., Gooi, P., Heckler, L., Hutnik, C., Jinapriya, D., Shuba, L., Yan, D. and Day, R., 2016. Medical management of glaucoma in the 21st Century from a Canadian perspective. *Journal of Ophthalmology*.

Hark, L., Waisbourd, M., Myers, J.S., Henderer, J., Crews, J.E., Saaddine, J.B., Molineaux, J., Johnson, D., Sembhi, H., Stratford, S. and Suleiman, A., 2016. Improving Access to Eye Care among Persons at High-Risk of Glaucoma in Philadelphia—Design and Methodology: The Philadelphia Glaucoma Detection and Treatment Project. *Ophthalmic Epidemiology*, 23(2), pp.122-130.

Holló, G., Hommer, A., and Delivery of Glaucoma Care Committee of the European Glaucoma Society, 2016. The status of glaucoma diagnostics and care in Europe in 2015: a European survey. *European Journal of Ophthalmology*, 26(3), pp.216-220.

Hussein, N. B. A., Eissa, I.M., and Abdel-Kader, A. A. 2015. Analysis of Factors Affecting Patients' Compliance to Topical Antiglaucoma Medications in Egypt as a Developing Country Model. *Journal of Ophthalmology*, Article ID 234157, 7 pages

Kaplan, R.S. and Norton, D.P., 2001. Transforming the balanced scorecard from performance measurement to strategic management: Part II. *Accounting Horizons*, 15(2), pp.147-160.

Kasser, S.L. and Kosma, M., 2012. Health beliefs and physical activity behavior in adults with multiple sclerosis. *Disability and Health Journal*, 5(4), pp.261-268.

Kayoma, D.H. and Ukponmwan, C.U., 2017. Knowledge and practice of the use of traditional eye medication in a semi-urban community. *Sahel Medical Journal*, 20(2), p.59.

Khandekar, R., Jaffer, M.A., Al Raisi, A., Zutshi, R., Mahabaleshwar, M., Shah, R. and Choudhury, A.H., 2008. Oman Eye Study 2005: prevalence and determinants of glaucoma. EMHJ-Eastern Mediterranean Health Journal, 14 (6), 1349-1359, 2008.

Kraukamp, P., 2013. Factors associated with late presentation of glaucoma: a study in a black South African population (Doctoral dissertation).

Khodake, A., Jambhrunkar, S., Kataria, S., Shah, N., Dudani, A. and Patel, R., 2019. Our Patient has High Eye Pressure: Is it a Problem? (Raised Intraocular Pressure-Glaucoma). Bombay Hospital Journal, 61(4), p.261.

Kim, Y.K., Jeoung, J.W. and Park, K.H., 2017. Understanding the reasons for loss to follow-up in patients with glaucoma at a tertiary referral teaching hospital in Korea. British Journal of Ophthalmology, 101(8), pp.1059-1065.

Konstas, A.G., Kahook, M.Y., Araie, M., Katsanos, A., Quaranta, L., Rossetti, L., Holló, G., Detorakis, E.T., Oddone, F., Mikropoulos, D.G. and Dutton, G.N., 2018. Diurnal and 24-h intraocular pressures in glaucoma: monitoring strategies and impact on prognosis and treatment. Advances in therapy, 35(11), pp.1775-1804.

Labuschagne, M. J. 2010. Glaucoma: what should the general practitioner know? *South African Family Practice*, 52(6), 493-497.

Lacey, J., Cate, H. and Broadway, D.C., 2009. Barriers to adherence with glaucoma medications: a qualitative research study. *Eye*, 23(4), p.924.

Law, S.K. and Li, T., 2013. Acupuncture for glaucoma. *Cochrane Database of Systematic Reviews*, (5).

Law, S.K., Lowe, S., Law, S.M., Giaconi, J.A., Coleman, A.L. and Caprioli, J., 2015. Prospective evaluation of acupuncture as treatment for glaucoma. *American Journal of Ophthalmology*, 160(2), pp.256-265.

Lee, B.W., Murakami, Y., Duncan, M.T., Kao, A.A., Huang, J.Y., Lin, S. and Singh, K., 2013. Patient-related and system-related barriers to glaucoma follow-up in a county hospital population. *Investigative Ophthalmology & Visual Science*, 54(10), pp.6542-6548.

Lee, B.W., Sathyan, P., John, R.K., Singh, K. and Robin, A.L., 2008. Predictors of and barriers associated with poor follow-up in patients with glaucoma in South India. *Archives of Ophthalmology*, 126(10), pp.1448-1454.

Li, H., Ye, Q. and Law, R., 2013. Determinants of customer satisfaction in the hotel industry: An application of online review analysis. *Asia Pacific Journal of Tourism Research*, 18(7), pp.784

Li, T., Lindsley, K., Rouse, B., Hong, H., Shi, Q., Friedman, D.S., Wormald, R. and Dickersin, K., 2016. Comparative effectiveness of first-line medications for primary open-angle glaucoma: a systematic review and network meta-analysis. *Ophthalmology*, 123(1), pp.129-140.

Makwindi, C.C., 2016. Retention in care amongst women initiated on antiretroviral therapy during pregnancy at King Sobhuza II Public Health Unit, Swaziland.

Mansberger SL, Sheppler CR, McClure TM, VanAlstine CL, Swanson IL, Stoumbos Z, Lambert WE. 2013. Psychometrics of a new questionnaire to assess glaucoma adherence: The Glaucoma Treatment Compliance Assessment Tool (an American Ophthalmological Society thesis). Transactions of the American Ophthalmological Society. Sep; 111:1

Maragesi, S.M., Kauke, B., Kagashe, G. and Kaali, R., 2016. Traditional eye medicines in Tanzania: Products, health risk awareness and safety evaluation. *Herb. Med. Open Access*, 2(1).

Masoud, M., Sharabi-Nov, A. and Pikkel, J., 2013. Noncompliance with ocular hypertensive treatment in patients with primary open angle glaucoma among the Arab population in Israel: a cross-sectional descriptive study. Journal of ophthalmology, 2013.

Masoumpour, M., 2019. Compliance with Glaucoma Therapy with Eye Drops and its Determinants in Glaucoma Pa-tients Presenting to Clinics Affiliated to Shiraz University of Medical Sciences. ISMJ, 22(2), pp.119-129.

Mathenge, W., Moreker, S., Muqit, M.M. and Resnikoff, S., 2018. Guidelines on diabetic eye care: The International Council of Ophthalmology Recommendations for screening, follow-up, referral, and treatment based on resource settings. *Ophthalmology*, 125(10), pp.1608-22.

Michaelov, E., Armstrong, J.J., Nguyen, M., Instrum, B., Lam, T., Denstedt, J. and Hutnik, C.M., 2018. Assessing the methodological quality of glaucoma clinical practice guidelines and their recommendations on microinvasive glaucoma surgery: a systematic review. *Journal of Glaucoma*, 27(2), pp. e44-e49.

Morris, J., Marzano, M., Dandy, N. and O'Brien, L., 2012. Theories and models of behaviour and behaviour change. Forest Research: Surrey, United Kingdom, pp.1-27.

Morse, A.R., 2015. Improving medication adherence to reduce vision loss in patients with glaucoma: low hanging fruit? Ophthalmology, 122(7), pp.1280-1282.

Movahedinejad, T. and Adib-Hajbaghery, M., 2016. Adherence to treatment in patients with open-angle glaucoma and its related factors. *Electronic physician*, 8(9), p.2954.

Newman-Casey, P.A., Weizer, J.S., Heisler, M., Lee, P.P. and Stein, J.D., 2013. A systematic review of educational interventions to improve glaucoma medication adherence. In *Seminars in ophthalmology*, 28(3), pp. 191-201.

Nieuwlaat, R., Wilczynski, N., Navarro, T., Hobson, N., Jeffery, R., Keepanasseril, A., Agoritsas, T., Mistry, N., Iorio, A., Jack, S. and Sivaramalingam, B., 2014. Interventions for enhancing medication adherence. Cochrane database of systematic reviews, (11).

Nijhawan, L, P., Janodia, M, D., Muddukrishna, B.S., Bhat, K.M., Bairy, K. L., Udupa, N and Musmade, P.B. 2013. Informed consent: Issues and challenges. *Journal of Advanced Pharmaceutical Technology & Research*, 4(3), pp. 134-140.

Noecker, C., Chiu, H.C., McNally, C.P. and Borenstein, E., 2019. Defining and evaluating microbial contributions to metabolite variation in microbiome-metabolome association studies. Msystems, 4(6).

Ntsoane, M.D., 2016. *Burden and determinants of blindness and visual impairment among elderly in the Dikgale Health and Demographic Surveillance System (HDSS), Capricorn District, Limpopo Province, South Africa* (Doctoral dissertation).

Ocansey, S., Kyei, S., Diafo, A., Darfor, K.N., Boadi-Kusi, S.B. and Aglobitse, P.B., 2016. Cost of the medical management and prescription pattern for primary open angle glaucoma (POAG) in Ghana–a retrospective cross-sectional study from three referral facilities. *BMC Health Services Research*, 16(1), p.282.

Ocansey, S., Kyei, S., Gyedu, B.N. and Awuah, A., 2014. Eye care seeking behaviour: a study of the people of Cape Coast Metropolis of Ghana. *J Behav Health*, 3(2), pp.101-6.

Okeke, C.N., Friedman, D.S., Jampel, H.D., Congdon, N.G., Levin, L., Lai, H. and Quigley, H.A., 2007. Targeting relatives of patients with primary open angle glaucoma: the help the family glaucoma project. *Journal of Glaucoma*, 16(6), pp.549-555.

Olthoff, C.M., Hoevenaars, J.G., van den Borne, B.W., Webers, C.A. and Schouten, J.S., 2009. Prevalence and determinants of non-adherence to topical hypotensive treatment in Dutch glaucoma patients. Graefe's archive for clinical and experimental ophthalmology, 247(2), p.235.

Onofrey, B., 2016. Controversies in glaucoma management. *Review of Optometry*, 153(10), pp.66-75.

Osterberg, L. and Blaschke, T., 2005. Adherence to medication N Engl J Med (Vol. 353, pp. 487-497). United States.

Parikh, R.S., Parikh, S.R., Navin, S., Arun, E. and Thomas, R., 2008. Practical approach to medical management of glaucoma. *Indian Journal of Ophthalmology*, 56(3), p.223.

Pfeiffer, N., Garcia-Feijoo, J., Martinez-de-la-Casa, J.M., Larrosa, J.M., Fea, A., Lemij, H., Gandolfi, S., Schwenn, O., Lorenz, K. and Samuelson, T.W., 2015. A randomized trial of a Schlemm's canal microstent with phacoemulsification for reducing intraocular pressure in open-angle glaucoma. *Ophthalmology*, 122(7), pp.1283-1293.

Price, A. and Price, B., 2009. Role modelling practice with students on clinical placements. *Nursing Standard* 24(11), p.51.

Quigley, H.A., Broman, A.T. 2006. The number of people with glaucoma worldwide in 2010 and 2020. *Br J Ophthalmol* 90: 262–267. doi: 10.1136/bjo.2005.081224.

Rakoma, T.F., 2017. Traditional eye treatments amongst patients consulting at eye clinic at the Letaba Regional Hospital, Limpopo Province of South Africa (Doctoral dissertation, University of Limpopo).

Raphael, D. ed., 2009. *Social determinants of health: Canadian perspectives*. Canadian Scholars' Press.

Reynolds WM. Reynolds adolescent depression scale. 2010. *The Corsini Encyclopedia of Psychology*. 30:1-.

Richardson, C., Brunton, L., Olleveant, N., Henson, D.B., Pilling, M., Mottershead, J., Fenerty, C.H., Spencer, A.F. and Waterman, H., 2013. A study to assess the feasibility of undertaking a randomized controlled trial of adherence with eye drops in glaucoma patients. Patient preference and adherence, 7, p.1025.

Robin, A. and Grover, D.S., 2011. Compliance and adherence in glaucoma management. Indian Journal of Ophthalmology, 59(Suppl1), p. S93.

Rotchford, A.P and Johnson, G. J. 2002. Glaucoma in Zulus: a population-based cross-sectional survey in a rural district in South Africa. **Archives of Ophthalmology**, 120 (4), pp. 471-478.

Sacharowitz, H. S. 2005. Visual impairment in South Africa: Achievements and challenges *S Afr Optom*. 64 (4) 139 -149.

Saeedi, B.J., Kao, D.J., Kitzenberg, D.A., Dobrinskikh, E., Schwisow, K.D., Masterson, J.C., Kendrick, A.A., Kelly, C.J., Bayless, A.J., Kominsky, D.J. and Campbell, E.L., 2015. HIF-dependent regulation of claudin-1 is central to intestinal epithelial tight junction integrity. *Molecular biology of the cell*, 26(12), pp.2252-2262.

Schellack, N., Schellack, G., Bezuidenhout, S. Malan, L & de Klerk, H. 2017. Glaucoma: a brief update for 2017. *South African Family Practice*. 59(6) 5-10.

Schwartz, G.F. and Quigley, H. A., 2008. Adherence and persistence with glaucoma therapy. *Survey of Ophthalmology*, *53*(6), pp. S57-S68.

Sena, D.F. and Lindsley, K., 2017. Neuroprotection for treatment of glaucoma in adults. *Cochrane Database of Systematic Reviews*, (1).

Sharma, M. and Romas, J.A., 2011. *Theoretical foundations of health education and health promotion*. Jones & Bartlett Publishers.

Skalicky, S.E., Goldberg, I. and McCluskey, P., 2012. Ocular surface disease and quality of life in patients with glaucoma. *American journal of ophthalmology*, *153*(1), pp.1-9.

Skinner, C.S., Tiro, J and Champion, V.L., (2015). The health belief model. *Health behavior: theory, research, and practice. 5th ed.* San Francisco (US): Jossey-Bass, pp.75-94. Accessed 14/01/2018

Sleath, B., Blalock, S.J., Carpenter, D.M., Sayner, R., Muir, K.W., Slota, C., Lawrence, S.D., Giangiacomo, A.L., Hartnett, M.E., Tudor, G. and Goldsmith, J.A., 2015. Ophthalmologist–patient communication, self-efficacy, and glaucoma medication adherence. *Ophthalmology*, *122*(4), pp.748-754.

Tamrat, L., Gessesse, G.W. and Gelaw, Y., 2015. Adherence to topical glaucoma medications in Ethiopian patients. *Middle East African Journal of Ophthalmology*, *22*(1), p.59.

Ten Cate, O., Hart, D., Ankel, F., Busari, J., Englander, R., Glasgow, N., Holmboe, E., Iobst, W., Lovell, E., Snell, L.S. and Touchie, C., 2016. Entrustment decision making in clinical training. *Academic Medicine*, 91(2), pp.191-198.

Tenkir, A., Solomon, B.., Deribew, A. 2010.Glaucoma awareness among people attending ophthalmic outreach services in Southwestern Ethiopia. *BMC Ophthalmol*; 10:17.

Tham, Y.C., Li, X., Wong, T.Y., Quigley, H.A., Aung, T. and Cheng, C.Y., 2014. The global prevalence of glaucoma and projections of glaucoma burden through 2040: a systematic review and meta-analysis. *Ophthalmology*, *121*(11), pp.2081-2090.

The International Council of Ophthalmology (ICO) Guidelines (February 2016).

Tse, A.P., Shah, M., Jamal, N. and Shaikh, A., 2016. Glaucoma treatment adherence at a United Kingdom general practice. *Eye*, 30(8), pp.1118-1122.

Wong, T.Y., Sun, J., Kawasaki, R., Ruamviboonsuk, P., Gupta, N., Lansingh, V.C., Maia, M., Wu, X. and Lin, H., 2015. Patient adherence to follow-up in clinical research: a systematic review of measurements, associated factors and intervention strategies. *J Clin Res Ophthalmol*, *2*, pp.58-64.

Zhao, Y., Fu, J.L., Li, Y.L., Li, P. and Lou, F.L., 2015. Epidemiology and clinical characteristics of patients with glaucoma: An analysis of hospital data between 2003 and 2012. *Indian Journal of Ophthalmology*, 63(11), p.825.

CHAPTER 2

Systematic Literature Review on strengthening Eye Care Follow Up Among Glaucoma Patients in Limpopo Province

Systematic Literature Review on strengthening Eye Care Follow Up Among Glaucoma Patients in Limpopo Province.

Published as Tshivhase, S., 2020. "***Systematic Literature Review on strengthening Eye Care Follow-Up Among Glaucoma Patients in Limpopo Province***." *The Open Public Health Journal,* 13(1).

Article Information

Identifiers and Pagination:

Year: 2020

Volume: 13

First Page: 134

Last Page: 143

Publisher Id: TOPHJ-13-134

DOI: 10.2174/1874944502013010134

Article History:

Received Date: 17/12/2019

Revision Received Date: 03/03/2020

Acceptance Date: 08/03/2020

Electronic publication date: 24/04/2020

Collection year: 2020

ABSTRACT

Background:

Adherence to prescribed glaucoma medications is often poor and proper adherence can be challenging for most patients

Objective:

The purpose of this systematic literature review is to identify and evaluate studies that have tested the impact of each intervention on glaucoma adherence based on their quality outcome.

Methods:

A comprehensive search of database was conducted from January 2009 to January 2019. We systematically reviewed the literature and identified sixteen studies that used educational interventions to improve glaucoma medication adherence. Eleven out of 16 eligible studies were subjected to Randomized Controlled Trial (RCTs) and the remaining four were reviewed as observational studies. One study was reviewed through both observational plus randomized control trial method.

Results:

Out of the eleven (68.75%) RCTs interventions done, five (31.25%) showed improvement in medication adherence and persistence with eye drop instillation, whereas (n=6) did not show any significant improvement on their medication adherence. The quality of each study was evaluated using the Jadad score calculation and the Ottawa-Newcastle.

Conclusion:

Using information from this systematic review and Health Behavior Model, we created a theoretical framework to illustrate how counseling and education can improve medication adherence amongst glaucoma patients in the country.

Keywords: Eye Care, Counseling, Glaucoma patients, Glaucoma medications, Education, Randomized control.

INTRODUCTION AND THEORETICAL BACKGROUND

The most contributing factor for progressive vision loss that lead to blindness is poor medication adherence. Adherence rate for patients receiving chronic glaucoma treatment is between 43% and 78% worldwide, while other studies reported that 10 - 30% of glaucoma patients often omit their prescribed doses [1]. The early manifestation glaucoma trial and Ocular Hypertension Treatment studies found that the use of medications to reduce IOP resulted to (54%) over five years and a 50% reduction in the risk of glaucomatous progression over six years among patients treated with trabeculoplasty and topical therapy as compared to their untreated control group [2]. Further, the United Kingdom Glaucoma Treatment Study has reduced the risk of glaucomatous progression by 44% in two weeks.

Appropriate glaucoma medication and follow up care are vital in preventing vision loss and can prevent blindness. The world Health Organization states that improving adherence may have a “far greater impact on the health of the population than any improvement in specific medical treatment” [2]. In addition, studies on glaucoma medication compliance also emphasize this need [2]. WHO further states that adherence to long term therapies among patients with chronic diseases in the general population is around 50%, and the percentage is much lower in developing countries. Notably, non-adherence among glaucoma patients has been reported to be as high as 80% [2,3]. However, inconsistence adherence to recommend follow up hinders the ability of the physician to track the disease progression. Patients who did not have a consistent follow up were more likely to have mild disease than those who had consistent follow up [4].

There are no standard criteria to determine adherence and methodologies. However, various techniques have been used to detect nonadherence in glaucoma follow up [4,6]. Efforts have been made to design and evaluate various interventions to improve glaucoma adherence with mixed achievement. In addition, various interventions strategies comprised: (1) patient education sessions; (2) written information; (3) medication reminders; (4) eye drop instillation training and (5) individualized adherence plans. Furthermore, adherence and persistence were mostly measured in different techniques such as electronic monitoring devices, pharmacy refill data and self-report [7].

Each technique has its own advantages and disadvantages. Some studies have identified and grouped risk factors for non-adherence with topical glaucoma medications into four major categories: patient-related factors, provider-factors, medication regimen and environmental factors [5,8,9]. It was against this background that this systematic literature

review was carried out.

Purpose

The purpose of this systematic literature review is to identify and evaluate studies that have tested the impact of each intervention on glaucoma adherence based on their quality outcome measure used to assess adherence.

Methodology

A systematic literature review is a scientific investigation that focuses on a specific question and uses clear, pre-specified scientific methods to assess, critically assess and synthesize all the literature on a topic. Also, the systematic review provides a starting point for clinical practice guideline developers [10]). For this study, through a systematic review method, we could identify and evaluate the scientific evidence of both qualitative and quantitative research. The search was limited to journal articles to exclude other types of publications such as book chapters, newspaper articles and conference proceedings. The following systematic steps as outlined by Cronin et al [11] and Ramdhani et al [12] as shown in Figure 1 below were applied to reduce literature-review errors and bias and to produce a transparent, structured and comprehensive overview of the available literature.

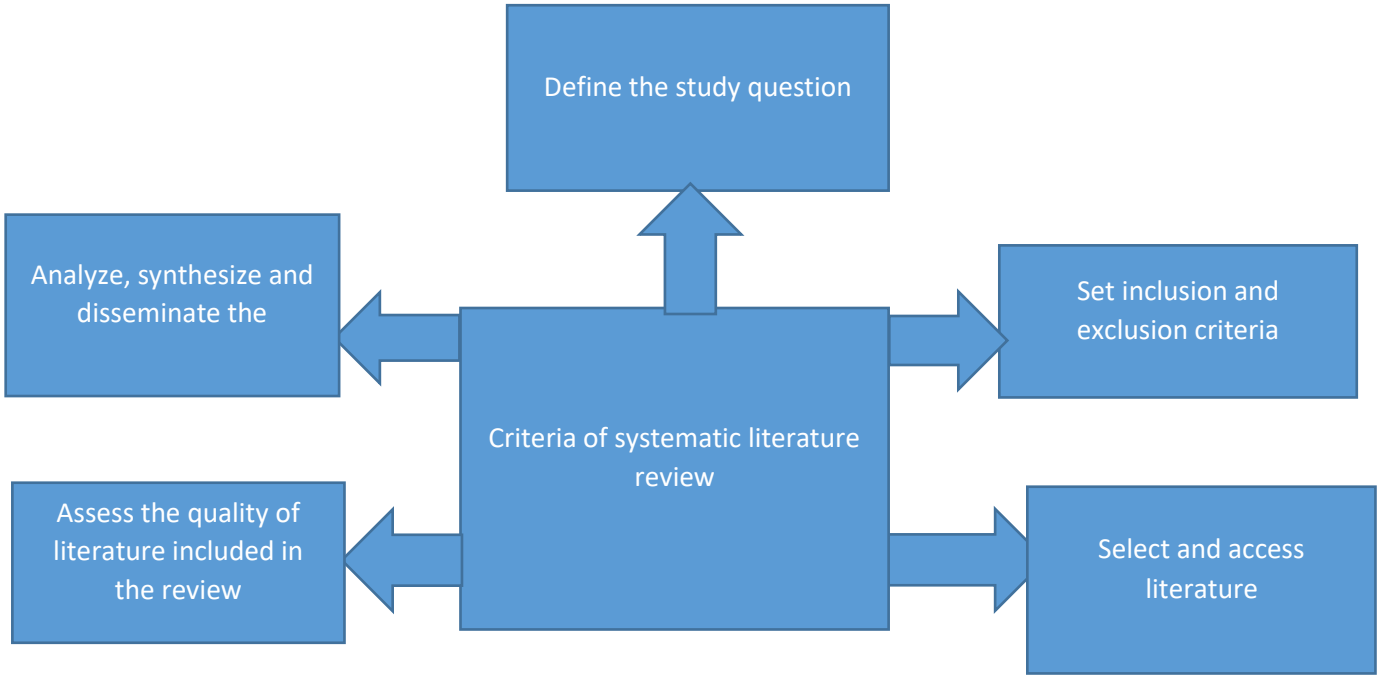


Figure 1: Systematic review steps adapted from Ramdhani et al [12]

Step 1: Defining the research question.

According to Demonceau et al [13], it is important to define the questions to be addressed in strengthening glaucoma follow up systematic review and to identify the purpose and scope of the review. Additionally, defining the questions will direct the reader on the kind of information reviewed and to determine the scope of the review. The research question was defined through the discussion with the supervisor and co-supervisor. Consultation with the eye care health workers and colleagues was also done to ensure that the review is relevant to real-world challenges. The research questions were: 1) What is the current state of compliance amongst glaucoma patients in Africa? 2. What strategies can be used to ensure that glaucoma patients remain in care within the health care facilities?

Step 2: Setting for inclusion and exclusion criteria

Shamseer, Moher, Clarke et al [14] outlined that setting for inclusion and exclusion criteria ensures that the review is conducted in an organized way. Additionally, it provides for transparency on how the strengths and limitations were assessed. Primary research studies were included in this systematic review. No restriction was made on study location. Studies were included if they were published in English and had a sample size of more than 50 participants. Studies were restricted to those that used randomized controlled trial (RCT) and observational studies. Included were also studies that used educational interventions with comparison groups and those that targeted patients diagnosed with glaucoma and whose ages was 18 years and above. Included also were all the studies that have been conducted and evaluated or assessed. All studies that focused on glaucoma surgery, children or juvenile glaucoma were excluded. If the sampled population of study was very specific, for instance, males or females, or recruited patients from one specific class (homeless, prisoners, workers from one employer etc) were also eliminated because results from the study might not be generalizable to the general population. To avoid including duplicate data, the newest and most informative articles were selected when multiple studies were conducted by the same authors.

Step 3. Conducting a literature search

The online database literature search was conducted by searching several relevant articles. The search was limited to journal articles to exclude other types of publications such as book chapters, newspaper articles and conference proceedings. The search strategy was used in collaboration with the School of Health Sciences librarian. Health and medical databases including SABINET, EBSCOHOST, SCIENCE DIRECT, MEDLINE and GOOGLE SCHOLAR were used. Key concepts and search terms were developed to capture literature related to strengthening eye care follow up among glaucoma patients. The search methodology

followed a PICO (population or patient, intervention, comparison, and outcome) format. The search strategy combined sets of keywords, using AND/OR terms. The terms from the following five categories of medical subject headings (MeSH) were used to search the articles and grey literature (Compliance, glaucoma, education, intervention and adherence).

Step 4: Assessing the quality of literature included in the review

This review included all the articles and reports obtained after databases were merged. Duplicate articles were removed and additional articles provided by content experts were identified. Secondary sources, which included textbooks and review articles or description or summary by somebody other than the original researcher, were removed. Only studies that were published between 2009 to 2019 in the English language peer-reviewed journals, reports or websites were reviewed to identify gaps in the adherence to glaucoma medications and the interventions strategies used to improve adherence. Furthermore, were a study only consisted of abstracts it was not included. The studies included were those that explored interventions strategies to improve glaucoma adherence. Titles and abstract were searched against the inclusion criteria and full texts that met the criteria were retrieved.

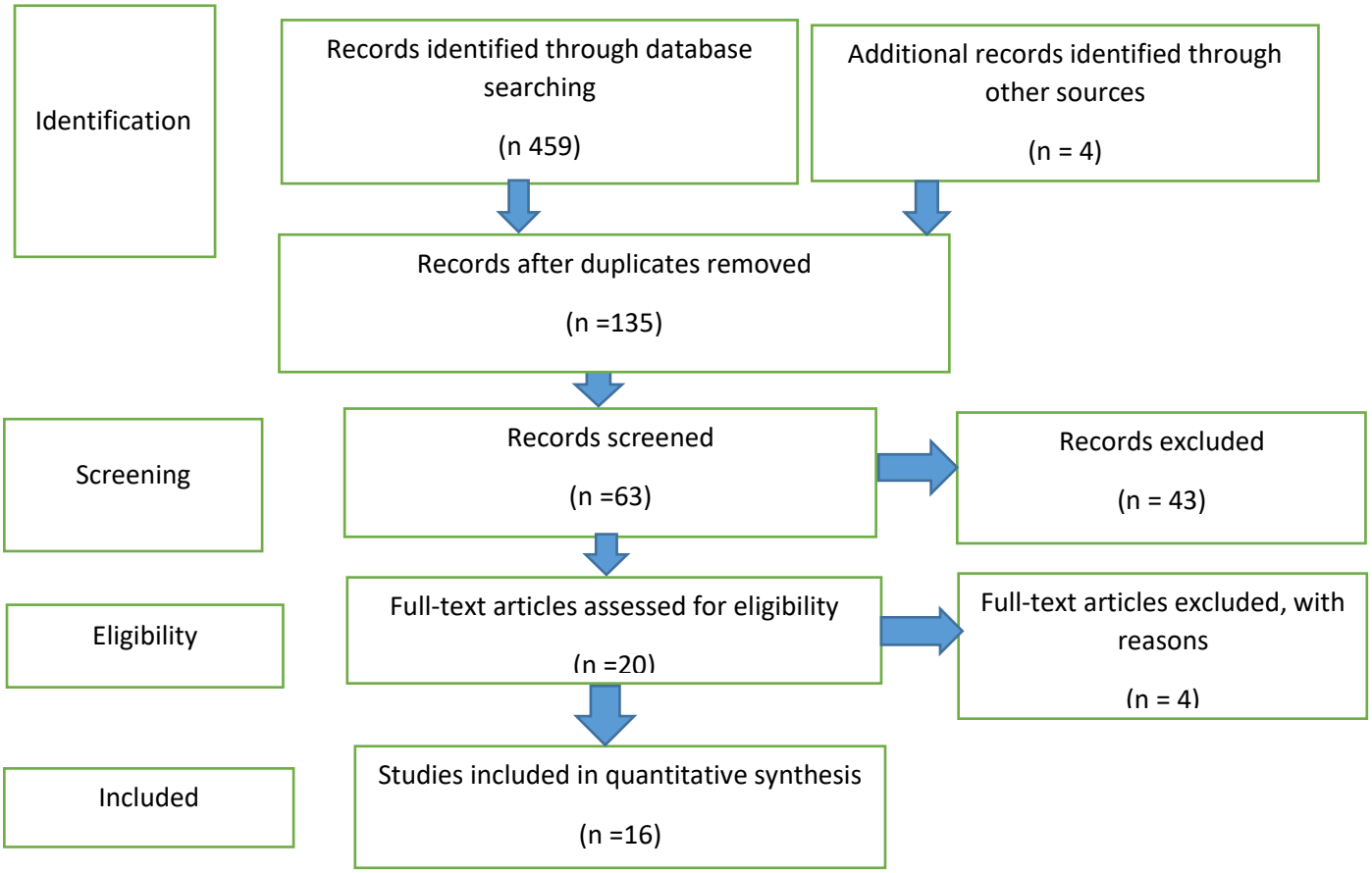


Figure 2: Adapted Flow chart of the literature search for the included and excluded studies (Wu & Lin) Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009).

Step 5. Analyze, Synthesize and Disseminate the Findings

The initial search yielded a total of 459 research articles and 135 were further assessed for their relevance to the study. After screening the titles and abstracts, an additional 63 articles were excluded from the search as they did not contain adequate evidence that can effectively assess the intervention. After the full text review, two researchers agreed on sixteen articles out of twenty articles that met the inclusion criteria. Finally, sixteen articles were included in the analysis as shown in Figure 2 above.

The studies which were included were clustered and organized by concepts which emerged from themes. To provide sufficient substance to a theme, concepts from a minimum of three articles were required. Two thematic domains emerged from the literature (1) Theme 1: The effectiveness of electronic interventions to assess treatment and procedures for glaucoma conducted(ii). Description of observational studies measuring baseline adherence to glaucoma medication.

Most countries identified the importance of conducting educational interventions strategies in this systematic literature reviews. Sixteen studies met the inclusion criteria in this literature review after doing verification by means of hand search. Out of sixteen articles that met the inclusion criteria, 11 of the studies were analyzed through a randomized controlled trial (RCTs) process and the remaining four were put through an observational process. Only one study was subjected to a mixed method process. All the eligible intervention studies were conducted outside sub-Saharan Africa.

The quality of each study was evaluated using the Jadad score calculation for all RTCs studies, while for observational studies, Ottawa-Newcastle score were used. Jadad score is a five -point scale used in the meta-analysis literature to judge the quality of RTCs. Jadad score rewards one point based on the following criteria: (i) was the study randomized; (ii) was the method of randomization appropriate; (iii) was the study described as double-blind; (iv) was the method of double-blinding appropriate;(v) was there a description of withdrawals and dropouts [15]. One point was assigned if the study was described as single blinded and another one point was given if the study outcomes were blinded specifically for the participant who received the intervention and lastly two points were awarded if the adherence was measured by pharmacy claims data as opposed to self-report as displayed in Table 1.

Table 1. Educational Interventions to Improve Glaucoma Medication Adherence according to titles and years.

(a)RCT studies using Electronic adherence measurement :2009-2014	**Author**	**Study setting &sample size**	**Intervention type**	**Study Quality**
1. Interventions improving poor adherence (2009)	Okeke et al	Glaucoma clinic Total:66 glaucoma	Video, reminder phone call and counselling	Jadad:5/5
2. Adherence to glaucoma medication (2013 Jadad:5/5	Lim et al	Academic center:80pts	Automated reminder &educational sessions	Jadad:5/5
3.Automated Telecommunicated-based reminders (2014)	Boland, et al	Glaucoma clinic:491pts	Text messages using personal health record	Jadad:5/5
4.Improving adherence to glaucoma medication (2014)	Cate et al	Glaucoma clinic:208pts	Behavioral counselling and motivational l support by glaucoma support assistants	Jadad:5/5
5.Adherence improvement in Dutch glaucoma patients (2014)	Becker et al	Hospital:805pts	4 types (1) Travel Alert dosing aid, (2) patient education, (3) TravAlert aye drop guider and combination of both.	Jadad:5/5
(b) RCT studies using pharmacy refill, self-report, data chart 2011-2016	**--**	**--**	**--**	**--**
1. Effectiveness and Cost of a personalized Reminder Intervention (2016)	Pizzi, et al	Hospital:256 glaucoma pts	Personal call and Customized letter,	Jadad:5/5
2.Motivational Interviewing or reminders for	Cook, et al	University	Motivational interview, reminder	Jadad:4/5

glaucoma (2016)		clinic:201pts	call, MEMs bottle	
3.Impact of a brief educational intervention on glaucoma (2015)	Djafari et al,	Hospital :165 glaucoma pts	60 to 90 minutes' educational session on glaucoma patients	Jadad:3/5
4. Influence of health literacy level (2012)	Muir et al	Glaucoma clinic:127pts	A video was used	Jadad:5/5
5. Impact of Health Communication Intervention (2012)	Glanz et al	Hospital:312pts	I-SIGHT program	Jadad:5/5
6.Individualized patient care controlled trial (2012)	Grey et al	Hospital:127 newly diagnosed patients	Personalized individualized health assessment	Jadad 5/5
(c) RCT studies using Electronic adherence measurement :2009-2014	**--**	**--**	**--**	**--**
Observational studies using pharmacy refill, self-report:2011-2015				
1.The eye drop chart: (2015)	McVeigh et al	Hospital:25pts	Eye drop chart. Audio reminder visual system	Ottawa-Newcastle score 4/5
2. A 2-hour information session (2012)	Blondeau, et al,	Glaucoma clinic:342pts	2hour educational session, eye drop instillation	Ottawa-Newcastle score 5/5
3.Web-based intervention for improving adherence (2011)	Lunnela, et al	Hospital	Glaucoma content link were emailed to the patients	Ottawa-Newcastle

				Score 4/5
(d) Observational studies using Electronic and a questionnaire	**--**	**--**	**--**	**--**
1.Glaucoma Management (2016) Glaucoma clinic:	Dreer, et al	14pts Patient education,	MI and problem solving training(PST)	Ottawa-Newcastle score 4/5
(e) Mixed RCT and Observational study	--	--	--	--
1.A study to assess the feasibility of undertaking a randomized controlled (2013)	Richardson et al	Glaucoma clinic:19pts	Group based educational program.	Ottawa-Newcastle score 4/5

Theme 1: Effectiveness of electronic intervention studies to assess treatment and procedures for glaucoma studies conducted

•Electronic interventions studies using randomized controlled trial.

Electronic interventions are electronic reminders (automatically sent reminders without personal contact between the healthcare provider and patient) that are now increasingly being used to improve adherence. Furthermore, electronic intervention strategies include short message service (SMS), telephone, Facebook, internet, electronic reminder devices (ERD) and voice message [16]. Most of the reviewed studies were subjected to a randomized control trial (RCT) process which a trial in where subjects are randomly assigned to one of the two groups. For instance, one (the experimental group) receiving the intervention that is being tested, and the other (the comparison group or control) receiving an alternative (conventional) treatment. The two groups are then followed up to see if there are any differences between them in the outcome. The results and subsequent analysis of the trial were used to assess the effectiveness of the intervention. RCTs are the strictest way of determining whether a cause-effect relation exists between the intervention and the outcome [17]. Results from this systemic literature review have shown that, out of the eleven-randomized control trial (RCT)studies, five used electronic monitoring as an adherence measurement, while five RCT used pharmacy refill, self-report and data chart. The eleventh study used both RCT and observational process. All five RCT studies that used electronic monitoring were conducted either at glaucoma clinic or hospital clinic. None of the studies were conducted in a community setting.

•Motivational Interviewing based glaucoma education as opposed to standard care

Motivational interviewing was used to improve glaucoma medication adherence. Patients were put in the following three groups: (1) The control group, (2) the comparison group and the (3) motivational interviewing group. Reminder call, Motivational interview (MI) and Medication Event Monitoring System (MEMS) were used. The medication event monitoring system (MEMS) is a cap that fits on standard medicine bottles and records the time and date each time the bottle is opened and closed [18]. All three groups received allocated intervention, but group 1 and 2 did not receive extra in-person visits while group 3 received three in -person visits with an ophthalmic technician (OT) trained in MI (at weeks 1,4, and 8 after randomization) plus three phone calls from the same OT (week 2, 6 and 12). Other studies used automated reminders and educational sessions. Group 2 and 3 received three reminder phone calls from the clinic staff member asking about their level of adherence, reasons of any missed doses and their use of MEMS [19].

- **Automated reminders and educational sessions**

In this electronic intervention, automated reminders and educational sessions were used to measure medication adherence. Educational sessions were conducted by facility caregiver. The intervention group undertook a 20-30-minutes scripted education session with a research assistant for three months, and their adherence was measured for more two months. The adherence level of the control group and the intervention group did not show any improvements. Instead, there was a decline after the intervention as reported by Lim, Watnik, Imson, Porter and Granier [20] in their study. Furthermore, some participants on the intervention group received daily messages through text or voice messages reminding them to take

their medication while participants in the control group only received the usual care. Both groups were further instructed to use the MEMSCap to monitor their medication use and the study coordinator did a follow-up after three months on the intervention group regarding the monitoring device, their drop use and their reminders [21].

- **Health literacy modified glaucoma education against standard care**

The impact of an educational intervention was modified to health literacy on glaucoma medication adherence. Participants in the intervention group used informational video about glaucoma at 4th, 7th, or 10th grade level, depending on the participants. Additionally, the intervention group members were further taught on the instillation of eye drops and they had to demonstrate to the study coordinator the proper technique on eye drop instillation. The control group only received standard care. Participants whose health literacy level was less than 10th grade were shown eye diagrams while the coordinator reviewed the educational information. Participants in the intervention group received a phone call once per month to check if they were experiencing any problems with glaucoma medication. After evaluating the intervention, the study showed that patients with low level of health literacy skills may benefit from educational efforts tailored to address their health literacy level [22].

- **Behavioral-counseling interventions**

Behavioral-counseling interventions empower patients to participate in their own care while positively changing their skill levels or normal routines. For example, skill building by a health care professional and problem solving are helpful [23]. The counselling comprised of glaucoma education and motivational support from trained para-professional staff called glaucoma support assistants(GSAs). Throughout the intervention, the GSA met three times over a period of eight months with the patients while the control group received standard care with their physician. Each brief-MI counselling technique done by the GSA was assessed for fidelity using standard measures [24].

- **Interventions based on technical reminder systems**

The participants whose baseline level of medication adherence was less than 75% were either put in an intervention group or control group (usual care). The intervention group watched a ten-minute educational video, reviewed prevailing barriers and possible solutions to eye drop taking with the study coordinator. The participants further received regular phone call reminders and had audible and visible reminders activated on their Dosing Aid (DA) devices. Furthermore, coordinators taught participants on their medication record keeping. In addition, study coordinators reminded patients to take their weekly and biweekly medication over a period of three months while the control group was told to take their eye drops as prescribed and received no additional intervention [22, 25].

- **RCT using customized letter and personal telephone outreach**

The groups were divided into two groups, that is the usual care that served as the control group and the intervention group. The control group did not receive any reminder letters or phone calls. The intervention groups were sent customized letters two weeks preceding to their appointment and telephone calls 2-3 days before the appointment. If the subject failed to attend to the scheduled appointment, the researcher made two additional personal telephone calls. In the event where the subject responded positively and agreed to the scheduled appointment, a telephone reminder was made 2-3 days prior to the scheduled appointment. In cases where the subject was not reached after two phone calls, the subject was not contacted again [26].

- **Impact of brief educational intervention on glaucoma medication adherence**

Patients were randomized to either an immediate intervention or normal care. The two 60-90 minute educational sessions on glaucoma and its management was led by a trained non-practicing ophthalmologist. The two sessions were conducted within two weeks apart. Sessions were given in small formats. Persistence to glaucoma medication was examined for a period of one year using hospital and pharmacy claims records. Questionnaires were administered and medication possession ratio were calculated (that is taking eye drops as prescribed) in all the patients at the end of the study [7].

- **RCT using self-report, pharmacy refill and chart review**

This is a randomized controlled trial using self-report, pharmacy refill data and chart review as a means of adherence measurement. The participants should all be non-adherents. The study described a patient to be glaucoma nonadherent if the patient failed to report for clinic appointment or failed to collect glaucoma medication in the past year. While adherence was measured using patient self-report, chart review of refill adherence, physician assessment of medication adherence and appointment adherence. The treatment group received an automated, interactive voice recognition, tailored telephone intervention and tailored printed materials. The control group received the usual care of recommendations of medical appointments and prescription refill on each visit [27].

- **Impact of individualized patient care as an aide to standard care**

Randomization was generated using a computer to get the intervention group and the control group (standard care). The trained glaucoma nurse implemented standard care and individualized care plan. The intervention began with a 45-minute counselling session of healthcare needs and beliefs, followed by a 20-minute educational session and then a 10-minute training session on eye drop instillation and proper technique.

Nurses collaborated with the patients to form a tangible plan of how to integrate eye drop regimen into the patients' daily routine. Individualized follow up care to each person's need was done. The same nurse met with the patients for approximately 15 minutes either in person or telephonically to discuss about glaucoma information, give feedback on adherence and to address other concerns. Patients could call the nurse in between visits for additional support. The intervention group showed significantly stronger belief in the

importance of eye drops and had more personal control over their condition. Therefore, an intervention had a positive effect on adherence behavior to glaucoma therapy. Thus, adherence was significantly higher in the intervention group as compared to the control group after 12 months [28].

Theme 2: Description of observational studies measuring baseline adherence to glaucoma medication

•Assessing the feasibility and preliminary effectiveness of a health promotion program

Studies had pre-post design in which the baseline adherence was measured prior to the implementation of an educational intervention and again after an intervention. The program wanted to improve adherence using three approaches:(1) patient education, (2) motivational interviewing, and (3) problem solving training (PST). The program focused on African-Americans (AAs) due to their higher risks of developing glaucoma. Furthermore, AAs are also at risk for poor medication adherence as compared to Caucasians [29]. The health educator (who is a licensed clinical psychologist) carried out the intervention. The health educator met separately with patients at glaucoma clinics. Each patient participated in a four-weekly session tailored to the overcome patient barriers and glaucoma medication adherence. The first session of face-to-face was conducted at the clinic, and the additional sessions took place over the phone [30].

•Assessing the efficacy of the eyedrops chart in improving patients' glaucoma medication adherence

The study used Eye Drop Chart (EDC) type of intervention which was an audio-visual reminder system for glaucoma medications. An EDC consists of a chart signifying medication, instillation times, and the eye that need treatment. The medication schedule was followed by eye instillation instruction, then each medication was placed underneath the chart. Therefore, the study did not show any significant difference in self-reported adherence before and after using EDC as an intervention [31].

•Group based educational program using observational and randomised control trial

It was a quasi-experimental pre-post analysis of a two sequential groups-based education program. The group used educational intervention and practical medical events monitoring system (MEMS) data. Baseline assessment of the outcome questionnaires were taken one month before the group-based educational program and again three months after the delivery of the program. Continuous observation on eye drops adherence was done from one month before to three months after the intervention. A glaucoma trained nurse supported by other health professionals led the educational programme which lasted less than two and half hours. The session allowed time for the participants to describe their experiences with glaucoma and had time to ask questions [32]

•Two-hour nurse led educational session observational study

Researchers were made to measure the persistence with glaucoma medication for two years before and one year after a group of educational sessions. The glaucoma nurse presented using PowerPoint to patients and their family members as they were also invited to the session. The sessions were limited to

fifteen people (including patients and family members). Patients demonstrate back on how to instill eye drops and glaucoma handouts were distributed after the session. Participants were each contacted three times over a period of ten months to address any questions, encourage adherence and plan follow up visits [33]

•An observational case- control study on web-based glaucoma education

The intervention group received an email with two kinds of web sites links with glaucoma information and its management. The other link was based on the personal information of the patient. Participants on the control group filled out their surveys regarding their adherence behaviour and were then given standard care by their ophthalmologist [34].

4. Discussion

Regular follow up is critical in glaucoma care to monitor the disease and adjust treatment when necessary. Systematic review of the literature was conducted to determine the effectiveness of educational intervention strategies in strengthening glaucoma eye care follow up. The primary outcomes measured were glaucoma medication adherence. Various literature database and grey literature were searched resulting in inclusion of sixteen studies after three level of screening. Results suggest that there is significant improvement with medication adherence after an educational intervention. Most (8/11) of the RCT studies reviewed showed some improvement in glaucoma medication adherence. However, three (3/11) studies showed that a trend towards an improvement in medication adherence was not statistically significant. Types of educational interventions that were used differ from one study to another. Therefore, it is not easy to determine which specific characteristics of the educational intervention had the most effect on medication adherence.

Overall, eleven studies focused on improving knowledge to improve Medication Compliance Patients who received automated text messages and voice calls reminding them to take their medication improved their adherence. Furthermore, patients who were shown educational videos on the instillation of eye drops using Dosing Aid devices had their medications improved as compared to the control group. All studies that used electronic monitoring only as their adherence measures showed significant improvement in glaucoma medication as shown in Table 1. Such studies used educational sessions, videos, automated reminder calls, counselling in the form of motivational interviewing, text messaging using personal health record and eye drop guide. Furthermore, patients who received short text messages (SMS) were more likely to attend their glaucoma appointments as compared to those who had not received an SMS [21]. A study that used MI as an educational intervention showed slight effect on the intervention group. Motivational interventions had smaller effect than reminder calls. But MI needs more training and practice because most ophthalmologist do not have ophthalmic technicians who are trained in MI. Therefore, reminder calls led to better adherence than usual care even though most studies support MI [19]. Cook et al,2016[19] focused on using motivational interviewing to improve self-efficacy to improve glaucoma medication adherence. The effects of multiple interventions such as reminder devices, patient education and eye drop guide on glaucoma medications adherence failed to improve adherence over a period of six months. Patients who received dropper guide were significantly more nonadherent than those without the dropper guide. Instead,

it made it more hard and led to reduced medication adherence [22]. Muir et al [36] tailored their intervention to patients' level of health literacy. They were concerned with patients with low and marginal health literacy as compared to patients with 10th grade health literacy level. Patients with low level of health literacy skills may benefit more from education efforts tailored to address their health literacy level. There were four observational studies that took place from 2011 to 2016 that met our inclusive criteria for this systematic review. All the studies that were reviewed had a pre-post design in which the adherence was measured prior to the implementation of an educational intervention, and the adherence was measured again after the educational intervention. Most observational studies used pharmacy refill.

An observational study of glaucoma knowledge and persistence conducted by Blondeau et al [33] did not show any improvement in persistence within a period of one year. This was a nurse led educational session were glaucoma medication were measured after a two-hour educational session by means of pharmacy refill. Furthermore, there were no significant difference in self-reported adherence before and after by the patients who were using eye drop chart as an intervention. Also, participants that received web sites link with glaucoma information and its management via the email for the intervention group did not show any adherence improvement [32, 34]. The only observational study that showed improvement in medication adherence after intervention was that assessed the feasibility and effectiveness of health promotion. Overall patient satisfaction and suitability was high for the program, interactions with the health educator, program materials and the length of sessions. The limitation of this study was that the time spent when counselling the patients was not described [30]. However, the group based glaucoma educational program did not improve adherence at either one month or three months after the intervention, but 58% of the participants showed improvement in adherence after electronic medication monitoring as this was the only study that used RCT and observations in this systematic literature review [32].

Assessment of outcomes:

The most used measurement assessment of medication adherence was an electronic medication monitoring. Out of the six randomised control trials, five used electronic medication monitoring in their studies [19,22.24,25]. Electronic medication monitoring is also called the gold standard for assessment of medication adherence because of its accuracy [15]. Another utmost commonly accepted measure of medication adherence was the use of medication pharmacy refill data as reported by Muir et al [36].

From the five observational studies that were reviewed in this systematic review, two studies conducted by McVeigh and Vakros [31] and Lunnela et al [34] used self-report and one used electronic medication monitoring (Dreer et al [30] as an assessment measure for adherence while Blondeau et al's [33] assessment of nurse-led group education session used prescription refill data. Only one observational study used a combination of both electronic medication monitoring and self-report [32]. However, the challenge that came with self-report as a measure of adherence was that it was often inaccurate although it can identify those who are nonadherent. It is most likely that those reporting nonadherences are being truthful.

Conclusion

Most of the systematic reviewed studies used electronic interventions and were hospital/pharmacy based. Few studies used motivational interviews and others used a combination of both electronic and pharmacy refill data. None of the studies were conducted in the community or family setting. Most of the studies that used self-report showed no significant improvement in medication adherence between the control group and the treatment group. However, with the electronic intervention, most showed an increase in glaucoma medication adherence between the two groups. During this study, a gap was identified that no publications or sources addressing a detailed strategy used in glaucoma adherence in South Africa / Africa were found. Some of the studies that were found were not evaluated to find out the outcome, such as the study protocol that was conducted in Nigeria on motivational interviewing to improve treatment uptake for glaucoma patients. All studies that have outcomes were conducted in developed countries. This necessitated consultation of unpublished dissertations and theses. Significantly, a lot of material is available on the knowledge attitude and self-care practices regarding glaucoma disease. This suggests that there are no known studies conducted on the intervention strategies to strengthen eye care follow up among glaucoma patients in Limpopo Province of South Africa.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical clearance to conduct the study was given by the University of Venda Research Ethics Committee (SHS/18/PH/35/0111).

FUNDING

None

CONFLICT OF INTEREST

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENT

Declared none

Reference list

[1] Olthoff CM, Hoevenaars JG, van den Borne BW, Webers CA, Schouten JS. Prevalence and determinants of non-adherence to topical hypotensive treatment in Dutch glaucoma patients. Graefe's archive for clinical and experimental ophthalmology. 2009 Feb 1;247(2):235.

[2] Newman-Casey PA, Dayno M, Robin AL. Systematic review of educational interventions to improve glaucoma medication adherence: an update in 2015. Expert review of ophthalmology. 2016 Jan 2; 11(1):5-20.

[3] Tamrat L, Gessesse GW, Gelaw Y. Adherence to topical glaucoma medications in Ethiopian patients. Middle East African journal of ophthalmology. 2015 Jan; 22(1):59.

[4] Murakami Y, Lee BW, Duncan M, Kao A, Huang JY, Singh K, Lin SC. Racial and ethnic disparities in adherence to glaucoma follow-up visits in a county hospital population. Archives of Ophthalmology. 2011 Jul 1; 129(7):872-8.

[5] Cakiner-Egilmez T. Glaucoma Medications Update: How to Improve Compliance and Adherence. Insight (American Society of Ophthalmic Registered Nurses). 2015; 40(3):5.

[6] Hark L, Waisbourd M, Myers JS, Henderer J, Crews JE, Saaddine JB, Molineaux J, Johnson D, Sembhi H, Stratford S, Suleiman A. Improving access to eye care among persons at high-risk of glaucoma in Philadelphia—design and methodology: the Philadelphia glaucoma detection and treatment project. Ophthalmic epidemiology. 2016 Mar 3; 23(2):122-30.

[7] Djafari F, Lesk MR, Giguère CÉ, Siam G, Freeman EE. Impact of a brief educational intervention on glaucoma persistence: a randomized controlled clinical trial. Ophthalmic epidemiology. 2015 Nov 2; 22(6):380-6.

[8] Moore DB, Walton C, Moeller KL, Slabaugh MA, Mudumbai RC, Chen PP. Prevalence of self-reported early glaucoma eye drop bottle exhaustion and associated risk factors: a patient survey. BMC ophthalmology. 2014 Dec;14(1):79.

[9] Leung VC, Jin YP, Hatch W, Mammo Z, Trope GE, Buys YM, Macrae WG. The relationship between sociodemographic factors and persistence with topical glaucoma medications. Journal of glaucoma. 2015 Jan 1; 24(1):69-76.

[10] Savović J, Weeks L, Sterne JA, Turner L, Altman DG, Moher D, Higgins JP. Evaluation of the Cochrane Collaboration's tool for assessing the risk of bias in randomized trials: focus groups, online survey, proposed recommendations and their implementation. Systematic reviews. 2014 Dec; 3(1):37.

[11] Dwan K, Altman DG, Arnaiz JA, Bloom J, Chan AW, Cronin E, Decullier E, Easterbrook PJ, Von Elm E, Gamble C, Ghersi D. Systematic review of the empirical evidence of study publication bias and outcome reporting bias. PloS one. 2008 Aug 28;3(8): e3081.

[12] Ramadhani HO, Bartlett JA, Thielman NM, Pence BW, Kimani SM, Maro VP, Mwako MS, Masaki LJ, Mmbando CE, Minja MG, Lirhunde ES. Association of first-line and second-line antiretroviral therapy adherence. In Open forum, infectious diseases 2014 Sep 1 (Vol. 1, No. 2, p. ofu079). Oxford University Press.

[13] Demonceau J, Ruppar T, Kristanto P, Hughes DA, Fargher E, Kardas P, De Geest S, Dobbels F, Lewek P, Urquhart J, Vrijens B. Identification and assessment of adherence-enhancing interventions in studies assessing medication adherence through electronically compiled drug dosing histories: a systematic literature review and meta-analysis. Drugs. 2013 May 1; 73(6):545-62.

[14] Moher D, Shamseer L, Clarke M, Ghersi D, Liberati A, Petticrew M, Shekelle P, Stewart LA. Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. Systematic reviews. 2015 Dec;4(1):1.

[15] Newman-Casey PA, Weizer JS, Heisler M, Lee PP, Stein JD. Systematic review of educational interventions to improve glaucoma medication adherence. In Seminars in ophthalmology 2013 May 1 (Vol. 28, No. 3, pp. 191-201). Taylor & Francis.

[16] Brandes K, Mullan B. Can the common-sense model predict adherence in chronically ill patients? A meta-analysis. Health psychology review. 2014 Apr 3;8(2):129-53.

[17] Skalicky SE, Goldberg I, McCluskey P. Ocular surface disease and quality of life in patients with glaucoma. American journal of ophthalmology. 2012 Jan 1; 153(1):1-9.

[18] Wachman JS, Rose DL, inventors; Vitality Inc, assignee. Medicine Bottle Cap with Electronic Embedded Curved Display. United States patent application US 12/770,436. 2010 Oct 28.

[19] Cook PF, Bremer RW, Ayala AJ, Kahook MY. Feasibility of motivational interviewing delivered by a glaucoma educator to improve medication adherence. Clinical Ophthalmology (Auckland, NZ). 2010; 4:1091.

[20] Lim MC, Watnik MR, Imson KR, Porter SM, Granier AM. Adherence to glaucoma medication: the effect of interventions and association with personality type. Journal of glaucoma. 2013 Aug 1; 22(6):439-46.

[21] Boland MV, Chang DS, Frazier T, Plyler R, Jefferys JL, Friedman DS. Automated telecommunication-based reminders and adherence with once-daily glaucoma medication dosing: the automated dosing reminder study. JAMA ophthalmology. 2014 Jul 1; 132(7):845-50.

[22] Beckers HJ, Webers CA, Busch MJ, Brink HM, Colen TP, Schouten JS, Dutch Adherence Study Group. Adherence improvement in Dutch glaucoma patients: a randomized controlled trial. Acta ophthalmologica. 2013 Nov; 91(7):610-8.

[23] Viswanathan M, Golin CE, Jones CD, Ashok M, Blalock SJ, Wines RC, Coker-Schwimmer EJ, Rosen DL, Sista P, Lohr KN. Interventions to improve adherence to self-administered medications for chronic diseases in the United States: a systematic review. Annals of internal medicine. 2012 Dec 4; 157(11):785-95.

[24] Cate H, Bhattacharya D, Clark A, Fordham R, Holland R, Broadway DC. Improving adherence to glaucoma medication: a randomised controlled trial of a patient-centred intervention (The Norwich Adherence Glaucoma Study). BMC ophthalmology. 2014 Dec; 14(1):32.

[25] Okeke CO, Quigley HA, Jampel HD, Ying GS, Plyler RJ, Jiang Y, Friedman DS. Interventions improve poor adherence with once daily glaucoma medications in electronically monitored patients. Ophthalmology. 2009 Dec 1; 116(12):2286-93.

[26] Pizzi LT, Tran J, Shafa A, Waisbourd M, Hark L, Murchison AP, Dai Y, Mayro EL, Haller JA. Effectiveness and cost of a personalized reminder intervention to improve adherence to glaucoma care. Applied health economics and health policy. 2016 Apr 1; 14(2):229-40.

[27] Glanz K, Beck AD, Bundy L, Primo S, Lynn MJ, Cleveland J, Wold JA, Echt KV. Impact of a health communication intervention to improve glaucoma treatment adherence: results of the interactive study to increase glaucoma adherence to treatment trial. Archives of ophthalmology. 2012 Oct 1; 130(10):1252-8.

[28] Gray TA, Fenerty C, Harper R, Spencer AF, Campbell M, Henson DB, Waterman H. Individualised patient care as an adjunct to standard care for promoting adherence to ocular hypotensive therapy: an exploratory randomised controlled trial. Eye. 2012 Mar; 26(3):407.

[29] Sleath B, Blalock SJ, Stone JL, Skinner AC, Covert D, Muir K, Robin AL. Validation of a short version of the glaucoma medication self-efficacy questionnaire. British Journal of Ophthalmology. 2012 Feb 1; 96(2):258-62.

[30] Dreer LE, Owsley C, Campbell L, Gao L, Wood A, Girkin CA. Feasibility, Patient Acceptability, and Preliminary Efficacy of a Culturally Informed, Health Promotion Program to Improve Glaucoma Medication Adherence Among African Americans: “Glaucoma Management Optimism for African Americans Living with Glaucoma” (GOAL). Current eye research. 2016 Jan 2; 41(1):50-8.

[31] McVeigh KA, Vakros G. The eye drop chart: a pilot study for improving administration of and compliance with topical treatments in glaucoma patients. Clinical ophthalmology (Auckland, NZ). 2015; 9:813.

[32] Richardson C, Brunton L, Olleveant N, Henson DB, Pilling M, Mottershead J, Fenerty CH, Spencer AF, Waterman H. A study to assess the feasibility of undertaking a randomized controlled trial of adherence with eye drops in glaucoma patients. Patient preference and adherence. 2013; 7:1025.

[33] Blondeau P, Carbonneau M, Esper P, Turcotte PC. A 2-hour information session and patient recall has minimal impact on glaucoma-treatment persistence in a mature practice. Journal of glaucoma. 2012 Aug 1; 21(6):379-82.

[34] Lunnela J, Kääriäinen M, Kyngäs H. Web-based intervention for improving adherence of people with glaucoma. Journal of Nursing and Healthcare of Chronic Illness. 2011 Jun; 3(2):119-29.

[35] Koshy, E., Car, J. and Majeed, A., 2008. Effectiveness of mobile-phone short message service (SMS) reminders for ophthalmology outpatient appointments: observational study. BMC ophthalmology, 8(1), p.9.

[36] Muir KW, Ventura A, Stinnett SS, Enfiedjian A, Allingham RR, Lee PP. The influence of health literacy level on an educational intervention to improve glaucoma medication adherence. Patient education and counseling. 2012 May 1; 87(2):160-4.

CHAPTER 3

Loss to Follow-Up Amongst Glaucoma Patients in Selected Hospitals of The Limpopo Province, South Africa

Loss to Follow-Up Amongst Glaucoma Patients in Selected Hospitals of The Limpopo Province, South Africa

Published as Tshivhase, S.E., Khoza, L.B. and Tshitangano, T.G., 2020." ***Loss to follow-up amongst glaucoma patients in selected hospitals of the Limpopo Province, South Africa***." African Vision and Eye Health, 79(1), pp.1-7.

ISSN: (Online) 2410-1516, (Print) 2413-3183

Dates:

Received: 17 Feb. 2020

Accepted: 29 July 2020

Published: 28 Oct. 2020

ABSTRACT

Background: Glaucoma is associated with visual field loss for which elevated intraocular pressure is the primary risk factor. Proper medication adherence requires daily intake of prescribed medication for a lifetime. Non-adherence patients are at greater risk of poor outcome than adherent patients.

Aim: To identify behavioural determinants contributing to loss to follow-up amongst glaucoma patients.

Setting: The study was conducted in selected hospitals of South Africa.

Methods: A hospital-based cross-sectional study was conducted on glaucoma patients with age ranging from 18 years and above. Quantitative methods were used to collect data from purposefully selected glaucoma patients. Structured questionnaires were distributed to collect data from patients attending glaucoma clinics. The patients should have missed an appointment review at least once during the 12-month period.

Results: Amongst the 429 glaucoma patients interviewed, the majority (79%, n = 341) of the patients missed their follow-up more than once during the 12-month period. The most cited contributory barriers to poor follow-up were accessibility (26%) followed by lack of escort and financial cost at 22% and 21%, respectively. About 115 of the 429 study respondents were found to be non-adherent. The main reasons given were shortage of medication and forgetfulness at 36% and 29%, respectively.

Conclusion: Accessibility and lack of escort were significant barriers to loss to follow-up. Identifying the predictors of poor follow-up can help in improving follow-up care. Therefore, patient education and support may improve adherence to glaucoma therapy.

Keywords: glaucoma; glaucoma patient; loss to follow-up; intraocular pressure; medication adherence; non-adherence.

Introduction

Glaucoma may cause vision loss and irreversible blindness if not treated. However, vision loss because of glaucoma can be prevented if detected early and properly treated. However, early identification of glaucoma and the effectiveness of screening programmes depend on the compliance with follow-up care.[1]There are many reasons why glaucoma remains difficult to arrest within populations. One of the reasons is that it is asymptomatic thus many people do not to seek immediate medical care.[2] There are many reasons why glaucoma remains difficult to arrest within populations. One of the reasons is that it is asymptomatic, and thus, many people do not seek immediate medical care.[2] For example, the United State of America's (USA) Preventive Service Task Force reports that evidence to support glaucoma or visual acuity screening is inadequate. More than half of the patients with abnormal screening results fail to come back for follow-up eye examination as expected. Furthermore, glaucoma affects the quality of life through its treatment, and vision loss requires a demanding life-long multidrug regimen.[3,4]

Loss to follow-up refers to patients who at one point in time were actively participating in a clinical research trial but have become lost (either by error in a computer tracking system or by being unreachable) at the point of follow-up in the trial. However, patients can become lost to follow-up for many other reasons.[5,6] Participants were considered lost to follow-up if they had not reported at the referral examination (up to 3 different scheduled times) and failed to answer contact calls or to reschedule a missed or cancelled an appointment in up to three attempts on different days. Several studies [(5,7,8)] have indicated that 80% of glaucoma patients do not adhere to treatment recommendations hence loss to follow-up. Poor adherence to medication is a multifactorial issue with many contributing factors such as patient-centered factors, therapy related factors, social and economic factors.[5,9]

Patient related factors can negatively affect adherence to glaucoma treatment. Non-adhering patients are at greater risk of poor outcomes than adherent patients. Poor adherence can result in the ineffectiveness of treatment while improvement of adherence could prevent the need to use multiple glaucoma treatment.[10,11] non-adherence to glaucoma treatment is a global problem. Several studies have been conducted worldwide regarding loss to follow-up amongst glaucoma patients. Lifelong monitoring is an integral part of glaucoma management and lack of adequate follow-up can pose serious consequences for glaucoma patients on medical or surgical therapy. A study conducted in sub-Saharan Africa by Kyari et al[12] indicated that some patients fail to return for follow-up if they assumed that their treatment was no longer effective and when patients felt better and concluded that they had no need of further treatment. Long distances from hospitals and economic implications of repeated consultations and negative attitude of health care workers were cited as factors contributing to loss to follow-up.

Though glaucoma is incurable, it is treatable. The primary objective of glaucoma therapy is to prevent the progressive vision loss, disability and blindness. Regular monitoring is vital in the lowering of IOP and maintaining vision. It is recommended that glaucoma patients are seen by the ophthalmologist at least every 6-12 months for a comprehensive eye examination according to the American Academy of Ophthalmology.[7] Similarly, the South African Glaucoma Guidelines, which are in line with International

Glaucoma Society Guidelines, 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.[13] Therefore, the purpose of this study was to increase the understanding of reasons for Loss to follow-up among glaucoma patients in the selected rural hospitals of the Limpopo province, South Africa.

RESEARCH METHODOLOGY

Study design

A purposive cross-sectional study was conducted on glaucoma patients who were attending follow-up clinic to increase the understanding of reasons for Loss to follow-up among glaucoma patients

Study Setting

The study was conducted in four selected hospitals of Vhembe District with patients of different ethnic cultural backgrounds. The spoken language of the population is mainly Tshivenda and Xitsonga. Vhembe is one out of the five districts of the Limpopo Province is the province is one of the nine provinces in South Africa. The researcher chose to conduct the study in the selected hospitals of Vhembe District because preliminary research indicated a high rate of loss to follow-up among glaucoma patients.

Study Design

The study involved the use of a quantitative approach to collect data from the respondents. A cross sectional descriptive study design was used to obtain information from the respondents.

Study Population

The study population consisted of glaucoma patients who were at least 18 years and above. Participants had to be established glaucoma patients who had been under review for at least three years. These criteria. ensured that respondents had sufficient experience of living with glaucoma and receiving treatment and follow-up care. Patients were excluded if they had other ocular conditions other than glaucoma (like age related macular degeneration, diabetic retinopathy or any other visual impairment causing disease). Respondents were also excluded if they had dementia or another isolated cognitive impairment.

Sample and Sampling methods

Participants were sampled from selected hospitals with the highest rate of glaucoma loss to follow- up within the district of Vhembe. Only patients diagnosed with glaucoma were purposively sampled as they serve best the purpose of the study. The study involved both male and female glaucoma patients from the age of 18years and above at four selected hospitals in Vhembe District of Limpopo Province. The total sample size for the study was 460.

Sample size

The sample size was calculated using the Guidelines for Sampling by Stoker (1985) as cited by de Vos, Strydom, Fouche and Deport.[14] For every population which is less than 20, the suggested percentage is

100%. In this study, for every population which was 100 and less, the researcher sampled the whole population.

Data collection instrument

The instrument was developed based on a comprehensive literature review by the first author. The instrument was drawn other relevant Studies. [15,16,17] The literature review was divided into six sections. Section A covered demographic characteristics of the participants. The other five sections covered the knowledge of glaucoma disease, practices regarding glaucoma disease, attitude regarding glaucoma disease and environmental determinants contributing to glaucoma loss to follow-up (LTFU). The questionnaire was given to a language expert who translated it into the local spoken languages. It was also translated back into English by the language expert to ensure that the original meaning was maintained. The researcher and the research assistant visited the study respondents at the eye clinic of the selected hospitals on the appointment dates. Prior to data collection, the researcher explained the purpose of the study to all respondents after obtaining an oral informed consent. The developed questionnaires were given to the respondents by the researcher and her research assistant. Respondents were given the questionnaires to complete on their own. However, a great number of respondents were unable to complete on their own due to illiteracy. Moreover, some respondents could not complete the questionnaire on their own because of poor vision. In the end, more than three quarter of the respondents were assisted to complete the questionnaires. The Morisky Medication Adherence Scale (MMAS) was used as an instrument for evaluating the adherence to the glaucoma medication.[18]

Compliance or adherence to medication is the extent to which patients act in accordance with the prescribed interval and dose of a dosing regimen. Compliance or adherence to medication has to do with the accuracy with which a patient follows the treatment plan.[5] In this study, adherence is when a patient does not miss more than two doses per week of his or her medications.

Validity and reliability

To ensure validity the instrument was developed guided by the study objectives and literature. The instrument was also reviewed by an expert in the Department of Public Health of the University of Venda before data collection. To ensure that respondents would understand the questions, the questionnaire was translated into Tshivenda and Xitsonga by a language expert from the University of Venda's Department of Linguistics. The test-retest method was done on 46 glaucoma patients who did not form part of the study to test for clarity and appropriateness of the questions and the feasibility of the study. This was done by administering the questionnaire twice to the same respondents. The first set of responses was compared with the second set by calculating the correlation coefficient. The correlation coefficient was 0.85 indicating that the reliability of the instrument was high.

Data Analysis

The completed questionnaires were scrutinized after data collection. The researcher used codes rather than respondents' names and checked data by frequency to identify missing or incorrect values. Those that

were not properly completed were excluded, and all completed questionnaires were collated and coded starting from 001 to 469. Data was then captured into the Statistical Package for Social Sciences (SPSS) software version 24. After cleaning the data, descriptive and inferential statistics were applied to the data.

Ethical consideration

The research proposal was presented to the School Higher Degrees Committee for recommendation to the University Higher Degrees Committee for approval. The University of Venda Ethics Committee evaluated the proposal and issued an ethical clearance no SHS/18/PH/0111. Using the UHDC's approval and the ethical clearance certificate, the researcher sought permission from the Limpopo Provincial Department of Health and Vhembe District Department of Health. Furthermore, permission was also obtained from the Hospital managers/CEO of all selected hospitals in Vhembe District where the study was conducted.

RESULTS

Socio demographic factors

The study populations comprised of 294 females (69%) and 135 males (31%), and 93(22%) of the respondents lived alone. Out of 460 questionnaires, 429 were satisfactorily filled by the respondents thus resulting in a response rate of 93%. Two hundred and seventy-eight respondents, (65%) were over 65 years old while 18(4%) were younger than 24 years. About 265 (62%) of the respondents were Christians and 164(38%) practiced forms of African religion. Three hundred and one (70%) respondents did not have any formal education while 13(3%) had tertiary education. Two hundred and sixty-three (61%) respondents said they would not accept surgery to treat their glaucoma. Two and fifty-four (59%) respondents indicated that they have had glaucoma disease for more than seven years.

Association between demographic factors and glaucoma awareness

Further analysis to establish the association between the age of the respondents and glaucoma knowledge and awareness was done. The chi-squared p-value at 0.05 was used. The findings showed significant association between age and awareness that glaucoma requires lifelong treatment (037). A large number of patients with glaucoma have no symptoms (0.19) and loss of vision due to glaucoma (0.01) was significant among the respondents who were 55 years and older. The finding could imply that older patients have higher knowledge of glaucoma awareness than younger patients. However, the Pearson Chi-square did not show any significance between gender, level of education and the above variables.

Table: 1. Respondents' level of glaucoma knowledge (n=429)

Statement:	Frequency	Percentage
Perceived cause of glaucoma is:	n	%
Disease that runs in family/Heredity	119	28
Eye disease that is caused by witchcraft	140	32
Don't know	170	40
Glaucoma is a treatable disease	311	72
Yes	118	28
No		
Glaucoma patient requires lifelong treatment		
Yes	315	73
No	114	27
Most patients with glaucoma have no symptoms		
Yes	180	42
No	249	58
Vision loss in glaucoma is permanent		
Yes	192	45
No	237	55
Glaucoma patients require follow-up care		
Yes	208	49
No	221	51
If left untreated, glaucoma can lead to blindness		
Yes	194	45
No	235	55

Out of 429 respondents, 170(40%) did not know that glaucoma is caused by heredity. On the other hand, 119(28%) respondents knew the causes of glaucoma. One hundred and forty (32%) of the respondents assumed that glaucoma disease was caused by witchcraft as shown in Table 1

About 311(72%) respondents knew that glaucoma is treatable and 315(73%) knew that glaucoma requires lifelong treatment. More than half of the respondents 235(55%) did not know that glaucoma can lead to blindness if left untreated. Two hundred and eight (49%) of the respondents knew that glaucoma usually requires follow-up whereas 221(51%) did not know. Less than half of the respondents180 (42%) indicated that glaucoma patients had no symptoms and 249 (58%) respondents did not know.

TABLE 2: Attitude and beliefs towards glaucoma disease(n=429)

Statement	Agree		Disagree	
	n	%	n	%
No benefit in taking glaucoma medication regularly	115	26.8	314	73.1
I don't want people to know that I suffer from glaucoma	252	58.7	117	47.2
I felt very bad when I was diagnosed with glaucoma	310	72.6	119	27.7
Regular glaucoma follow-up is important	208	49.0	208	49.0
Glaucoma is a disease of the aged	101	23.5	318	74.0
I feel comfortable when doctors prescribe more than two eye medication to use in a day	324	75.5	105	24.4
I believe that using eye drops worsen my condition	140	32.6	289	67.3

On the one hand 310 (73%) respondents agreed that they felt very bad when they were diagnosed with glaucoma disease (Table 2). On the other hand, 119 (28%) respondents accepted the diagnosis. Almost three quarter of the respondents, 318 (74%) agreed that glaucoma is a disease of the aged, whereas 101 (24%) disagreed. About 324 (76%) of the respondents agreed that they felt comfortable when doctors prescribed more than two eye drops to use as opposed to 105 (24%) who disagreed. More than half 289 (67%) of the respondents agreed that using eye drops can worsen their condition compared with 140 (33%) who disagreed.

TABLE 3: Practice regarding level of compliance (n = 429).

Demographic variable	Frequency= n	Percentage %
Number of missed eye drops per week		
None	210	49
1–2	104	24
3–5	40	9
More than five	75	17
Compliance		
Yes	210	49
No	219	51
Reasons for non-compliance		
Lack of knowledge	60	27.3
Forgetfulness	56	25.5
Denial	40	18.2
Misunderstanding	35	15.9
No specific reason	28	12.7

A total of 219(51%) respondents had missed doses more than once per week compared to 210(49%) who had never missed any dose. This study defined non-compliance as missing at least one dose of medication per week. Respondents who had a compliance rate <100% were asked to give reasons for their failure to comply to the prescribed medication. Compliance rates were defined as good if they ranged between 95% and 100% and as poor or inadequate if they were less than 95%. Inadequate knowledge 60(27%)) followed by forgetfulness 56(26%) were the common specified reasons for not complying with glaucoma medication regimen. In addition, 35(16%) of the respondents stated that they had misunderstood dosage instructions while 28(13%) could not point to specific reasons for their non-compliance.

The study revealed other socio-demographic reasons for missed clinic appointment over 12 months. Out of 341 (79%) respondents who missed their clinic visit, 89 (26%) missed because of lack of escort, followed by long distance and financial cost at 22% and 21%, respectively. About 48.3% (n = 207) of the respondents travelled more than15 km to the clinic concerned.

Discussion of the study findings

There were more female (69%) than male (31%) respondents for this study. This disproportionate sex distribution of respondents might have been influenced by the fact that more female respondents access healthcare facilities than male respondents. Similar findings were reported by different authors who indicated high numbers of female respondents than male respondents in their studies.[19,20,21] Regarding the demographic data, ages of the respondents were found significant in relation to knowledge and awareness that glaucoma requires lifelong treatment. This is similar to the findings of Aghedo et al.[20] in KwaZulu-Natal, South Africa. In an urban population of South India Durowade et al.[21] revealed that there is a strong relationship between the age of the respondents and glaucoma knowledge. Respondents older than 30 years were significantly more likely to be aware of glaucoma than those below 30 years. In Australia, Curtis et al.[22] reported that patients who are 65 years and older had adequate knowledge than younger patients in understanding eye drop instillation. The study further reported that older patients (above 65 years) were often happy to ‘do as they are told’ because of the trust they had in healthcare provider. However, this study contrasts with many other study findings by Ogbonnaya et al.[23] and Mbadugha et al.[24] in Lagos, Nigeria, and Prabhu et al.[25] in South India who reported that age and religion had no influence on glaucoma awareness.

Also in contrast with the present study’s findings, a study in Eastern Nepal found that there was no association amongst age, awareness and knowledge.[26] Some studies further indicated that even though many of the respondents had heard about glaucoma, only a few of them had accurate understanding of glaucoma disease.[26,27] However, in the present study, we observed a reduction in the higher level of knowledge of patients with increasing age. A possible explanation for this finding may be the fact that older patients forget information more easily than younger patients because of senility. Most respondents (249), that is, about 58% in this study, reported that glaucoma disease has no symptoms. Similar results were reported by Abdull et al.[28] and Altangerel et al.[29] In India, Bart et al.[30] stated that glaucoma is asymptomatic

and painless and causes irreversible damage to the optic nerve. Similarly, Ichhpujani et al.[31] indicated that damage caused by glaucoma disease to the optic nerve is reversible.

In this study, respondents exposed relatively little or a lack of knowledge about the glaucoma disease. Ichhpujani et al.[31] and Altangerel et al.[29] reported similar results that knowledge about glaucoma disease was inadequate amongst patients in North India and Canada respectively, as most participants claimed to be aware of glaucoma but did not understand the symptoms, risk factors and treatment. These authors further reported a startling fact of medical personnel (35% of nurses and 20% of doctors) who did not understand that glaucoma is associated with high blood pressure in the eye and that it had an effect on the optic nerve.[31] However, in Northern Nigeria, Abdull et al.[32] stated that there was adequate knowledge amongst patients although patients failed to understand that the purpose of glaucoma treatment is to preserve the existing vision rather than restoring sight.

Respondents in this study revealed that they sometimes forget to administer their eye drops. Different authors Kontoh[11] and Ajayi[33] and Blondeau et al. [34] similarly found that forgetfulness to medications contributes to nonadherence. Olthoff et al.[35] and Tsai[36] stated that glaucoma patients forgot their medications because there is no direct advantage from the eye drops and no immediate disability from the disease. Also, patients who failed to accept their glaucoma disease and the use of treatment for life tend to forget easily as attested by Tsai.[36] The findings concur with the study results by Newman-casey et al.[5] who reported that 62% of the patients cited forgetfulness as their number one barrier with both non-adherent and adherent patients.

This study revealed that some respondents had a negative attitude towards glaucoma treatment and management. Most respondents (73%) felt very bad when they were diagnosed with glaucoma and did not want other people to know about their disease. This is attributed to the fact that respondents are afraid of going blind and are worried about living with a chronic condition. Some respondents felt uncertain about their future because of glaucoma disease. Similar results were reported in a South African study conducted in KwaZulu-Natal with 95% patients showing a negative attitude towards their glaucoma diagnosis but on the other hand feeling happy with the use of their eye drops.[20] In this study, more than half of the study respondents were not aware that they should do regular glaucoma follow-up. This is attributed to the ineffective information given to some of the patients. Similar results were attested by Demirtaş et al.[37] who mentioned that glaucoma patients were not aware about the importance of regular eye examination. However, the study by Thompson et al.[17] reported that other patients believed in the importance of follow-up even when there is no visible change in their vision after using the medications.

This study also revealed that some respondents' poor practice contributed to non-compliance with the treatment and management of their condition leading to LTFU. The study showed that 219 (51%) of the respondents were not compliant with treatment and management. Patients on single eye drop adhered more to their glaucoma medication than those on multiple eye drops. Stryker et al.[38] and Castel et al.[39] stated that adherent patients believed that medications prevent disease progression and maintain vision. The study further mentioned about the benefits of using eye drops regularly. However, some of the study

respondents indicated that they sometimes use traditional eye medications to treat glaucoma disease and others consult their spiritual healers. Some of the respondents perceived that glaucoma is caused by witchcraft or evil spirit. De-gaulle et al.[40] reported similar findings in their study stating that glaucoma patients preferred alternative eye care service such as traditional healers and preferred local pharmaceutical shops than visiting an ophthalmologist or optometrist. Similar studies conducted Abdull et al [28] reported that traditional healers were the most respected and trusted people in some of the African countries. The study further indicated that environmental factors greatly contributed to respondents' missing clinic visits resulting in non-compliance. Factors such as financial means, no escort to accompany respondents and long queues at the clinics were raised.

The study showed consistency with those conducted by Sunet al.[41] in China and Radhakrishnan et al[42] in India who reported that patients had failed to attend their follow-up and travelling difficulty were noted as reasons for nonattendance. Ehiemua[43] also obtained similar findings in Namibia. Several researchers found that patients spend many hours waiting to access care at every point because of reasons such as hospital staffs' inability to retrieve patients' files, patients queuing for a long time, difficulty in scheduling the appointment making use of an interpreter during consultation and patients from different clinics made to attend at a single point.[44,45,46] Similar studies conducted by Momoh et al.[46] in Southern Nigeria and Abdull44 in South East Nigeria discovered that patients residing more than 50 km from the health facility showed poor follow-up than respondents living nearer to health facilities. In California (United States [US]) and Philadelphia (US), researchers reported that glaucoma patients expressed financial barriers and lack of escort to access healthcare services as attributing to LTFU. Thompson et al.[17], Kim et al.[47], Lee et al[48] and Landers et al.[49] pointed out that rural healthcare is characterized by challenges such as longer commuting distances, which lead to slower access to critical care during emergencies. One study shows that travel and financial cost are intrinsically linked and it is so difficult to separate them as distinct components.[38]

Limitations

The study was only conducted in selected hospitals of Vhembe district. Therefore, the results cannot be generalized to the rest of Limpopo Province. Moreover, the study was restricted to patients with established glaucoma presenting themselves at hospitals that only provide glaucoma services. Further research work should be done on glaucoma patients using qualitative methods to try and get detailed information regarding LTFU.

Conclusion

Our study shows that non-adherence with scheduled follow-up appointment among glaucoma patients in rural hospitals is prevalent. Patients outlined various reasons that contributed to their glaucoma loss to follow-up. The reasons included inadequate knowledge regarding the disease itself, perception that compliance to medications and follow-up are less important, forgetfulness, financial difficulties, lack of an escort to the clinic, travel distance from home to the clinic exceeding more than 15km, long hospital ques and the belief that glaucoma is caused by witchcraft or evil spirit. Similarly, the study concurs with other studies that were conducted mostly in sub-Saharan Africa. Therefore, appropriate measures need to be done to strengthen eye care follow-up amongst glaucoma patients.

Recommendations

Patients should be informed about the advantages and disadvantages of glaucoma loss to follow-up. Family members and community should be educated on eye conditions such as glaucoma so that they should be involved in the care and offer support. Vhembe District Department of health should provide Mobile Clinic Van for easy access for most glaucoma patients who stays far from the health facilities. Eye health care practitioners should be provided with training on motivational interviewing to equip them with skills to motivate glaucoma patients to remain in care. Campaigns to enhance public eye awareness on glaucoma diseases should be done to improve the effectiveness of health promotion and prevent unnecessary blindness. All this could significantly improve the quality of life for these people and their families, while at the same time reducing national expenditure by health care services and increasing productivity in the economy of the country.

Acknowledgements

The authors thank all the participants who participated in the study and the University of Venda Research and Innovation for funding this project.

Competing interests

The authors have declared that no competing interests exist.

Authors' contributions

All the authors have contributed equally to this work.

Funding information

The research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Data availability statement

Data have been saved by the principal author and are available upon request**.**

Reference List

1. Rumelt S, Schreiber S. Why Do Patients with Controlled Glaucoma Continue to Lose Their Vision? Causes and Coping with Visual Impairment and Blindness. 2018 Sep 19:23.

2. Susanna R, De Moraes CG, Cioffi GA, Ritch R. Why do people (still) go blind from glaucoma? Translational vision science & technology. 2015 Mar 1;4(2):1.

3. Quaranta L, Riva I, Gerardi C, Oddone F, Floriano I, Konstas AG. Quality of life in glaucoma: a review of the literature. Advances in therapy. 2016 Jun 1;33(6):959-81.

4. Zheng CX, Hu WD, Tran J, Siam L, Berardi GG, Sembhi H, Hark LA, Katz LJ, Waisbourd M. Barriers to receiving follow-up eye care and detection of non-glaucomatous ocular pathology in the Philadelphia Glaucoma Detection and Treatment Project. Journal of community health. 2016 Apr 1;41(2):359-67.

5. Newman-Casey PA, Robin AL, Blachley T, Farris K, Heisler M, Resnicow K, Lee PP. The most common barriers to glaucoma medication adherence: a cross-sectional survey. Ophthalmology. 2015 Jul 1;122(7):1308-16.

6. Dettori JR. Loss to follow-up. Evidence-based spine-care journal. 2011 Feb;2(01):7-10.

7. Fudemberg SJ, Lee B, Waisbourd M, Murphy RA, Dai Y, Leiby BE, Hark LA. Factors contributing to nonadherence to follow-up appointments in a resident glaucoma clinic versus primary eye care clinic. Patient preference and adherence. 2016; 10:19.

8. Cate H, Bhattacharya D, Clark A, Holland R, Broadway DC. Patterns of adherence behaviour for patients with glaucoma. Eye. 2013 Apr;27(4):545-53

9. Kulkarni SV, Damji KF, Buys YM. Medical management of primary open-angle glaucoma: Best practices associated with enhanced patient compliance and persistency. Patient preference and adherence. 2008; 2:303.

10.Njenga LN. Determinants of Non-adherence to Long Term Therapy with Prescription Medicines in Adult Patients Attending Medical Outpatient Clinic at Mbagathi Hospital (Doctoral dissertation, University of Nairobi).

11. Kontoh DO. Factors Influencing Non-Adherence to Topical Anti-Glaucoma Medications among Patients Attending Crystal Eye Clinic, Adenta (Doctoral dissertation, University of Ghana).

12.Kyari F, Adekoya B, Abdull MM, Mohammed AS, Garba F. The current status of glaucoma and glaucoma care in sub-Saharan Africa. The Asia-Pacific Journal of Ophthalmology. 2018 Nov 1;7(6):375-86.

13. Tham YC, Li X, Wong TY, Quigley HA, Aung T, Cheng CY. Global prevalence of glaucoma and projections of glaucoma burden through 2040: a systematic review and meta-analysis. Ophthalmology. 2014 Nov 1;121(11):2081-90.

14.De Vos AS, Delport CS, Fouche CB, Strydom H. Research at grass roots: A primer for the social science and human professions. Van Schaik Publishers; 2011.

15. Sathyamangalam RV, Paul PG, George R, Baskaran M, Hemamalini A, Madan RV, Augustian J, Prema R, Lingam V. Determinants of glaucoma awareness and knowledge in urban Chennai. Indian journal of ophthalmology. 2009 Sep;57(5):355.

16. Welge-Lussen U, Weise S, Alice LY. Assessing the adherence behavior of glaucoma patients to topical eye drops. Patient preference and adherence. 2015; 9:17

17. Thompson AC, Thompson MO, Young DL, Lin RC, Sanislo SR, Moshfeghi DM, Singh K. Barriers to follow-up and strategies to improve adherence to appointments for care of chronic eye diseases. Investigative ophthalmology & visual science. 2015 Jul 1;56(8):4324-31.

18. de Oliveira-Filho AD, Morisky DE, Neves SJ, Costa FA, de Lyra Junior DP. The 8-item Morisky Medication Adherence Scale: validation of a Brazilian–Portuguese version in hypertensive adults. Research in Social and Administrative Pharmacy. 2014 May 1;10(3):554-61.

19 Jin YP, Miller G, Lin K, Trope GE. Glaucoma knowledge in a black community in Toronto. Int J Ophthalmol Eye Res. 2014 Aug 22;2(5):59-64.

20. Aghedo, A.V., Tlou, B. And Mahomed, S.,2018. Knowledge, attitudes and self-care practices of patients with glaucoma in uThungulu in KwaZulu-Natal. African Vision and Eye Health,77(1), pp.1-6.

21. Durowade KA, Babatunde OA, Salaudeen AG, Musa OI, Bolarinwa OA, Anyaike C. Knowledge and Risk Factors for Glaucoma among Adults in a Rural Community of Kwara State, North-Central Nigeria. TAF Preventive Medicine Bulletin. 2014 Sep 1;13(5).

22.Curtis JR, Xi J, Westfall AO, Cheng H, Lyles K, Saag KG, Delzell E. Improving the prediction of medication compliance: the example of bisphosphonates for osteoporosis. Medical care. 2009 Mar;47(3):334.

23 Ogbonnaya CE, Ogbonnaya LU, Okoye O, Kizor-Akaraiwe N. Glaucoma awareness and knowledge, and attitude to screening, in a rural community in Ebonyi State, Nigeria. Open Journal of Ophthalmology. 2016 May 4;6(2):119-27.

24. Mbadugha CA, Onakoya AO. The awareness, perceptions and experiences of primary open angle glaucoma patients in Lagos Nigeria. Scientific reports. 2014 Dec 23;4(1):1-6.

25. Prabhu M, Patil SH, Kangokar PC. Glaucoma awareness and knowledge in a tertiary care hospital in a tier-2 city in South India. Journal of the Scientific Society. 2013 Jan 1;40(1):3.

26. ATALAY K, KIRGIZ A, AŞIK Ş. Awareness and Knowledge of Glaucoma Among Healthcare Workers and Patients in a Big City of Turkey. Glokom-Katarakt. 2019 Sep 1;14(3).

27.Shakya-Vaidya S, Povlsen L, Shrestha B, Grjibovski AM, Krettek A. Understanding and living with glaucoma and non-communicable diseases like hypertension and diabetes in the Jhaukhel-Duwakot Health

Demographic Surveillance Site: a qualitative study from Nepal. Global health action. 2014 Dec 1;7(1):25358.

28. Abdull MM, Gilbert CC, Evans J. Primary open angle glaucoma in northern Nigeria: stage at presentation and acceptance of treatment. BMC ophthalmology. 2015 Dec 1;15(1):111.

29 Altangerel U, Nallamshetty HS, Uhler T, Fontanarosa J, Steinmann WC, Almodin JM, Chen BH, Henderer JD. Knowledge about glaucoma and barriers to follow-up care in a community glaucoma screening program. Canadian Journal of Ophthalmology. 2009 Feb 1;44(1):66-9.

30.Batra R, Tailor R, Mohamed S. Ocular surface disease exacerbated glaucoma: optimizing the ocular surface improves intraocular pressure control. Journal of glaucoma. 2014 Jan 1;23(1):56-60.

31. Ichhpujani P, Bhartiya S, Kataria M, Topiwala P. Knowledge, attitudes and self-care practices associated with glaucoma among hospital personnel in a tertiary Care Center in North India. Journal of current glaucoma practice. 2012 Sep;6(3):108.

32. Abdull MM, Chandler C, Gilbert C. Glaucoma, “the silent thief of sight”: patients’ perspectives and health seeking behaviour in Bauchi, northern Nigeria. BMC ophthalmology. 2016 Dec 1;16(1):44.

33.Ajayi IA, Omotoye OJ, Ajite KO, Fadamiro CO, Ajayi EA. Self-medication practices among patients seen in A suburban tertiary eye care center in Nigeria. Asian Journal of Medical Sciences. 2014;5(2):85-90.

34.. Blondeau P, Esper P, Mazerolle É. An information session for glaucoma patients. Canadian journal of Ophthalmology. 2007 Dec 1;42(6):816-20.

35. Olthoff CM, Hoevenaars JG, van den Borne BW, Webers CA, Schouten JS. Prevalence and determinants of non-adherence to topical hypotensive treatment in Dutch glaucoma patients. Graefe's archive for clinical and experimental ophthalmology. 2009 Feb 1;247(2):235

36. Tsai JC. A comprehensive perspective on patient adherence to topical glaucoma therapy. Ophthalmology. 2009 Nov 1;116(11): S30-6. Tsai JC. A comprehensive perspective on patient adherence to topical glaucoma therapy. Ophthalmology. 2009 Nov 1;116(11): S30-6.

37. Demirtaş Z, Dağtekin G, Önsüz MF, Soysal A, Yıldırım N, Metintaş S. Validity and reliability of the glaucoma knowledge level questionnaire. Turkish journal of ophthalmology. 2018 Jun;48(3):115.

38. 38 Stryker JE, Beck AD, Primo SA, Echt KV, Bundy L, Pretorius GC, Glanz K. An exploratory study of factors influencing glaucoma treatment ad

39. Cohen Castel O, Keinan-Boker L, Geyer O, Milman U, Karkabi K. Factors associated with adherence to glaucoma pharmacotherapy in the primary care setting. Family practice. 2014 Aug 1;31(4):453-61.

40 De-Gaulle VF, Dako-Gyeke P. Glaucoma awareness, knowledge, perception of risk and eye screening behaviour among residents of Abokobi, Ghana. BMC ophthalmology. 2016 Dec;16(1):1-7.

41. Sun J, Zhou X, Kang Y, Yan L, Sun X, Sui H, Qin D, Yuan H. Prevalence and risk factors for primary open-angle glaucoma in a rural northeast China population: a population-based survey in Bin County, Harbin. Eye. 2012 Feb;26(2):283-91.

42.. Radhakrishnan M, Venkatesh R, Valaguru V, Frick KD. Economic and social factors that influence households not willing to undergo cataract surgery. Indian journal of ophthalmology. 2015 Jul;63(7):594.

43. Ehiemua UR. Reasons for poor adherence to Antiretroviral Therapy (ART) by young female (15-24 years) HIV/AIDS patients in Oshakati district (Doctoral dissertation, Stellenbosch: Stellenbosch University).

44. Abdull M. Patients and glaucoma: what are the challenges? Community Eye Health. 2012;25(79-80):44.

45. Adio AO, Onua AA. Economic burden of glaucoma in Rivers State, Nigeria. Clinical ophthalmology (Auckland, NZ). 2012; 6:2023.

46. Momoh RO, Bunce C, Oko-oboh GA, Gilbert CE. Advanced glaucoma at presentation is associated with poor follow-up among glaucoma patients attending a tertiary eye facility in Southern Nigeria. Ophthalmic epidemiology. 2018 May 4;25(3):266-72.

47. Kim CY, Park KH, Ahn J, Ahn MD, Cha SC, Kim HS, Kim JM, Kim M.J, Kim TW, Kim YY, Lee JW. Treatment patterns and medication adherence of patients with glaucoma in South Korea. British Journal of Ophthalmology. 2017 Jun 1;101(6):801-7.

48. Lee BW, Sathyan P, John RK, Singh K, Robin AL. Predictors of and barriers associated with poor follow-up in patients with glaucoma in South India. Archives of Ophthalmology. 2008 Oct 13;126(10):1448-54.

49. Landers J, Henderson T, Craig J. The prevalence of glaucoma in indigenous Australians within Central Australia: The Central Australian Ocular Health Study. British journal of ophthalmology. 2012 Feb 1;96(2):162-6

CHAPTER 4

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

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

Published as Tshivhase S, Khoza LB. **"*Challenges Contributing to Loss to Follow-up as Experienced by Glaucoma Patients in the Vhembe District of Limpopo Province, South Africa*".** The Open Public Health Journal. 2020 Oct 26;13(1).

Identifiers and Pagination:

Year: 2020

Volume: 13

First Page: 531

Last Page: 537

Publisher Id: TOPHJ-13-531

DOI: 10.2174/1874944502013010531

Article History:

Received Date: 24/6/2020

Revision Received Date: 1/8/2020

Acceptance Date: 20/8/2020

Electronic publication date: 26/10/2020

Collection year: 2020

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. On-adherence to medical treatments typically leads 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 anti-glaucoma 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:

Patients' lost to follow-up is negatively influenced by travel cost for the patients from home to the health facilities and insufficient understanding of glaucoma disease. Providing patients with transport from home to the clinics and improving on patient education may strengthen follow-up visits.

Keywords: Adherence; appointment, glaucoma, glaucoma patient; loss to follow-up

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 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 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 thus, more follow-up visits, additional medications, more diagnostic tests and 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 24-80 years, 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 saturation point at participant no 8, the researchers continued to conduct interviews until participant's number 18. This helped researchers obtained 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 their challenges that made them to 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 poor vision which limited their ability to read.

2.4 Data analysis

Data were analysed 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 audio tapes 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 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 to participate. Participants' rights to privacy and confidentiality were observed throughout the study. Ethical clearance (SHS/18/PH/35/03111) 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 from participating 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 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 15 km 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).

3.2 Theme 1. Challenges experienced by glaucoma patients 'during glaucoma follow-up visits. Throughout the interview sessions conducted, similar challenges were revealed by both glaucoma patients in the district hospitals.

Sub-theme 3.2.1. Lack of understanding the need for chronic therapy

It was revealed during 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:

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 appointment/shortage of medications.
2. Suggestions made by glaucoma patients for overcoming barriers contributing to LTFU.	2.1 A need for more education and counselling on glaucoma disease and the importance of follow-up. 2.2. Glaucoma eye care services to be provided in primary health care facilities.

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".*

Participants 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".*

Table 1: Themes and sub-themes reflecting the challenges experienced by glaucoma patients during follow-up visits and suggestions made by the patients themselves.

Sub-theme: 3.2.2. 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 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:

Participants 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".*

Participants 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".*

Participants 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*".

Sub-theme: 3. 2.3. 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:

Participants 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".*

Participants 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".*

Sub-theme 3.2.4. 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 behaviour from some of the hospital staff. Patients complained that some hospital staff are 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*".

Sub-theme: 3.2.5. 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 15 km 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 at 2 to 3months.

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, Iam afraid to ask permission because I am still new in this firm".*

3.3 Theme 2: Suggestion made by glaucoma patients for overcoming barriers contributing to LTFU.

I 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 subthemes below.

3. 3.1. 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 remain in care.

This was confirmed by the following excerpt:

Participant 9"*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*".

Another patient added participant 18: "*I think there should be more education in the community to increase glaucoma awareness".*

3.3.2. A need for providing glaucoma eye care service in the primary health care facilities

Patients emphasized that they would appreciate it if glaucoma eye service could be provided in the 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".*

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 barriers faced by glaucoma patients during their follow-up clinic visit. The current study revealed several findings that are like other study findings conducted around the globe (Thompson, Thompson, Young, et al [22; Lee et al [23]. 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 that lack of understanding that glaucoma needed frequent follow-up like any other diseases 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 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 at 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 the 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 (31,32,33,34].

Fewer patients in the study become LTFU because they resort to 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 the eye care and their beliefs in divine healing contributed to most patients to trust 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 grant. 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 [37,38,39,40]. The findings of our study concur with those by Thompson et al [41], who state that transport and follow-up cost 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 eyedrops 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 nonadherence which also limit compliance with follow-up appointments. Similar results were reported by Quigley et al (44) and Thompson et al, (41) in their study. They mentioned that 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 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 [47,48,49,50]. 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 this would help in improving glaucoma adherence and follow-up. Transport services that can ferry

patients from home and 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.

6. 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 clinic and back home, glaucoma eye care services (including supply of glaucoma medications) should be provided at the Primary Health Care facilities, create 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.

ETHICAL APPROVAL

Ethical clearance was obtained from the Ethics and Research Committee of the University of Venda. Ethical clearance certificate no. (SHS/13.PH/02/0621 was approved.

HUMAN AND ANIMAL RIGHTS

No animals were used in this research. All human research procedures followed were per the ethical standards of the committee responsible for human experimentation institutional and national) and with the Helsinki Declaration of 1975, as revised in 2013.

CONSENT FOR PUBLICATION

Informed consent was obtained from all participants in the research

AVAILABILITY OF DATA AND MATERIALS

The data used to support the findings of this study are available from the corresponding author upon request.

FUNDING:

None

CONFLICT OF INTEREST:

The authors declare no conflict of interest, financial or otherwise.

ACKNOWLEDGEMENT:

The researchers thank all the study participants and the University of Venda's Directorate of Research and Innovation for supporting this project. Special thanks go to Vhembe District Hospitals that gave us access to their patients.

REFERENCES

[1]. Kyari F, Adekoya B, Abdull MM, Mohammed AS, Garba F. The current status of glaucoma and glaucoma care in sub-Saharan Africa. The Asia-Pacific Journal of Ophthalmology. 2018 Nov 1;7(6):375-86.

[2] Chibueze LM. Glaucoma in Nigeria–factors influencing late presentation of the disease.

[3] Kamari, S., Savadi, V. and Raddi, S., Statement of the Problem 'A Study To Assess The Knowledge Regarding Glaucoma And Its Management Among Patients With Glaucoma In Selected Hospitals At Tumkur With A View To Develop An Information Booklet.

[4] Fiscella R, Caplan E, Kamble P, Bunniran S, Uribe C, Chandwani H. The effect of an educational intervention on adherence to intraocular pressure-lowering medications in a large cohort of older adults with glaucoma. Journal of Managed Care & Specialty Pharmacy. 2018 Dec; 24(12):1284-94.

[5] Tamrat L, Gessesse GW, Gelaw Y. Adherence to topical glaucoma medications in Ethiopian patients. Middle East African Journal of Ophthalmology, 2015 Jan; 22(1):59.

[6] Dreer, L.E., Girkin, C. and Mansberger, S.L., 2012. Determinants of medication adherence to topical glaucoma therapy. Journal of Glaucoma, 21(4), p.234.

[7] Stryker, J.E., Beck, A.D., Primo, S.A., Echt, K.V., Bundy, L., Pretorius, G.C. and Glanz, K. An exploratory study of factors influencing glaucoma treatment adherence. Journal of Glaucoma, 2010;19(1), p.66.

[8] Abu Hussein NB, Eissa IM, Abdel-Kader AA. Analysis of factors affecting patients' compliance to topical antiglaucoma medications in Egypt as a developing country model. Journal of Ophthalmology. 2015 Jan 1; 2015.

[9] Kim CY, Park KH, Ahn J, Ahn MD, Cha SC, Kim HS, Kim JM, Kim M.J, Kim T.W, Kim YY, Lee JW. Treatment patterns and medication adherence of patients with glaucoma in South Korea. British Journal of Ophthalmology. 2017 Jun 1; 101(6):801-7.

[10] Eshun, V.M., 2015. Psychological Experience of Clients Diagnosed with Glaucoma in Some Selected Clinics in Accra (Doctoral dissertation, University of Ghana).

[11] Movahedinejad T, Adib-Hajbaghery M. Adherence to treatment in patients with open-angle glaucoma and its related factors. Electronic Physician. 2016 Sep;8(9):2954

[12] O'Leary N, Crabb DP, Mansberger SL, Fortune B, Twa MD, Lloyd MJ, Kotecha A, Garway-Heath DF, Cioffi GA, Johnson CA. Glaucomatous progression in series of stereoscopic photographs and Heidelberg retina tomograph images. Archives of Ophthalmology. 2010 May 1; 128(5):560-8.

[13] Killeen OJ, Pillai M.R, Udayakumar B, Shroff S, Vimalanathan M, Cho J, Newman-Casey PA. Understanding Barriers to Glaucoma Treatment Adherence among Participants in South India. Ophthalmic Epidemiology. 2020 May 3; 27(3):200-8.

[14] Abdull M. Patients and glaucoma: what are the challenges? Community Eye Health. 2012; 25(79-80):44.

[15] Michaelov E, Armstrong JJ, Nguyen M, Instrum B, Lam T, Denstedt J, Hutnik CM. Assessing the methodological quality of glaucoma clinical practice guidelines and their recommendations on microinvasive glaucoma surgery: a systematic review. Journal of Glaucoma. 2018 Feb 1; 27(2):e44-9.

[16] Stulting A. and du Toit, Nagib. Introduction. South African Ophthalmology Journal. 2016; 11(4):12-4.

[17] Fudemberg SJ, Lee B, Waisbourd M, Murphy RA, Dai Y, Leiby BE, Hark LA. Factors contributing to nonadherence to follow-up appointments in a resident glaucoma clinic versus primary eye care clinic. Patient preference and adherence. 2016; 10:19.

[18] Oduntan OO, Mashige KP, Hansraj R, Ovenseri-Ogbomo G. Strategies for reducing visual impairment and blindness in rural and remote areas of Africa. African Vision and Eye Health. 2015 May 29; 74(1):5.

[19] Bevan MT. A method of phenomenological interviewing. Qualitative health research. 2014 Jan; 24(1):136-44.

[20] Creswell JW. A concise introduction to mixed methods research. SAGE publications; 2014 Mar 31.

[19] De Vos AS, Delport C.S, Fouche C.B, Strydom H. Research at grass roots: A primer for the social science and human professions. Van Schaik Publishers, 2011.

[21] Brink H, Van der Walt C, Van Rensburg G. Fundamentals of research methodology for health care professionals. Juta and Company Ltd, 2006.

[22]. Lee BW, Sathyan P, John RK, Singh K, Robin AL. Predictors of and barriers associated with poor follow-up in patients with glaucoma in South India. Archives of Ophthalmology. 2008 Oct 13;126(10):1448-54.

[23] Thompson AC, Thompson MO, Young DL, Lin RC, Sanislo SR, Moshfeghi DM, Singh K. Barriers to follow-up and strategies to improve adherence to appointments for care of chronic eye diseases. Investigative Ophthalmology & Visual Science. 2015 Jul 1; 56(8):4324-31.

[24]. Zhao J, Solano MM, Oldenburg CE, Liu T, Wang Y, Wang N, Lin SC. Prevalence of normal-tension glaucoma in the Chinese population: A systematic review and meta-analysis. American journal of ophthalmology. 2019 Mar 1; 199:101-10.

[25]. Demirtaş Z, Dağtekin G, Önsüz MF, Soysal A, Yıldırım N, Metintaş S. Validity and reliability of the glaucoma knowledge level questionnaire. Turkish Journal of Ophthalmology. 2018 Jun; 48(3):115.

[26] Bassett IV, Coleman SM, Giddy J, Bogart LM, Chaisson CE, Ross D, Flash MJ, Govender T, Walensky RP, Freedberg KA, Losina E. Barriers to care and 1-year mortality among newly diagnosed HIV-infected people in Durban, South Africa. Journal of Acquired Immune Deficiency Syndromes (1999). 2017 Apr 1; 74(4):432.

[27] Wasti SP, Randall J, Simkhada P, Van Teijlingen E. In what way do Nepalese cultural factors affect adherence to antiretroviral treatment in Nepal? Health Science Journal. 2011; 5(1):37-47

[28] Hahn SR. Patient-centered communication to assess and enhance patient adherence to glaucoma medication. Ophthalmology. 2009 Nov 1;116(11): S37-42.

[29]. Morse AR. Improving medication adherence to reduce vision loss in patients with glaucoma: low hanging fruit? Ophthalmology. 2015 Jul 1; 122(7):1280-2.

[30] Buchberg MK, Fletcher FE, Vidrine DJ, Levison J, Peters MY, Hardwicke R, Yu X, Bell TK. A mixed-methods approach to understanding barriers to postpartum retention in care among low-income, HIV-infected women. AIDS patient care and STDs. 2015 Mar 1;29(3):126-32.

[31] Stewart WC, Konstas AG, Pfeiffer N. Patient and ophthalmologist attitudes concerning compliance and dosing in glaucoma treatment. Journal of Ocular Pharmacology & Therapeutics. 2004 Dec 1;20(6):461-9.

[32] Olthoff CM, Hoevenaars JG, van den Borne BW, Webers CA, Schouten JS. Prevalence and determinants of non-adherence to topical hypotensive treatment in Dutch glaucoma patients. Graefe's Archive for Clinical and Experimental Ophthalmology. 2009 Feb 1; 247(2):235.

[33] Curtis C, Lo E, Ooi L, Bennett L, Long J. Factors affecting compliance with eye drop therapy for glaucoma in a multicultural outpatient setting. Contemporary Nurse. 2009 Feb 1; 31(2):121-8.

[34] Agarwal, S., Shamshad, M.A., Goel, D. and Ansari, M., Distribution of glaucoma in the major religious communities of a north Indian town: a hospital survey. Journal of Clinical and Diagnostic Research: JCDR, 2013; 7(3), p.499

[35] Khandekar R, Chauhan D, Yasir ZH, Al-Zobidi M, Judaibi R, Edward DP. The prevalence and determinants of glaucoma among 40 years and older Saudi residents in the Riyadh Governorate (except the Capital)–A community based survey. Saudi Journal of Ophthalmology. 2019 Oct 1; 33(4):332-7.

[36] Achigbu EO, Achigbu KI. Traditional eye medicine use among ophthalmic patients attending a secondary health care Centre in Southeast Nigeria. Port Harcourt Medical Journal. 2017 May 1; 11(2):79.

[37] Newman-Casey PA, Robin AL, Blachley T, Farris K, Heisler M, Resnicow K, Lee PP. The most common barriers to glaucoma medication adherence: a cross-sectional survey. Ophthalmology. 2015 Jul 1;122(7):1308-16.

[38] Okoye RS, Bell L, Papadopoulos I. Investigating the level of glaucoma awareness and perception of its risk factors in Anambra State, Nigeria. Public Health. 2018 Jul 1; 160:100-7.

[39] Foreman J, Keel S, van Wijngaarden P, Bourne RA, Wormald R, Crowston J, Taylor HR, Dirani M. Prevalence and causes of visual loss among the Indigenous peoples of the world: a systematic review. JAMA Ophthalmology. 2018 May 1; 136(5):567-80.

[40] Momoh RO, Bunce C, Oko-oboh GA, Gilbert CE. Advanced glaucoma at presentation is associated with poor follow-up among glaucoma patients attending a tertiary eye facility in Southern Nigeria. Ophthalmic Epidemiology. 2018 May 4; 25(3):266-72.

[41] Thompson AC, Thompson MO, Young DL, Lin RC, Sanislo SR, Moshfeghi DM, Singh K. Barriers to follow-up and strategies to improve adherence to appointments for care of chronic eye diseases. Investigative Ophthalmology & Visual Science. 2015 Jul 1; 56(8):4324-31.

[42] Altangerel U, Nallamshetty H.S, Uhler T, Fontanarosa J, Steinmann WC, Almodin J.M, Chen B.H, Henderer JD. Knowledge about glaucoma and barriers to follow-up care in a community glaucoma screening program. Canadian Journal of Ophthalmology. 2009 Feb 1; 44(1):66-9.

[43] Munro SA, Lewin SA, Smith HJ, Engel ME, Fretheim A, Volmink J. Patient adherence to tuberculosis treatment: a systematic review of qualitative research. PLoS Medicine. 2007 Jul; 4(7).

[44] Quigley HA, Broman AT. The number of people with glaucoma worldwide in 2010 and 2020. British journal of ophthalmology. 2006 Mar 1; 90(3):262-7.

[45] Ganle JK, Otupiri E, Obeng B, Edusie AK, Ankomah A, Adanu R. Challenges women with disability face in accessing and using maternal healthcare services in Ghana: a qualitative study. PloS one. 2016 Jun 27; 11(6): e0158361.

[46] Bogard E, Kuntz KM. The impact of a partially effective HIV vaccine on a population of intravenous drug users in Bangkok, Thailand: a dynamic model. JAIDS-HAGERSTOWN MD-. 2002 Feb 1; 29(2):132-41.

[47] Muir KW, Ventura A, Stinnett SS, Enfiedjian A, Allingham RR, Lee PP. The influence of health literacy level on an educational intervention to improve glaucoma medication adherence. Patient Education and Counselling. 2012 May 1; 87(2):160-4.

[48]. Lim MC, Watnik MR, Imson KR, Porter SM, Granier AM. Adherence to glaucoma medication: the effect of interventions and association with personality type. Journal of glaucoma. 2013 Aug 1; 22(6):439-

[49]. Boland MV, Chang DS, Frazier T, Plyler R, Jefferys JL, Friedman DS. Automated telecommunication-based reminders and adherence with once-daily glaucoma medication dosing: the automated dosing reminder study. JAMA Ophthalmology. 2014 Jul 1;132(7):845-50.

[50] Dreer LE, Owsley C, Campbell L, Gao L, Wood A, Girkin CA. Feasibility, Patient Acceptability, and Preliminary Efficacy of a Culturally Informed, Health Promotion Program to Improve Glaucoma Medication Adherence Among African Americans: “Glaucoma Management Optimism for African Americans Living with Glaucoma” (GOAL). Current Eye Research. 2016 Jan 2; 41(1):50-8.

CHAPTER 5 (a)

Application of an Information-Motivation-Behavioural Skills Model to Strengthen Eye Care Follow-Up Amongst Glaucoma Patients

Application of an Information-Motivation-Behavioural Skills Model to Strengthen Eye Care Follow-Up Amongst Glaucoma Patients

Published as Tshivhase SE, Khoza LB,Tshitangano TG. ***Application of an information motivation behavioural skills model to strengthen eye care follow-up amongst glaucoma patients.***

African Vision Eye Health.2021;80(1), a642. https://doi. org/10.4102/aveh.v80i1.642

ISSN: (Online) 2410-1516, (Print) 2413-3183

Dates:
Received: 02 Dec. 2020

Accepted: 05 Apr. 2021

Published: [to be released]

ABSTRACT

Background: Many factors influence glaucoma medication adherence. A better understanding of the relationships between knowledge, attitude and patients' practice problems in using glaucoma medications may reveal opportunities for intervention that could improve patients' clinical outcomes. The challenge of non-adherence to glaucoma follow-up and treatment plans remains a significant global healthcare concern. Non-adherence to medication is a challenge to effective treatment of many chronic diseases, including glaucoma and remains so even with the implementation of strategies aimed at improving adherence. In South Africa, the Information-Motivation and Behavioural Skills Model (IMBSM) of glaucoma adherence constructs might be useful in describing and predicting adherence behaviours that have not been articulated to people with glaucoma.

Aim: The study applied IMBSM in strengthening eye care follow-up amongst glaucoma patients in the Limpopo province of South Africa.

Setting:The study was conducted at a selected hospital of Vhembe District, Limpopo province, South Africa.

Methods: A cross-sectional quantitative descriptive study via questionnaire was conducted on patients who were taking intraocular pressure-lowering medications and subject to follow up at a glaucoma clinic. A total of 429 eligible patients were purposefully selected for data collection using structured questionnaires. Oral informed consent was obtained from all respondents before they completed the questionnaires.

Results: Only 55% of the total sample reported a glaucoma non-adherence rate of less than or equal to 95% compared with 45% who reported glaucoma adherence rate of more than or equal to 95%. Independent predictors of non-adherence were: inadequate glaucoma knowledge (29%), forgetfulness (26%) and patients' beliefs (18%).

Conclusion: The findings revealed the need for on-going glaucoma educational and informational interventions to address the motivation and adherence behavioural skills of patients to strengthen the current levels of glaucoma adherence behaviour. These findings suggest that the application of the IMBSM might improve glaucoma patients' adherence.

Keywords: anti-glaucoma medication; adherence to glaucoma medication; eye care; glaucoma patients; IMBSM;

Introduction

Several studies show that Glaucoma is the second leading cause of blindness worldwide, accounting for an approximately 3.12 million cases globally, and the leading cause of irreversible blindness.[1,2] The number of glaucoma patients is expected to rise to about 76.0 million in 2020 and to 111.8million in the year 2040.[3] The most common risk factor for glaucoma is raised intraocular pressure (IOP). Lowering of IOP is the only proven strategy for preventing the risk of glaucoma progression. Good adherence to ocular hypotensive agents is essential to control the intraocular pressure and optic nerve damage.[4]

Medication is often suboptimal for glaucoma and non-adherence is a significant barrier to effective use of medication. An approximately 12-month adherence period is too short for the therapeutic effects in 30% – 50% of patients based on self-reports, pharmacy refills and electronic monitoring.[5,6.]Although there are serious consequences such as disease progression and eventual vision loss,non-adherence is common in glaucoma patients.

Appropriate treatment and follow-up care are crucial in preventing vision loss due to glaucoma. Numerous studies estimated non-adherence to follow-up eye appointments to be as high as 43% among patients prescribed with eyedrops to lower intra-ocular-pressure (IOP). Lowering IOP is one possible intervention to slow down the disease progression.[7.,8,9.] Adherence is generally defined as the extent to which patients take medications as prescribed by their eye care providers.[9] Generally, glaucoma drug adherence and associated factors are classified into four general groups. These are: patient-related, medication-related, provider-related, and environmental-related factors.[10]

Non-adherence to chronic disease treatment remains a global problem.The World Health Organization(WHO) estimates that 50% of the developed countries patients fail to adhere to their recommended treatment, and the situations is worse in developing countries.[11,12] The purpose of any prescribed medical intervention is to achieve a certain anticipated outcome in patients. However, despite the best intentions and efforts on the part of healthcare professionals, positive outcomes might not be achievable if patients are non-compliant. The inability to use medications as prescribed can result in decreased treatment effectiveness and outcomes, increased complications, and worsened health status. Glaucoma medication non-adherence is a complex matter that might lead to a huge burden to the healthcare system if not adequately addressed.[10]

Although evidence exists showing that lowering of IOP and medication adherence substantially reduces the risk of vision loss, strategies to strengthen glaucoma eye care service are complicated. These include modifying a range of behaviour related to health such as attending eye clinic appointments and regular use of prescribed eyedrops. Researchers recommend different strategies that have been employed in different countries to improve medication adherence and alleviate the effects of the loss to follow-up (LTFU) among glaucoma patients.[13,14]

However, more research is needed to determine appropriate targets for interventions to increase the uptake rate of glaucoma medication adherence. One basis for the prevention of medication non-adherence is the Information-Motivation-Behavioural-Skills Model (IMBSM).[15] The IMBSM theorizes information behaviour about a target behaviour, that is, knowledge and motivation to perform behaviour is based on

factors such as attitudes and social norms which lead to the development of relevant behavioural skills such as individuals' objective and perceived abilities to perform the target behaviour.

However, no known study on strategy to strengthen glaucoma eye care follow-up was found for the Limpopo Province of South Africa where the current study was conducted. Therefore, this study hopes to provide information that will guide hospitals and primary health care facilities in addressing specific barriers experienced by glaucoma patients in improving treatment adherence and retention in care in an exclusive cultural setting of the Vhembe District of Limpopo Province. Studies document numerous motivational, cognitive, and psychological theories of behavioural change that increase the importance of medication adherence among patients on lifelong treatment and management.[16.] The researchers analysed a specific theoretical model for improving knowledge, attitude, and practices (KAP) of glaucoma patients as a springboard for strategy development. Therefore, the study investigated how the application of IMBSM can strengthen eye care follow-up of glaucoma patients in Limpopo Province of South Africa.

CONCEPTUAL FRAMEWORK: INFORMATION MOTIVATIONAL BEHAVIOURAL SKILLS MODEL

The IMBSM has been widely used in understanding and improving health behaviour in different chronic diseases and populations.[17] The IBMSM has three main constructs which are: information and knowledge, motivation to perform the behaviour and the behavioural skills necessary to improve health-related behaviours.[18] Each construct can have a direct influence on health-related behaviour. The model proposes that individuals who are well informed and highly motivated and have skills to perform health-related behaviour are more likely to endorse and maintain health-related behaviour. The IMBSM model can also be used to identify key factors to implement and maintain the adherence behaviour in patients with chronic diseases.[17] These reasons make the IMBSM model relevant for this study. The key constructs and empirical support of the model are discussed here.

The first component information and knowledge refers to the basic knowledge and awareness about one's medical condition such as glaucoma and the efficient strategies to manage it. Studies have reported a significant correlation between medication knowledge and adherence to chronic diseases.[19] Deeb et al.,[20] and Joseph, Ainsworth, Keller and Dodgson[21] reported that knowledge alone is insufficient to increase healthy eating and physical activity. The IMBSM suggests that knowledge alone may be sufficient to change behaviour if the behaviour is not complicated. According to IMBSM, knowledge may collaborate with motivations, this collaboration may translate into healthy practices when facilitated by necessary behavioural skills. Also, the IMBSM indicates that knowledge may be more important to certain populations than others.[22,23]

The second component of the IMBSM is motivation. Motivation comprises an individual's drives, that is, his or her attitudes and beliefs about engaging or not engaging in a behaviour, and his or her social motivation.[24,25] Patients with adequate social support for adherence are likely to adhere to medication. In addition, behavioural skills determine whether a well informed and highly motivated person can adhere to medication. It includes components such as ensuring that the patient has skills, tools and strategies and the confidence or the belief that he or she can achieve the desirable behaviour. Behavioural skills are the individual's ability and willingness to do all the necessary skills that might improve adherence.[26,27]

Interventions using these constructs can address the patient barriers and help them to remain in care. Kelly, McCarthy and Sahm[28] stated that patients' understanding of their conditions and treatment is positively linked to adherence. Similarly, Zullig et al.,[10] argued that medication adherence, satisfaction and recall are all related to the amount and type of information given to patients. Sankar et al.,[29] also observed that patients who understand the reasons for taking medication adhere more to their treatment than those who do not. In addition, Cook et al.,[30] and Ehret et al.,[31] argued that the IMBSM model suggests that knowledge does affect adherence, along with behavioural skills (including self-efficacy) and treatment motivation. Zhao et al.,[32] also reported that older patients with multimorbid ties adhere less to their chronic medications because of insufficient knowledge, negative attitude and lack of confidence.

Methods and design

The study employed a cross-sectional survey distribution method. A quantitative study was conducted amongst glaucoma patients who were 18 years and older. The study was conducted at Elim Hospital of Vhembe District, the Limpopo province, South Africa. Elim Hospital is the only specialised ophthalmic hospital in the region and the largest referral centre in the Vhembe District. The hospital provides comprehensive eye care services including major surgeries, minor surgeries, glaucoma follow-up, general outpatient and inpatient eye care services for patients coming from different areas of the country. This study employed a non-probability convenience sampling technique, which was appropriate because of the practical difficulty of using other sampling methods from the target population of interest in the entire district. Moreover, patients happened to be at the right place at the right time at the selected hospital. Preliminary research showed that there was a challenge of LTFU amongst glaucoma patients. A sample of 450 people was reached and this was adequate for yielding reliable results. Only patients diagnosed with glaucoma were purposively sampled and had been under review for at least 3 years. The instrument was developed out of a comprehensive literature review by the first author (see Welge-Lussen et al.[33]). The developed questionnaire was administered to the participants by trained interviewers. Most study participants were unable to complete the questionnaire on their own as they could not read and write and others had poor vision. Those who were unable to read and write were assisted by the researchers.

To ensure validity, the instrument development was guided by the study objectives and literature. The pre-test ensured that questions were of high quality and clear. The instrument was pre-tested amongst 45 patients who were not part of the main study. Pilot study participants were given 30 min to complete the questionnaire, which helpfully revealed that the time allocated for completion of the questionnaire was inadequate and that some participants could not interpret some questions and these confusing questions were rephrased. Their comments were used to revise the questionnaire and additional time was allocated for completing because some participants were slow because of poor vision. The questionnaire was administered twice to the same participants and then the correlation coefficient calculations were used to compare the first responses with the second responses. For this study, non-adherence was defined as missing at least one dose of medication per week. Participants who had adherence rate <100% were asked to give reasons for their failure to comply with the prescribed medication if any. Adherence rates were

defined as good if their score ranged from 95% to 100% and as poor or inadequate if they were less than 95%. Closed-ended questions were used to gather data about patients' demographics, level of glaucoma knowledge, practice regarding glaucoma and factors affecting adherence to medical treatment and motivating factors for adherence. The study used the Morisky Medication Adherence Scale (MMAS) as an instrument to evaluate glaucoma medication adherence. The instrument was developed in the English language and was translated into the local language.

Data analysis

After all the completed questionnaires were scrutinised, data were entered into Microsoft Excel version 2010 and the Statistical Package for Social Sciences (SPSS) version 24.0 for statistical analysis. Level of education was categorised as none (no formal education), primary education (Grades 1–7), secondary education (Grades 8–12) and tertiary education (colleges, technical schools and universities). Patients with tertiary education were grouped with patients with secondary education for data analysis because of the small percentage of participants with tertiary education. Adherence is defined as the degree to which a patient follows the instructions to take a prescribed treatment during a defined period whilst non-adherence describes the failure of a patient to follow health behaviour and treatment advice given by a health provider.[11]

Ethical considerations

Ethical approval to conduct the study was granted by the University of Venda Research Ethics Committee SHS/18/ PH/0111. Using the UHDC's approval and the ethical clearance certificate, the researchers sought permission from the Limpopo Provincial Department of Health and Vhembe District Department of Health. Permission was also obtained from the Hospital managers and CEO of all selected hospital in the Vhembe District

Results

A total of 450 glaucoma patients were seen during the period of the study. Twenty-one of the patients did not meet the inclusion criteria as they were all newly diagnosed. All participants who met the criteria participated resulting in a response rate of 95% (429). Most study participants (68%, *n* = 294) were females and only 32% were males. A total of 278 (65%) participants were above 65 years. More than half (62%) of the participants claimed to be Christians. Of the 429 participants, 70% had no formal education and only 3% had tertiary education as shown in Table 1

Table 1:Socio -Demographic characteristics of the study participants (n=429)

Variable	Frequencies	Percentages
Gender		
Male	135	32
Female	294	68
Age in years:		
18–24	18	4
25–54	52	12
55–64	81	19
65 and above	278	65
Educational level:		
Never attended school	301	70
Primary education	84	20
Secondary education	31	7
College or tertiary	13	3
Employment status:		
Employed	86	20
Unemployed	343	80
Religious affiliation		
Christianity	265	62
Non-Christian	164	38

Information factor

This section assessed how much the participants knew about glaucoma and its treatment adherence (Table 2). Almost half of the participants (46%) did not know the cause of glaucoma whilst 30% attributed it to witchcraft. About 59% of the participants stated that vision lost because of glaucoma could be reversed whilst 41% indicated that it is permanent. A total of 249 participants did not knew that glaucoma needs lifelong medication whilst 180 said glaucoma needs lifelong medication. A total of 240 patients indicated that a patient with glaucoma disease does not require regular follow-up care. However, 221 participants indicated that glaucoma is asymptomatic.

Table 2: Participants knowledge of Glaucoma n=429

Variable	Characteristics	Frequencies	%
Perceived cause of glaucoma disease	Hereditary	102	24
	Eye disease that is caused by witchcraft	131	30
	Do not know	196	46
Skipping glaucoma treatment can lead to blindness	Yes	194	45
	No	235	55
Knowledge of lifelong glaucoma medication	Yes	180	42
	No	249	58
Vision loss because of glaucoma is permanent	Yes	174	41
	No	255	59
Most patients with glaucoma have no symptoms	Yes	221	51
	No	208	49
Glaucoma patients may require follow-up care	Yes	189	44
	No	240	56

Motivation factors

This section assessed the personal and social motivation of the patients towards glaucoma adherence (Table 3). Out of the total number of the study participants, 62% said there is no benefit in regular glaucoma medication use. More than half (60%) of the participants disagreed with the idea that glaucoma is a disease that afflicts old people compared with 40% who agreed. About 249 (58%) participants believed that using eye drops can worsen their eye condition (Table 3) whilst 42% did not agree that using eye drops can worsen glaucoma disease. A total of 53% of the participants agreed with the statement that it would frustrate them to think that they would have to instill glaucoma eye drops all their lives. More than half (56%) of the participants agreed that they like to be supported by their family members when taking their medications compared with 44% who said they did not need any support. About 51% participants disagreed with the statement that they are afraid of glaucoma side effects.

Table 3: Participants 'attitude and beliefs towards glaucoma disease n=429

Statement	Agree		Disagree	
	Frequency	%	Frequency	%
There is no benefit in regular use of glaucoma medication	266	62	163	38
I do not want people to realise that I use glaucoma medication	219	53	200	46
I like it when family members give me support during medication refill.	241	56	188	44
I believe that glaucoma is an old people's disease	171	40	258	60
I dislike using eye drops as it worsens my condition	249	58	180	42
It is frustrating to take glaucoma medication for life	230	54	199	46
I am afraid of the glaucoma medication's side effects	179	49	220	51

Behavioural skills

This section assessed the behavioural skills of the patients regarding glaucoma medication adherence (Table 4). A total of 257 (55%) participants had missed their daily doses more than once in a week whilst 45% were classified as 100% adherent according to the study definition. This study evaluated adherence in terms of self-reporting by patients regarding medication use, and keeping appointments on adherence. Reasons for non-adherence were poor knowledge at 70 (29%), followed by forgetfulness 61 (26%). Medications' side effects were cited as the least reason for non-compliance 18 (8%). Of the 237 patients who were classified as non-adherence, they identified motivating factors that can improve their medication adherence.

Table 4: Patients 'practice regarding glaucoma medication(n=429)

Statement	Practices	Frequencies	%
Number of doses missed per week	None	192	45
	1–2	105	24
	3–5	51	12
	> 5	81	19
Level of glaucoma medication compliance	Adherence	192	45
	Non-adherence	237	55
Reasons for non-adherence or non-compliance	Poor knowledge	70	29
	Forgetfulness	61	26
	Religious beliefs	42	18
	Inability to access medication	26	11
	Denial (My eyes are ok)	22	9
	Side effects	16	8

The most frequently reported motivating factor was getting more education on the importance of follow-up (85%, Table 5), followed by understanding the risk of negative effects of glaucoma treatment non-adherence such as blindness and pre-appointment reminder (by phone, SMS or email) at 83% and 80%, respectively. Almost three quarters (72%) of the participants reported that understanding the benefits of their glaucoma medication motivated them to adhere to their medication regimen. Having mobile eye clinic visit once per month and having someone to help in eye drops administration were the fifth and sixth frequently reported motivating factors for the participants (70% and 53%), respectively. Notably, only one-third (39%) of participants indicated that forming support groups with other patients with glaucoma disease were also an important motivating factor to strengthen adherence (Table 5).

Table 5: Motivating factors cited by participants to strengthen medication adherence (n=237)

Statement	Frequency	
	n	%
Pre-appointment reminder (by phone, text, or email)		
Yes	191	80%
No	48	20%
More education on the importance of follow up		
Yes	202	85%
No	35	15%
Understanding the risk of negative effects of nonadherence to glaucoma such as blindness.	197	83%
Yes	40	17%
No		
Understanding the benefits of regular use of glaucoma medication like halting disease progression	170	72%
	67	28%
Have someone to help with eye drops administration		
Yes	125	53%
No	112	47%
Mobile eye care clinic		
Yes	166	70%
No	71	30%
Forming support groups with others patient with glaucoma disease		
Yes	93	39%
No	144	61%

Discussion

The IMBSM was used as a guiding framework to assess factors that influence glaucoma medication adherence in a sample of 429 participants. Most participants were elderly females (69%) whose age is above 65 years. Almost three**,** quarters (70%) of the participant did not have formal education and were mostly unemployed likely because the study was conducted in a rural setting. Similar findings were reported in Nigeria and South Africa, where the number of female participants without formal education were in the majority.[2,34]

Participants exposed relatively little or no knowledge about glaucoma. This was revealed when most participants said they did not know what causes glaucoma disease (46%), whilst others believed that it is caused by witchcraft (30%). More than half (59%) of the participants said that vision loss because of the glaucoma disease is temporary. These participants assumed that the effects of the glaucoma disease could be reversed and therefore does not need lifelong medication. Our study concurs with findings obtained in

Ghana, Botswana and Southeast Nigeria.[35,36,37] In South Africa, Tshivhase et al.[34] also mentioned that 55% of their participants believed that blindness because of glaucoma is reversible. By contrast, Uche et al.[2] reported high glaucoma awareness amongst glaucoma patients. Similar results were cited by Abdull et al.[38] in Nigeria who stated that there was satisfactory knowledge amongst patients although they did not fully understand the purpose of glaucoma treatment.

In this study, most participants (62%) were not motivated to adhere to glaucoma medication. Participants claimed that there is no benefit in the regular use of glaucoma medication and disliked using eye drops believing that it worsens their eye condition. Moreover, some participants were depressed by the fact that they were expected to use glaucoma medication for the rest of their lives. This suggests that participants should be given adequate relevant information about glaucoma and its management. This observation is supported by Demirtaş et al.[39] who reported that participants in their study were not aware about the importance of regular eye examination. However, Thompson et al.[40] revealed that there are glaucoma patients who believed that it was important to do follow-up even if there was no visible change in their vision. A South African Study observed that glaucoma patients were reluctant to go for their routine follow-up care as advised by the health providers.[34] Significantly, most participants were motivated to do follow-up when it was explained to them that the glaucoma disease affects all age groups. Sleath et al.[41] revealed that younger patients were more likely to report being less adherent than older patients because younger patients perceived a lower risk of disease-related morbidity than elderly patients.

In this study, more than half (55%) of the participants had inadequate behavioural skills relevant for glaucoma adherence whilst only less than half (45%) were associated with adequate behavioural skills relevant for glaucoma adherence. A total of 237 participants revealed that they had missed their doses more than once in a week. We assessed glaucoma medication adherence using a self-report measure, which asked about the number of days that participants had adhered to treatment. Just over half (55%) of participants were classified as non-adherent to their glaucoma regimens and 192 (45%) were classified as 100% adherent. The most frequently reported barriers to glaucoma medication adherence in our study sample were lack of knowledge (information barrier), forgetfulness (behavioural skills barrier), religious beliefs (information barrier) and inability to access medication (motivation barriers). This can be explained by the fact that the study had many elderly participants who may be prone to forgetfulness. Other participants stopped taking their glaucoma medication because of their conflicting religious and traditional beliefs. Another contributing factor is that patients are not able to easily access glaucoma clinics because of economic or time factors. Cohen Castel et al.[42] also found that elderly patients who depended on others for help with their glaucoma medications were at risk for non-adherence than those who do not depend on others.

Our study's findings concur with those by Nayak, Gupta et al.[43] and Leung et al.[44] who found that glaucoma medication and clinics visits can negatively affect the patients because of financial costs. Sleath et al.[41] also reported that elderly patients with chronic disease are at risk of glaucoma non-adherence if they have poor support from healthcare providers. Uche et al.[2] and Tshivhase et al.[34] found that glaucoma patients used

traditional eye medication (TEM), visited spiritual and traditional healers to try and deal with the disease. These studies indicated that the most common TEM used by glaucoma patients was topical plant extracts. However, some patients still believed in eye drops adherence and making glaucoma follow-up care.[40]

Targeting individual patients' needs in order to promote their adherence is challenging but important. To achieve adherence and health behaviour change, patients should be given adequate information, motivated to carry out their recommended treatment and to have a workable strategy for following recommended treatment.[11] Instilling eye drops every day without missing any doses can be challenging. Therefore, when counselling patients, each patients' life style should be considered to promote adherence. Health practitioners should communicate information effectively with patients and their care givers because most of them have poor vision, build trust with the patients, involve patients to participate in decision-making and allow patients to say which methods work better for them. This study found that patients are not motivated to carry out their prescribed medications because they do not believe that they can instill their own eye drops. Therefore, health practitioners should motivate patients to believe in themselves, provide adequate support to patients and their family members during clinic visits, offer emotional support and give necessary skills related to medication adherence, provide patients with pamphlets, listen to them and discuss any negative perception that they might have and help patients to make commitment to adherence. Most patients indicated that they needed someone to remind them to administer their medication. Therefore, community healthcare workers should be involved in providing support and reminding patients about their follow-up dates. Patients should also be provided with written instruction or reminders; electronic reminders, such as short messages via cell phones and emails and be advised to join support groups.

The most frequently cited motivating factors were related to knowing more about the benefits of medications and understanding the risk of negative effects of non-adherence to glaucoma such as blindness. Most patients believed that being given adequate education about the importance of follow-up visits and having mobile eye care clinics might help them to adhere to their medication. There is also a need to discourage TEM use amongst glaucoma patients. This should be carried out using health education and encouraging good eye care practice.

Limitations

One of the limitation in this study is that 'gold standard' for assessment of adherence does not exist. Therefore, adherence was measured through self-report assessment measure. Participants in self-report studies tend to overestimate adherence and self-reported adherence measurements are known to increase adherence rates.45 The problem with self-reports of health behaviour is that they may be influenced by a subject's reluctance to report non-adherence to treatment recommendations. Moreover, the study was conducted in one public hospital in the Vhembe District, therefore its results are not generalisable to other districts in the province. In addition, as it is not a longitudinal or a follow-up study, this study's findings may have limited application.

Conclusion

Non-adherence limits the potential of successful treatments to improve patients' health and quality of life. Healthcare providers experience substantial frustration over the high propotion of their patients who fail to follow treatment recommendations. The study's findings revealed that non-adherence to glaucoma medication is still a challenge in the study setting. Moreover, the study identified that glaucoma knowledge is low as it is cited as the most contributing factor for glaucoma medication non-adherence. Participants lacked adequate knowledge regarding the importance of glaucoma follow-up. The study showed that information, motivation and behavioural skills are interrelated. Moreover, the study found that glaucoma patients need more information about their condition. Furthermore, it was discovered that strategies such as using cell phone reminders might improve strengthening glaucoma medication adherence. Therefore, education should focus on improving glaucoma knowledge, improving perceptions of the benefits of glaucoma medication and adoption of good eye practices such as avoiding the use of TEM. It is vital that patients should adequately understand the importance of adherence and the serious consequences of non-adherence. In addition, educating the patients and their caregivers should be a priority.

Recommendations

Recommendations of this study are closely linked to the conclusions drawn from the data: The study found that strategies to improve adherence to glaucoma medication are likely to be effective when they include multiple components such as educating the patient and their family members, educating the community, giving adequate information to patients, providing counselling to patients, providing information about the use of adherence support tools such as using cell phones or email reminders. Health-care providers should provide specific information about health risks and benefits of change and identify reasons for missing doses and address the challenges accordingly in order to improve adherence. The study's findings indicate that a glaucoma clinic should be set up separately from the general outpatient department so that it can operate on weekends.

Acknowledgements

We would like to thank the university of Venda Research and Innovation Directorate for funding this project, the School of Health Sciences and all the respondents who participated in this project.

Competing interests

The authors declare that they have no financial or personal relationships that may have inappropriately influenced them in writing this article.

Authors' contributions

All authors contributed equally to this work.

Funding information

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.'

Data availability

Data sharing is not applicable to this article as no new data were created or analysed in this study.

Disclaimer

The views and opinions expressed in this article are those of the authors and do not necessarily reflect the official policy or position of any affiliated agency of the authors.'

References

1. Pascolini D, Mariotti SP. Global estimates of visual impairment: 2010. Br J Ophthalmol. 2012;96(5):614–618. https://doi.org/10.1136/bjophthalmol-2011- 300539

2. Uche NJ, Udeh NN, Chuka-Okosa CM, Kizor-Akaraiwe NN, Uche EO. Glaucoma care and follow-up in sub-Saharan Africa: Is there a need for modification of counselling practices to improve awareness, knowledge and treatment acceptance profiles? A prospective cross-sectional study. Int Ophthalmol. 2020;40:1539–1546. https:// doi.org/10.1007/s10792-020-01323-1

3. Quigley HA, Broman AT. The number of people with glaucoma worldwide in 2010 and 2020. Br J Ophthalmol. 2006 1;90(3):262–267. https://doi.org/10.1136/bjo. 2005.081224

4. Assem AS, Fekadu SA, Yigzaw AA, Nigussie ZM, Achamyeleh AA. Level of glaucoma drug adherence and its associated factors among adult glaucoma patients attending Felege Hiwot Specialized Hospital, Bahir Dar City, Northwest Ethiopia. Clin Optometry. 2020;2020(12):189. https://doi.org/10.2147/OPTO. S274850

5. Schimier JK, Covert DW, Lau EC, Robin AL. Trends in annual Medicare expenditures for glaucoma surgical procedures from 1997 to 2006. Arch Ophthalmol. 2009;127(7):900–905. https://doi.org/10.1001/archophthalmol.2009.122

6. Hawkins LA. Health literacy, cognitive impairment, and medication adherence in veterans with heart failure. University of San Diego,2013. Calfornia,United State Of America.3538789.

8. Hark L, Waisbourd M, Myers JS, et al. Improving access to eye care among persons at high-risk of glaucoma in Philadelphia – Design and methodology: The Philadelphia glaucoma detection and treatment project. Ophthalmic Epidemiol. 2016;23(2):122–130. https://doi.org/10.3109/09286586.2015.1099683

7. Mandalos A, Bourne R, French K, Newsom W, Chang L. Shared care of patients with ocular hypertension in the Community and Hospital Allied Network Glaucoma Evaluation Scheme (CHANGES). Eye. 2012;26(4):564–567. https://doi. org/10.1038/eye.2011.350

9. Shalaby WS, Shankar V, Razeghinejad R, Katz LJ. Current and new pharmacotherapeutic approaches for glaucoma. Expert Opin Pharmacother. 2020:1–4. VOL. 21, NO. 16, 2027–2040

10. Zullig LL, Deschodt M, Liska J, Bosworth HB, De Geest S. Moving from the trial to the real world: Improving medication adherence using insights of implementation science. Ann Rev Pharmacol Toxicol. 2019;59:423–445. https://doi.org/10.1146/ annurev-pharmtox-010818-021348 21(4)

11. DiMatteo MR, Haskard-Zolnierek KB, Martin LR. Improving patient adherence: A three-factor model to guide practice. Health Psychol Rev. 2012;6(1):74–91. https://doi.org/10.1080/17437199.2010.537592

12. Ajite KO, Fadamiro OC, Ajayi IA, Omotoye OJ. Utilization of eye care services among staff of a Tertiary Hospital. Asia-Pacific J Ophthalmol. 2013;2(1):28–31. https://doi.org/10.1097/APO.0b013e31827f2d12

13. Cakiner-Egilmez T. Glaucoma medications update: How to improve compliance and adherence. Insight (Am Soc Ophthalmic Reg Nurs). 2015;40(3):5–7. https:// doi.org/10.1097/APO.0b013e31827f2d12

14 Tamrat L, Gessesse GW, Gelaw Y. Adherence to topical glaucoma medications in Ethiopian patients. Middle East Afr J Ophthalmol. 2015;22(1):59. https://doi. org/10.4103/0974-9233.148350

15. Smith LR, Fisher JD, Cunningham CO, Amico KR. Understanding the behavioural determinants of retention in HIV care: A qualitative evaluation of a situated information, motivation, behavioural skills model of care initiation and maintenance. AIDS Patient Care STDs. 2012;26(6):344–355. https://doi.org/ 10.1089/apc.2011.0388

16. Bosworth HB, Blalock DV, Hoyle RH, Czajkowski SM, Voils CI. The role of psychological science in efforts to improve cardiovascular medication adherence. Am Psychol. 2018;73(8):968. https://doi.org/10.1037/amp0000316

17. Yang C, Hui Z, Zeng D, Liu L, Lee DTF. Examining and adapting the information– motivation–behavioural skills model of medication adherence among community-dwelling older patients with multimorbid: Protocol for a cross-sectional study. BMJ Open. 2020;10(3):e033431. https://doi.org/10.1136/bmjopen-2019-033431

18. Espada Sánchez JP, Morales Sabuco A, Guillen-Riquelme A, Ballester-Arnal R, Orgilés Amorós M. Predicting condom use in adolescents: A test of three socio-cognitive models using a structural equation modelling approach. BMC Public Health. 2016;16(1):35. https://doi.org/10.1186/s12889-016-2702-0

19. Okuyan B, Sancar M, Izzetin FV. Assessment of medication knowledge and adherence among patients under oral chronic medication treatment in community pharmacy settings. Pharmacoepidemiol Drug Saf. 2013;22(2):209–214. https:// doi.org/10.1002/pds.3275

20. Deeb A, Suliman S, Tomy M, et al. Is there a correlation between body weight and awareness of healthy life style components in children? Open J Pediatr. 2015;5(01):49. https://doi.org/10.4236/ojped.2015.51010

21. Joseph RP, Ainsworth BE, Keller C, Dodgson JE. Barriers to physical activity among African American women: An integrative review of the literature. Women Health. 2015;55(6):679699.

22. Bartholmae MM. The information-motivation-behavioural skills model: An examination of obesity prevention behavioural change in children who participated in the after school program Virginia Beach Let's Move [Doctor of Philosophy (PhD), dissertation]. Health Services Research, Old Dominion University. https://doi.org/10.25777/xv08-0b09

23. Greyson DL, Johnson JL. The role of information in health behaviour: A scoping study and discussion of major public health models. J Assoc Inform Sci Technol. 2016;67(12):2831–2841.

https://doi.org/10.1002/asi.23392

24. Fisher KE, Marcoux E, Miller LS, Sánchez A, Cunningham ER. Information behaviour of migrant Hispanic farm workers and their families in the Pacific Northwest. Inform Res. 2004;10(1):10.

25. Lemieux AF, Brachman JM, Levitt J, Wood J. Inspire magazine: A critical analysis of its significance and potential impact through the lens of the information, motivation, and behavioural skills model. Terror Politic Viol. 2014;26(2):354–371. https://doi.org/10.1080/09546553.2013.828604

26. Osborn CY, Rivet Amico K, Fisher WA, Egede LE, Fisher JD. An information-motivation-behavioural skills analysis of diet and exercise behaviour in Puerto Ricans with diabetes. J Health Psychol. 2010;15(8):1201–1213. https://doi.org/ 10.1177/1359105310364173

27. Somers TJ, Blumenthal JA, Guilak F, et al. Pain coping skills training and lifestyle behavioural weight management in patients with knee osteoarthritis: A randomized controlled study. Pain. 2012;153(6):1199–1209. https://doi.org/ 10.1016/j.pain.2012.02.023

28. Kelly M, McCarthy S, Sahm LJ. Knowledge, attitudes and beliefs of patients and carers regarding medication adherence: A review of qualitative literature. Eur J Clin Pharmacol. 2014;70(12):1423–1431. https://doi.org/10.1007/s00228-014- 1761-3

29. Sankar A, Golin C, Simoni JM, Luborsky M, Pearson C. How qualitative methods contribute to understanding combination antiretroviral therapy adherence. J Acquir Immune Defic Syndr (1999). 2006;43(01):S54. https://doi.org/10.1097/01. qai.0000248341.28309.79

30. Cook PF, Schmiege SJ, Mansberger SL, Kammer J, Fitzgerald T, Kahook MY. Predictors of adherence to glaucoma treatment in a multisite study. Ann Behav Med. 2015;49(1):29–39. https://doi.org/10.1007/s12160-014-9641-8

31. Ehret PJ, Hodges HE, Kuehl C, Brick C, Mueller S, Anderson SE. Systematic review of household water conservation interventions using the information–motivation– behavioural skills model. Environ Behav. 2019:0013916519896868. https://doi. org/10.31234/osf.io/Volume: 53 issue: 5,

32. Zhao J, Li W, Guo X, Wang H, Rogers JA, Huang Y. Theoretical modeling of tunable vibrations of three-dimensional serpentine structures for simultaneous measurement of adherent cell mass and modulus. MRS Bull. 2021;46:107–114. https://doi.org/10.1557/mrs.2020.253

33. Welge-Lussen U, Weise S, Alice LY. Assessing the adherence behaviour of glaucoma patients to topical eye drops. Patient Prefer Adherence. 2015;2015(9):17. https:// doi.org/10.2147/PPA.S69943

34. Tshivhase SE, Khoza LB, Tshitangano TG. Loss to follow-up amongst glaucoma patients in selected hospitals of the Limpopo Province, South Africa. Afr Vis Eye Health. 2020;79(1):7. https://doi.org/10.4102/aveh.v79i1.559.

35.Nwosu SN. Patients' knowledge of glaucoma and treatment options. Niger J Clin Pract. 2010;13(1).

36. Nkum G, Lartey S, Frimpong C, Micah F, Nkum B. Awareness and knowledge of glaucoma among adult patients at the eye clinic of a teaching hospital. Ghana Med J. 2015;49(3):195–199. https://doi.org/10.4314/gmj.v49i3.11

37. Olushola O, Oluwatoni O, Omodele J, et al. Spectrum of glaucoma presentation in a Suburban Teaching Hospital in South Western Nigeria. Health Sci J. 2016;10(6):1. https://doi.org/10.21767/1791-809X.1000466

38. Abdull MM, Gilbert C, McCambridge J, Evans J. Adapted motivational interviewing to improve the uptake of treatment for glaucoma in Nigeria: Study protocol for a randomized controlled trial. Trials. 2014;15(1):149. https://doi.org/10.1186/1745- 6215-15-149

39. Demirtaş Z, Dağtekin G, Önsüz MF, Soysal A, Yıldırım N, Metintaş S. Validity and reliability of the glaucoma knowledge level questionnaire. Turk J Ophthalmol. 2018;48(3):115. https://doi.org/10.4274/tjo.26576

40. Thompson AC, Thompson MO, Young DL, et al. Barriers to follow-up and strategies to improve adherence to appointments for care of chronic eye diseases. Investing Ophthalmol Vis Sci. 2015;56(8):4324–4331. https://doi.org/10.1167/iovs.15-16444

41. Sleath BL, Blalock SJ, Muir KW, et al. Determinants of self-reported barriers to glaucoma medicine administration and adherence: A multisite study. Ann Pharmacother. 2014;48(7):856–862. https://doi.org/10.1177/1060028014529413

42. Cohen Castel O, Keinan-Boker L, Geyer O, Milman U, Karkabi K. Factors associated with adherence to glaucoma pharmacotherapy in the primary care setting. Fam Pract. 2014;31(4):453–461. https://doi.org/10.1093/fampra/ cmu031

43. Gupta SK, Nayak RP, Shivaranjani R, Vidyarthi SK. A questionnaire study on the knowledge, attitude, and the practice of pharmacovigilance among the healthcare professionals in a teaching hospital in South India. Perspect Clin Res. 2015;6(1):45. https://doi.org/10.4103/2229-3485.148816

44. Leung VC, Jin YP, Hatch W, et al. The relationship between sociodemographic factors and persistence with topical glaucoma medications. J Glaucoma. 2015;24(1):69–76. https://doi.org/10.1097/IJG.0000000000000081

45. Sarna A, Kellerman S. Access to antiretroviral therapy for adults and children with HIV infection in developing countries: Horizons studies, 2002–2008. Public Health Rep. 2010;125(2):305–315. https://doi.org/10.1177/0033354910 12500221.

CHAPTER 5(b)

Manuscript to be submitted for publication as: Tshivhase, S.E., Tshitangano, T.G. "***Proposed Strategy to Strengthen Eye Care Follow-Up amongst Glaucoma Patients in Limpopo Province, South Africa".***

Abstract

Background

The challenge of nonadherence to glaucoma follow-up and treatment plans remains a significant global healthcare concern. Non-adherence to medication is a challenge to effective treatment of many chronic diseases, including glaucoma. This challenge continues even with interventions aimed at improving adherence. Patients in the current study identified various factors that contributed to their loss to follow-up. The identified factors included financial difficulties, forgetfulness, travel distance to the clinic, traditional/religious beliefs, lack of understanding of glaucoma disease itself that visual loss cannot be reversed, lack of an escort to the clinic, unawareness of the importance of regular follow-up visits, difficulty in taking time off and unavailability of glaucoma medications. Various intervention strategies have been employed to strengthen glaucoma eye care services and to alleviate the effects of the loss to follow-up amongst glaucoma patients in different countries.

Purpose: To develop a strategy to strengthen eye care follow-up among glaucoma patients in Limpopo province,

Methodology: The study used different models such as Information Motivation Behaviour Skills Model to address patient behavioral barriers; the Social Cognitive Theory to address system barriers; Social Action Theory to address structural barriers, and Health Belief Model to address psychosocial barriers.

Conclusion: Taking into consideration the study findings and literature on the efficacy of various psychological models in health behavior change, the developed strategy summaries the need to strengthen information, motivation, behavioral skills, and social support for patients to remain in care and adhere to their glaucoma medications.

Keywords: Adherence, glaucoma, loss to follow-up, models, non-adherence,strategy

Introduction

Appropriate treatment and follow-up care are crucial in preventing vision loss due to glaucoma disease as treatment can prevent blindness. Numerous studies estimate non-adherence to follow-up eye appointment to be as high as 43% among those patients who are prescribed eyedrops to lower intra-ocular pressure(IOP) (Mandalos, Bourne, Frenchmen's & Chang,2012; Hark, Johnson, Berardi*., et al* 2016). Although evidence exists that lowering of IOP and medication adherence substantially reduces this risk of vision loss, strategies to strengthen glaucoma eye care service are complex. These include modifying a range of behaviours related to health including attending eye clinic appointments and regular eyedrops use. Researchers have recommended different strategies that have been employed in different countries to improve medication adherence and alleviate the effects of the loss to follow-up amongst glaucoma patients (Egilmez, 2015; Hark et al, 2016; Tamrat, Gessesse & Gelaw, 2015). However, no known study was found in the Limpopo Province of South Africa where the current study was conducted. This section will guide the hospitals and primary health care facilities on how to address specific barriers experienced by glaucoma patients in improving treatment adherence and retention in care in an exclusive cultural setting of the Vhembe District of Limpopo Province. The proposed strategy indicates what can be done to address various types of barriers such as patient's factors and organizational factors. The proposed strategy was developed from both qualitative and quantitative findings of the current study guided by research theories. Literature reports numerous motivational, cognitive, and psychological theories of behavior change that increase the importance of medication adherence among patients on lifelong treatment and management. The researchers analyzed specific theoretical models that were found relevant for improving knowledge, practice, and beliefs of glaucoma patients and to serve as the springboard for strategy development. It is envisaged that the proposed strategy if implemented, the quality of life for glaucoma patients would be improved. Therefore, the study aimed to develop the strategy to strengthen eye care follow-up among glaucoma patients and suggest recommendations that may be useful in lowering the rate of glaucoma medication non-adherence in Limpopo Province, South Africa.

A brief review of the study aims and findings

The subsections below report the results and findings of the current study according to objectives and how they contributed to the proposed strategy. Various models were explored to guide the proposed strategies as follows: (1) strategy to improving knowledge and understanding of glaucoma disease, its treatment, and management; 2) strategy to promote a positive attitude and psychosocial wellbeing of glaucoma patients; 3) strategy to modify/discourage untoward patients' beliefs and cultural practices.

Chapter 2 of the study was published in *The Open Public Health Journal* (2020) titled "Strengthening Eye Care Follow-Up Among Glaucoma Patients in South Africa: A systematic review". The purpose of the systematic literature review was to analyze intervention strategies used to ensure that glaucoma patients remain in care within the health care facilities. Various techniques have been used globally to detect non-adherence in glaucoma follow up (Murakami, Lee, Duncan, Kao, Huang & Singh, 2011; Tamrat, Gessesse & Gelaw, 2015). Therefore, efforts have been made to design and evaluate various interventions

to improve glaucoma adherence with mixed achievement. Such intervention strategies comprised the following: (1) patient education sessions; (2) written information; (3) medication reminders; (4) eye drop administration training and (5) individualized adherence plans. Each technique has its advantages and disadvantages (Moore, Walton, Moeller, Slabaugh, Mudumbai & Chen, 2014; Cakiner-Egilmez, 2015; Leung, Jin, Hatch, Mammo, Trope, Buys & Macrae, 2015).

Based on the review, it was concluded that educational intervention was the most used strategy in improving glaucoma adherence in most countries. The reviewed studies were conducted either in the hospital/pharmacy setting and none was done in the community setting. The findings from the review revealed that there was a significant improvement in medication adherence after using educational interventions. The studies used a randomized control trial (RCT) and observational studies approach to guide the development of educational interventions. It was also revealed from the review that most RCTs studies used electronic monitoring while observational studies used a pharmacy refill. Studies that used self-report showed no significant improvement in medication adherence in between control and treatment groups. However, with electronic intervention, most studies showed an increase in glaucoma medication adherence between the two groups (Muir et al,2012; Lim, Watnik, Imson, Porter & Granier,2013; Boland, Chang, Frazier, Plyler, Jefferys, Friedman,2014; Dreer, Owsley, Campbell, Gao, Wood &, Girkin, 2016; Newman-Casey, Weizer, Heisler, Lee & Stein, 2013). Most studies for this review were conducted in developed countries.

Many countries have identified the importance of conducting educational intervention strategies for improving health risk behavior among glaucoma patients. Seven studies met the criteria for inclusion in this literature review after doing verification utilizing hand search. Out of seven articles that met the inclusion criteria, only four were randomized controlled trials (RCTs) and the remaining three were observational studies. Most studies (7) were conducted in developed countries (United States of America, Canada, South Korea, and Australia) while only one of the studies was done in developing countries (Nigeria). Of the four RCTs, three showed an improvement in medication adherence after using educational interventions such as videos, patients counselling reminder calls, slideshow and leaflets. Of the three observational studies that were done, all confirmed an improvement in adherence after using motivational interviewing but showed no significant improvement in adherence after using educational interventions. Therefore, observational studies using motivational interviewing improved medication adherence than using educational interventions that showed no improvement in medication adherence. Consequently, a gap was identified in that there were no publications or sources providing a detailed strategy for glaucoma intervention adherence in South Africa. Hence, the current study further aimed at increasing the understanding of challenges contributing to the LTFU among glaucoma patients in the Limpopo Province. Moreover, the study endeavoured to develop a strategy to strengthen glaucoma eye care follow-up in health care services.

Chapter Three, a survey was conducted to increase the understanding of the reasons for loss to follow-up among glaucoma patients. The chapter was published in the journal of *African Vision and Eye Health* (AVEH) with the following title: "***Loss to follow-up amongst glaucoma patients in selected hospitals of the Limpopo Province, South Africa*** "Behavioural determinants such as knowledge, attitude and

practices contributing to loss to follow-up amongst glaucoma patients were determined quantitatively in this chapter. A cross-sectional quantitative study was conducted among 429 glaucoma patients. The study showed that non-adherence with scheduled follow-up appointments among glaucoma patients in rural hospitals was still prevalent. However, factors varied due to people's unique experiences. Respondents exposed relatively little knowledge about the glaucoma disease. The limited knowledge of patients correlated with increasing age. Due to senility, older patients seem to forget information more easily than younger patients. This study revealed that some respondents have a negative attitude toward glaucoma treatment and management. Most respondents (73%) were overwhelmed when they were diagnosed with glaucoma and did not want other people to know about it. These respondents were afraid of going blind and were worried about living with a chronic condition. Some respondents felt uncertain about their future because glaucoma is an incurable disease. More than half of the respondents were not aware that they should do regular glaucoma follow-ups. Other patients held traditional or religious beliefs which assumed that glaucoma is caused by witchcraft or evil spirits. Other patients misunderstood the dosage instructions while others could not point to specific reasons for their non-adherence. This study also revealed that some respondents' poor practice contributed to non-compliance to the treatment and management of their condition leading to loss to follow-up. The study showed that 219 (51%) of the respondents were not compliant with treatment and management. The researcher felt the need to propose a strategy for closing the gaps in knowledge and practice deficiencies and negative attitudes amongst glaucoma patients. The challenges contributing to LTFU as experienced by glaucoma patients were further explored and are discussed in Chapter 4. This was the second phase of data collection which was conducted qualitatively to get detailed information from those patients who were identified as glaucoma LTFU during the first phase of the quantitative study. The population consisted of LTFU glaucoma patients who had been on anti-glaucoma medications for over three years. Data were collected through in-depth individual interviews guided by a single unstructured question: *"**What are the* challenges *that you have experienced that led to your LTFU when accessing glaucoma follow-up care?"*** The question was followed by probing the individual patient's responses. The duration of the individual interviews depended on how the participant answered the probing questions. The study findings revealed that patient-related, socio-economic, and environmental factors were contributing to LTFU among glaucoma patients. Variables such as fatigue due to prolonged use of glaucoma medication, forgetfulness, financial constraints, and use of alternative therapy were associated with patient behavioral factors whereas, lack of employment and family support, distance to the clinic, long waiting time, transport cost, and the negative attitude of medical staff toward patients were some of the socio-economic and environmental/health system variables contributing to LTFU. Additionally, LTFU glaucoma patients revealed other barriers that were mentioned during the first phase of data collection (quantitative stage). The patients mentioned that they were experiencing negative attitudes from the hospital staff, shortage of glaucoma medications, stigmatization, long waiting time and long queues and belief in traditional and spiritual healers.

Theoretical models that guided the development of a strategy for glaucoma eye care management

The ultimate purpose of any prescribed medical intervention is to achieve a certain anticipated outcome in the patients concerned. However, despite the best intention and efforts on the part of the healthcare professionals, those outcomes might not be achievable if the patients are non-compliant. The inability to use medications as prescribed can result in decreased treatment effectiveness and outcomes, increased complications, and worsened health status (Jin, Sklar, Oh & Li, 2008; Morse, 2015). Therefore, the development of intervention strategies to strengthen glaucoma medication adherence in developing countries like South Africa is required. There are several theoretical models of health behaviour change within Health Behaviour Theory that have been tested and found to be useful in improving health behaviours and adherence (Rimer & KA,1997 Newman-Casey,2013). Therefore, the following theories were explored and found to be appropriate for strengthening glaucoma eye care follow-up by checking both on the quantitative and qualitative study findings:the Health Belief Model (HBM); Social cognitive theory (SCT); Information Motivation Behavior Skill Model (IMB) and the Social Action Theory (SAT). These theories were chosen because they have been tested in practice with positive health benefits and used effectively in health behavior change programs worldwide (Chang, Choi, Kim, and Song, 2014). The selected theories have the potential to improve medication adherence and contribute to the development of effective interventions in the strengthening of glaucoma eye care in the Limpopo Province.

Besides, the Health Belief Model (HBM) and Social-Cognitive Theory (SCT) were chosen because they include a focus on cognitive variables as part of behavior change (Stroebe, 2000). Gerhard and Maes (2001) argues that these theories share the assumption that attitudes, beliefs and expectations of future events and outcomes are major determinants of health-related behavior. The theories further propose that individuals will choose their actions leading to positive results. Furthermore, IMB was precisely selected because of its effectiveness for behavior change. For instance, studies found that giving basic information to patients, and engaging them in a discussion about helping them to overcome cognitive barriers were effective in improving adherence (Simoni, Pearson, Pantalone, Marks and Crepaz, 2006; Cook et al.,2015). The identified four models will be integrated into formulating the intervention strategies to strengthen glaucoma eye care follow-up for this study.

Information Motivational Behavioral skills model (IMB)

The IMB model is one of the established social behavior theories. The model has been widely used in understanding and improving health behavior in different chronic diseases and populations as indicated by Fisher and Fisher in 1992(Yang, Hui, Zeng, Liu & Lee,2020). The IMB model captures three essential constructs that are: information, motivation and behavioral skills to improve health-related behaviors. Each construct can have a direct influence on health-related behaviors. Nonetheless, behavior skills mainly facilitate the effects of information and motivation behaviors. The model proposes that individuals who are well informed and highly motivated and have skills to perform health-related behaviors are more likely to

endorse and maintain health-related behaviors. The IMB model can also identify the key factors to implement and maintain the adherence behaviors in patients with chronic diseases like glaucoma (Yang et al, 2020). This makes the IMB model a relevant for this study. The key constructs and empirical support of the model are discussed below:

Information: Information refers to the basic knowledge and awareness about one's medical condition such as glaucoma and the efficient strategies to manage it. Information is a requirement for behavior change. It contains relevant patients' medication information in terms of dosage, timing, frequency, purpose, and side effects. Studies have reported that there is a significant correlation between medication knowledge and adherence to chronic diseases (Okuyan, Sancar & Izzetin, 2013). The second component is adherence **motivation**. This includes two sub-areas construct, that is, personal and social motivation. Adherence personal motivations include an individual's attitude and belief towards medication adherence, perceived social support for the behavior; and the patients' perception of how others with the condition might behave. Lastly, behavioral skills are key constructs of the IMB model that determine whether a well informed and highly motivated person can adhere to medication. It includes components such as ensuring that the patient has the skills, tools and strategies to perform the behavior as well as the confidence (self-efficacy) to perform medication adherence behaviors or the belief that they can achieve the behavior. All these components need to be directly relevant to the desired behavior to be effective.

Information, motivation, and behavior skills are vital in the improvement of glaucoma adherence and retention in care. Interventions using these constructs can address the patient barriers experienced and help them remain in care. However, all constructs outlined by IMB were shown in this study to be inadequate among patients. Specifically, there are substantial gaps in information among glaucoma patients. In the current study, concerned patients stated that they lack understanding of glaucoma disease and the importance of medication adherence. Patients further said they did not have adequate information about glaucoma and its medications. Other patients assumed that since they were not feeling pain, therefore, it was no longer necessary to continue with anti-glaucoma treatment (AGT) and follow-up visits. Another patient presumed that AGT was only needed while he was still working, but now that he is unemployed, he no longer needs AGT. Due to glaucoma misconceptions, and lack of information, patients, especially young patients, believe that glaucoma only affects elderly people. Some patients believed that glaucoma is caused by witchcraft and that it can only be cured by a traditional healer or spiritual healer. These assumptions and myths about glaucoma disease result in patients' LTFU from care. About 13% of the study participants indicated that they stopped taking treatment for no apparent reasons.

Patients further indicated that they left care because they were not aware that glaucoma is a chronic condition that needs lifetime treatment and that nonadherence to glaucoma medication can lead to permanent blindness. Without information about the likelihood of and the nature of glaucoma medication, and its side effects, they felt that the medication was reducing their vision, and not making them better, and patients discontinued taking their medication. Some stopped taking medication because of side-effects. They failed to understand that AGT slows the disease progress and reduces vision loss. Therefore, Cook et

al (2015) showed in their Multi-Site study that the IMB model showed that knowledge does affect adherence, along with behavioral skills, including self-efficacy and treatment motivation. Zhao et al (2020) also reported that older patients with multimorbid adhere less to their chronic medications because of insufficient knowledge, negative attitude, and lack of confidence. This was revealed in their IMB model of medication adherence study.

Glaucoma patients reported that they were not well informed about the disease, the importance of attending glaucoma eye services, the disadvantages of missing clinic visits and the lack of information about facts and myths about glaucoma and AGT. This knowledge gap contributes to low motivation among glaucoma patients to remain in care., Patients also indicated that health education would give them 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 choose to remain in care. The study also identified some gaps in motivation as other patients said they did not feel motivated to remain in care. Patients stated that they did not have adequate social support from both health care providers and family members. They specifically pointed out that some hospital workers such as clerks and doctors were not welcoming. Patients complained about poor doctor-patient communication. They further explained that this poor communication prevents them from getting necessary information that would help them adhere to their medication regimen.

According to Morse (2015), most communication between patients and doctors tends to be unilateral. Some patients said if family members could support them with transport or accompany them to the clinic, they would feel motivated to remain in care. Patients recognized motivation as the key construct needed to improve and encourage them to remain in care. Patients also stated that there is a need for creating a support group that would motivate them to remain in care. They passionately discussed how this would help them not feel that glaucoma is for a specific group like the elderly people. Patients also revealed that they preferred to be encouraged by their nurses and that such motivation would make them feel supported.

However, even if glaucoma patients have the information and motivation they need, patients may not necessarily develop the relevant behavioral skills to overcome barriers experienced on their own. Other glaucoma patients would develop the confidence to remain in care regardless of the challenges experienced. The needed skills include those related to medication adherence, such as not forgetting when to take treatment, when to go for clinic visits, and those skills needed to help them to get appropriate social support, whether from family members/friends who had glaucoma or health care providers. Currently, skills building in these areas is not provided. If skills building in these areas were provided, adherence to glaucoma medication would improve and result in better health outcomes.

The following quotations illustrate the need to equip patients with correct information on glaucoma disease and the importance of medication adherence. Patients reported how they dropped out of care because of a lack of information regarding glaucoma diseases. They said:

“*Look at me, my eyes look perfectly well, I don’t need any eyedrops”.*

“I have stopped using my eye drops because my vision is not improving; I feel it is a waste of time”.

Another vital reason to give patients relevant information is that some patients believed that glaucoma can be cured by either traditional healers or pastors from the church. Here is what one patient said:

"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 again".

"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 (a mixture of different herbs) because somebody has put some spells in my eyes so that I cannot work for my family".

This implies that patients should be educated on the importance of AGT with emphasis that glaucoma is a chronic disease that needs lifetime treatment and if untreated may lead to blindness. To improve adherence when using the IMB model, physicians are encouraged to educate patients about the natural course of glaucoma and the need for lifelong treatment, address medication side effects. Clear communication between the patient and eye care provider remains an important factor in the management of the disease. Above all, the IMB model constructs are important for glaucoma adherence only when taken observed careful during the intervention. There is need to apply this evidence-based model to facilitate possible behavioral change for glaucoma patients to remain in care. Figure 1 explains how the IMB model could be applied to improving adherence in glaucoma treatment and management.

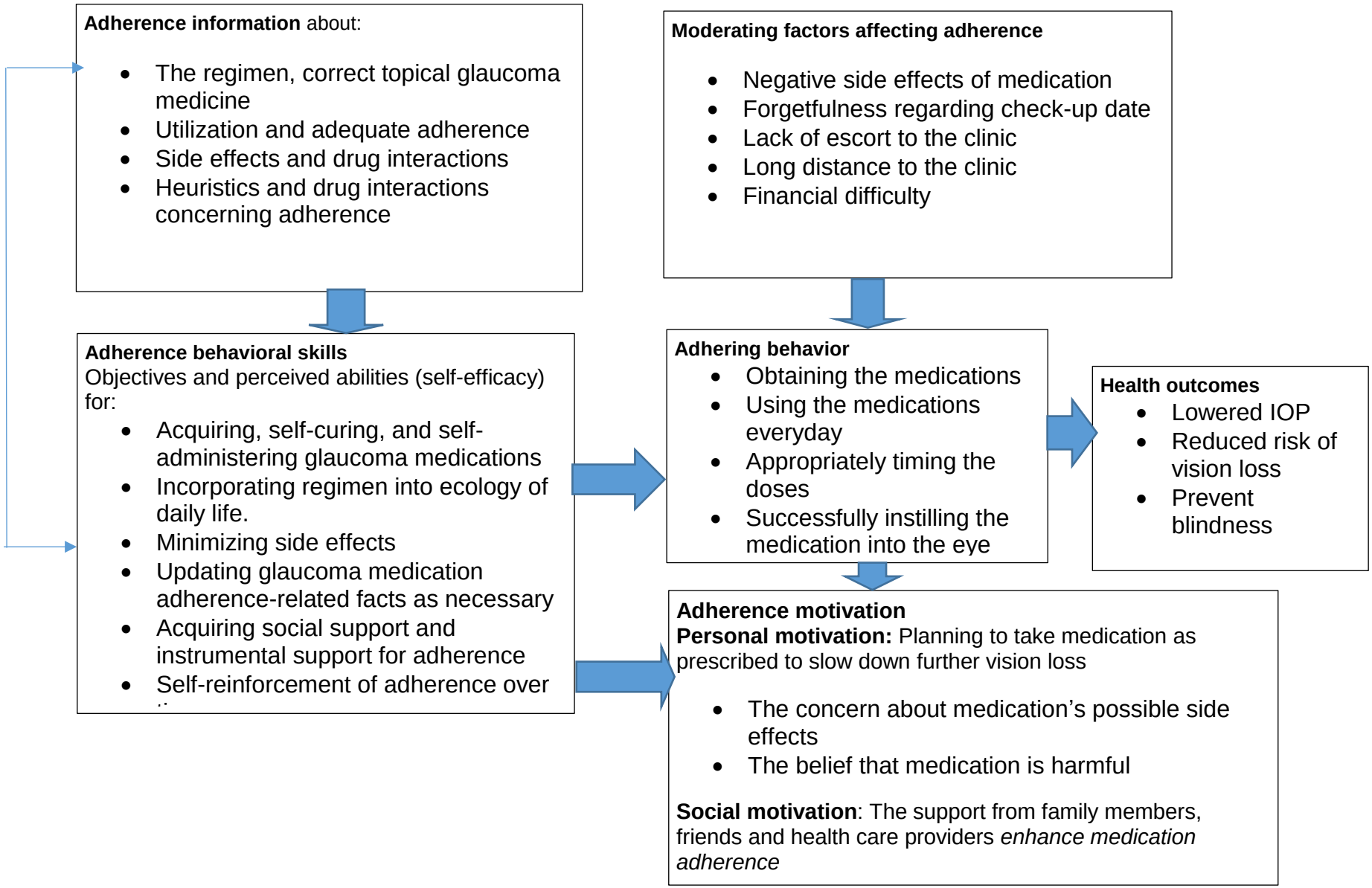


Figure 1: Adapted IMB Skills Model by Fisher et al., 2008 to increase knowledge and awareness of glaucoma disease.

The social cognitive theory (SCT)

Social cognitive theory is a psychosocial (interpersonal) model that describes how social relationships influence cognition and behavior. The SCT explains human behavior in terms of a dynamic and continuous interaction between an individual and the environment. It has been proven to have a positive influence on health behavior change (Coreil, 2008; Adefolalu,2018). In this study, SCT was used to address (1) system/organizational barriers such as negative staff attitude, unavailability of medications, poor access to glaucoma information, long hospital queues, hospital not adequately equipped, and (2) social barriers such as medication and travel cost, inability to drive oneself or write, feelings of isolation or alienation, stigmatization, abandonment, fear of the effects of sight loss, financial stress and loss of economic or social productivity.

Most of these barriers are out of the patient's control such as long waiting time, but, can be resolved through the guidance of SCT for better medication adherence. Thus, a detailed discussion follows on why SCT is of relevance to address some of the system barriers described by patients. This theory states that learning is achieved in a social context, emphasizing the importance of internal and external social reinforcement in learning.

SCT was chosen to address the system barriers stipulated in this study. Based on the evidence in the literature, SCT is appropriate to tackle the specified obstacles. Consequently, this section discusses why SCT is the appropriate theory for addressing system barriers in the study context. Considering that the current study was conducted in a rural context and affected by low socio-economic barriers, the researcher found it imperative to propose the SCT model to mitigate the impact of educational interventions in improving the quality of life among glaucoma patients in the Limpopo Province.

According to Bandura (2004)), it is not enough that SCT acknowledges that knowledge of health risks and the benefits of treatment are necessary to perform health behaviors. Moreover, self-influences are necessary to achieve changes that will result in the anticipated health behavior; and this concept is called self-efficacy. So, the two cognitive processes that influence behavior in SCT are called self-efficacy and outcome expectations.

Self-efficacy is a known predictor of health behavior in patients with chronic medical conditions and influences adherence. Self-efficacy is one of the key constructs of SCT and Sleath (2015) observes that it is significantly associated with glaucoma medication adherence. Also, studies in HIV, diabetes, asthma and depression have found a positive association between self-efficacy and medication adherence (Parsons, Rosof & Mustanski, 2008; Sleath, 2015). Glaucoma medication adherence self-efficacy is an individual's belief in the ability to continue using glaucoma medication despite the various challenges they may encounter in doing so. It also proposes that positive behavior change occurs because of the person's belief about how capable they are, in performing those behaviors that would lead to the desired outcome. As anticipated, patients in this study did not have the self-efficacy to remain in care and adhere to glaucoma medication. Once patients received hostile treatment from the eye care providers, they stayed away from

care, showing their need to strengthen the skills of staying in care despite experiencing challenges. In this case, according to SCT, glaucoma patients with high self-efficacy will choose to adhere to their medication if they believe that using glaucoma medications will result in lowering of IOP or slow down further vision loss regardless of the hostile treatment by eye care providers. This means that if patients assume that regular follow-up visits may result in better health care and reduce the risk of vision loss they will adhere to glaucoma medication.

This theory further shows that human behavior is learned. Family members and friends diagnosed with glaucoma disease also play a crucial role in medication adherence. Several studies have reported that patients who had one or more relatives with a glaucoma diagnosis possess more knowledge than patients without relatives with glaucoma disease (Aghedo, Tlou & Mahomed,2018). About 43% of the study participants, especially the elderly, do not want anyone to know that they have glaucoma disease. Patients who had a positive family history of glaucoma were more compliant than patients who had a negative family history of glaucoma. Therefore, family members diagnosed with glaucoma act as peer supporters. This has helped glaucoma patients to remain in care. The peer supporters encourage and support other glaucoma patients to stay in care. Through the support from family members and friends, glaucoma patients get stimulated as they see other glaucoma patients (family members diagnosed with glaucoma) in care and living a good quality life. Seeing those family members with glaucoma, looking healthy with controlled IOP and good vision, encouraged many glaucoma patients to stay in care and use their glaucoma medication regularly regardless of all the challenges they experienced. Moreover, the peer supporters could also use cognitive and behavioral strategies to empower patients to negotiate problems around AGT adherence and to establish supportive relationships which strengthen patients' ability to adhere. All these would subsequently lower LTFU rates and improve health outcomes resulting in good quality of life.

Bandura (year and page) describes four sources of information that influence self-efficacy. These are performance mastery, vicarious experience, verbal persuasion, and physiological symptoms. The integration of information from one or more different sources is important for the effectiveness of self-efficacy (Adefolalu, 2018). These sources are equally applicable for AGT adherence among glaucoma patients who are on lifetime medications. Some patients mentioned that they stopped going for their follow-up appointment because of the rude behavior of hospital staff. Patients complained that some hospital staff is not welcoming and treat them as if they were small children. These contribute to their unwillingness to stay in care. Since they lack sufficient knowledge about Glaucoma and behavioral skills, they dislike being disrespected and therefore default from care. The study findings showed that nurses should strengthen patients' health education and enhance their behavioral skills to improve the expected outcomes.

Below is what patients said about the negative attitude of health care workers. This emphasized their reason for not staying in care:

"*Nurses speak to us in a very disrespectful manner, I am not a kid, …..*

I will rather not visit this hospital again than to be treated like a nobody".

"The doctors who work here in this clinic do not care about us……

They are always in a hurry, we hardly ask anything regarding our condition or medications,

they are unfriendly, such behavior is very much unwelcoming".

Social Cognitive Theory (SCT) has been proven to have a positive impact on health behavior change. The review of the literature below shows how SCT can be effective in improving glaucoma medication adherence and keeping eye care visits. A study conducted in North Carolina (USA) by Sleath et al (2014) revealed that there is an association between patients with higher glaucoma medication adherence self-efficacy and outcome expectations. Patients with higher glaucoma adherence self-efficacy were more adherent to using their medications. Also, studies in HIV, diabetes, asthma, and depression have reported positive associations between self-efficacy and medication adherence where SCT has been applied (Parson, Rosof & Mustanski, 2008; Bonner Zimmerman, Evans, et al, 2002; Sleath et al, 2012).

These studies found self-efficacy to be vital in glaucoma medication adherence. Health care providers can impart self-efficacy to all glaucoma patients together with their family members for easy support. The healthcare providers should attempt to educate and motivate glaucoma patients from different age groups about the risks associated with nonadherence to glaucoma medications. These could be done during patients' consultations, and pharmacists too could help patients determine how to overcome their problems in using their glaucoma medications. All hospitals and clinics that provide glaucoma care in the district could have the capacity to carry this out. If the hospitals and clinics could adopt this strategy, patients may have the confidence and the capacity to remain in care and adhere to their glaucoma medications. The figure below outlines the SCT.

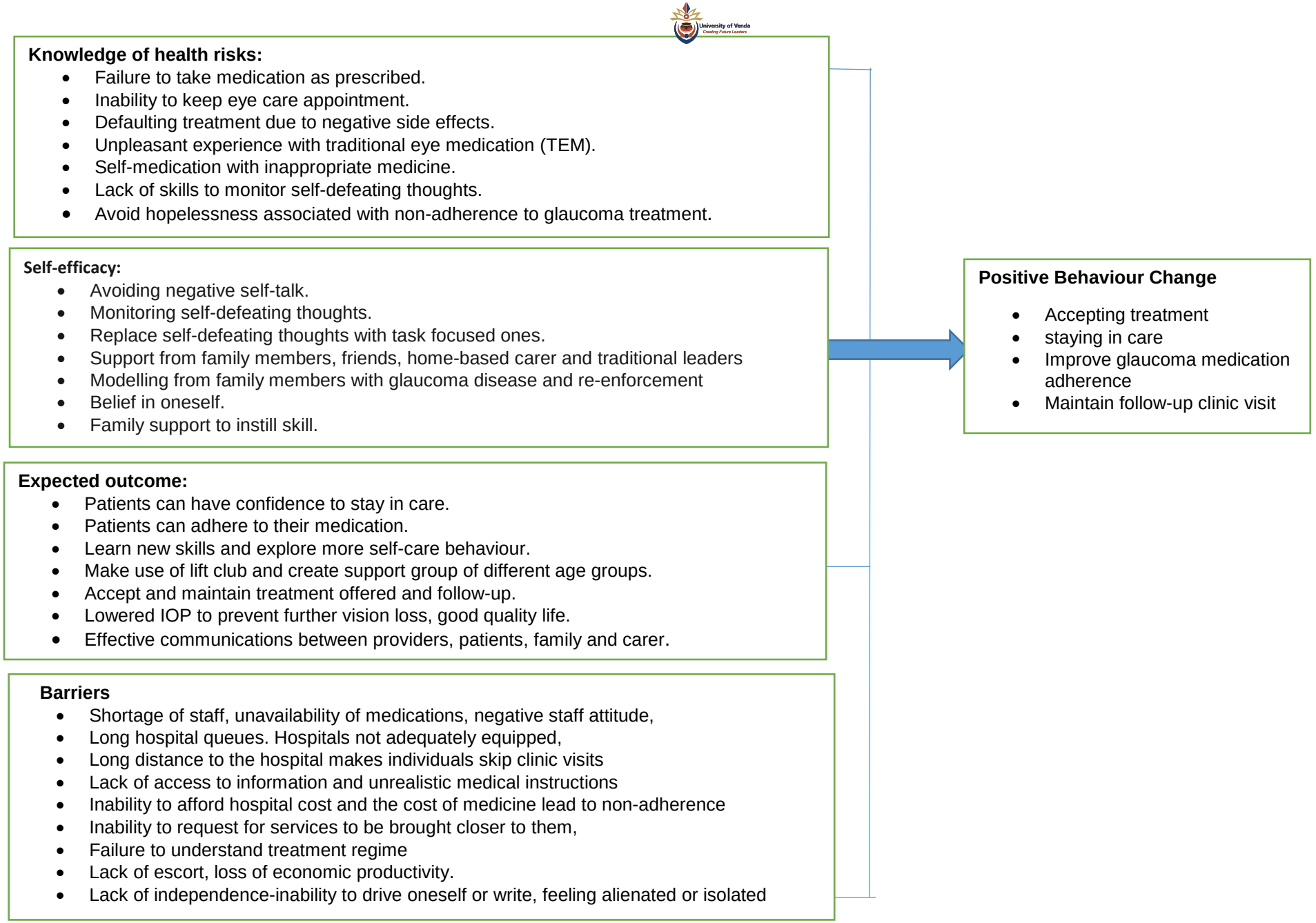


Figure.2: Adapted SCT model by Bandura (1977) to promote self-efficacy and psychosocial skills among glaucoma patients

Social action theory (SAT) was also analysed for its relevance in addressing the socio-economic and system/organizational barriers reported in the current study. Barriers such as long distance to the clinic, forgetfulness, lack of escort to the clinic, and long hospital queues. Social action theory has been indicated by various scholars to be effective in improving medication adherence such as for glaucoma disease, hence the researchers chose it to guide the current study on how to address stipulated system/organizational and socio-economic barriers to improve AGT adherence.

The SAT focuses on behavior change and social support that can assist in fostering and maintaining that change (Mukumbang, Van Belle, Marchal, & van Wyk, 2017). It is appropriate to minimize the systematic and socio-economic barriers experienced by glaucoma patients. This theory is also relevant to improving AGT adherence in the study area because of its ability to identify and eliminate factors that contribute to negative health behaviors, which are detrimental to good health and introduce positive health behaviors, which, in turn, will enhance good health (Reynolds, et al.,2010, Ewart, 2009). The SAT theory further suggests the need to expand individually-focused concepts by including inter-dependence with others as a determinant of continued behavior change.

Regrettably, in the current study, both social support and inter-dependence on others are challenges for participants. Patients stated that they do not have sufficient social support from their family members to strengthen their follow-up. Patients reported that they sometimes lack an escort to take them to the clinic as they cannot travel alone due to their poor vision and age. Others reported that they did not have transport money as they are unemployed and would appreciate the financial support from their families such as transport fares or to be given a lift for their medication refills.

One of the patients said,

"*I stay far away from the hospital and at times…*

I cannot afford the transport fare to the clinic,

that is the main reason I stopped going for my follow-up visit".

Another participant said:

"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….

So, I decided to stop going for my medication refills".

Hospitals that offer glaucoma services are situated far away from the villages. Patients revealed that they cannot visit nearer clinics or mobile clinics as there are no glaucoma eye care services. Therefore, they have to travel to a far distant hospitals to receive glaucoma services. So, the unavailability of glaucoma eye services in the local clinics contributes to barriers such as long-distance, waiting time, and long queues. In Nigerian

studies, several authors (Abdull, 2012; Adio, 2012; Ehiemua, 2014) stated that patients were dissatisfied because of the long waiting time in health facilities. These studies further highlighted hospital staff's failure to retrieve patients' files and patients' refusal to queue, as other factors contributing to the long waiting time. Equally, the use of an interpreter contributes to long waiting time and makes patients dissatisfied with hospital visits (Adio & Onua 2012; Abdul., Gilbert & Evans, 2012; Foreman et al, 2018).

Participants said they would be grateful to receive financial assistance from government and that nurses should also provide them with emotional support. Such support would encourage them to adhere to their follow-up. Other glaucoma patients identified forgetfulness as another factor that contributes to their glaucoma LTFU. The patients requested that the nurses working at the eye clinic should remind them of the datesthrough SMS messages via their cell phone or their family members. Nurses /CHWs can create a song that would remind patients to take treatment. Nurses/CHWs can introduce the direct observation treatment (DOTs) program to ensure that glaucoma patients are taking their medications as prescribed. This would help in enhancing their glaucoma follow-up.

The theory reveals a need to expand individually-focused action state concepts by including interdependence with others as a determinant of sustained behavior change. For instance, in the helpful provision, patients can ease their financial woes by replacing a taxi with a bus to the eye clinic to reduce transport costs. For social support, patients could form a lift club with fellow glaucoma patients, family members, or friends if they are willing to offer such support. A more effective way to reduce transport costs to the clinic would be to give patients medications that can last for 2-3 months. Nayak et al (2015) reported similar results in India (Delhi), that there is a need for proper follow-up guidelines to avoid unnecessary outpatient visits at short intervals, as it is too costly for glaucoma patients coming for routine check-up. The study further indicated that most patients are from a distant rural area, a fact which increased in direct medical costs for the patients (Nayak *et al*, 2015). Such support might inspire them to stay in care. Geng *et al* (2010) pointed out that social support like hospital accompaniment, transport costs and supportive health staff enhances medication adherence.

The study further indicated that social support in the form of financial or emotional support plays an important role in strengthening glaucoma follow-up. A Ugandan study also revealed that instrumental support in the form of goods or services facilitated adherence by helping patients to take their medications, as well as by alleviating daily tasks to allow patients to attend the clinic (Rouhani, O'Laughlin, Faustin, & Ware, 2017). Additionally, *Tripathi et al* (2017) also mentioned that glaucoma patients who lack family support have a lower compliance rate compared to those with good family support. Then, all the above studies found that inter-dependence with others and social support (emotional/ financial) played a vital role in medication adherence and remaining in care. If these are present, patients can remove barriers to their LTFU and improve access to the clinic for medication refills.

Therefore, if patients remain in care and improvement in adherence can result in the lowering of IOP. Medication can slow down further vision loss. Taking into consideration that most participants in this study were unemployed, financial support from family members or friends, especially for transport fare seems

important. In a situation where family members are unemployed, the best they can offer to patients is emotional support and assistance in escorting them to the clinic. The escort or caregiver also reminds the patients to take their medication and becomes their eyes and ears. Therefore, the SAT recommends that patients receive social support, whether instrumental or emotional support for them to stay in care and adhere to their glaucoma medications. **Figure 4** demonstrates the SAT model adapted to promote medication adherence among glaucoma patients.

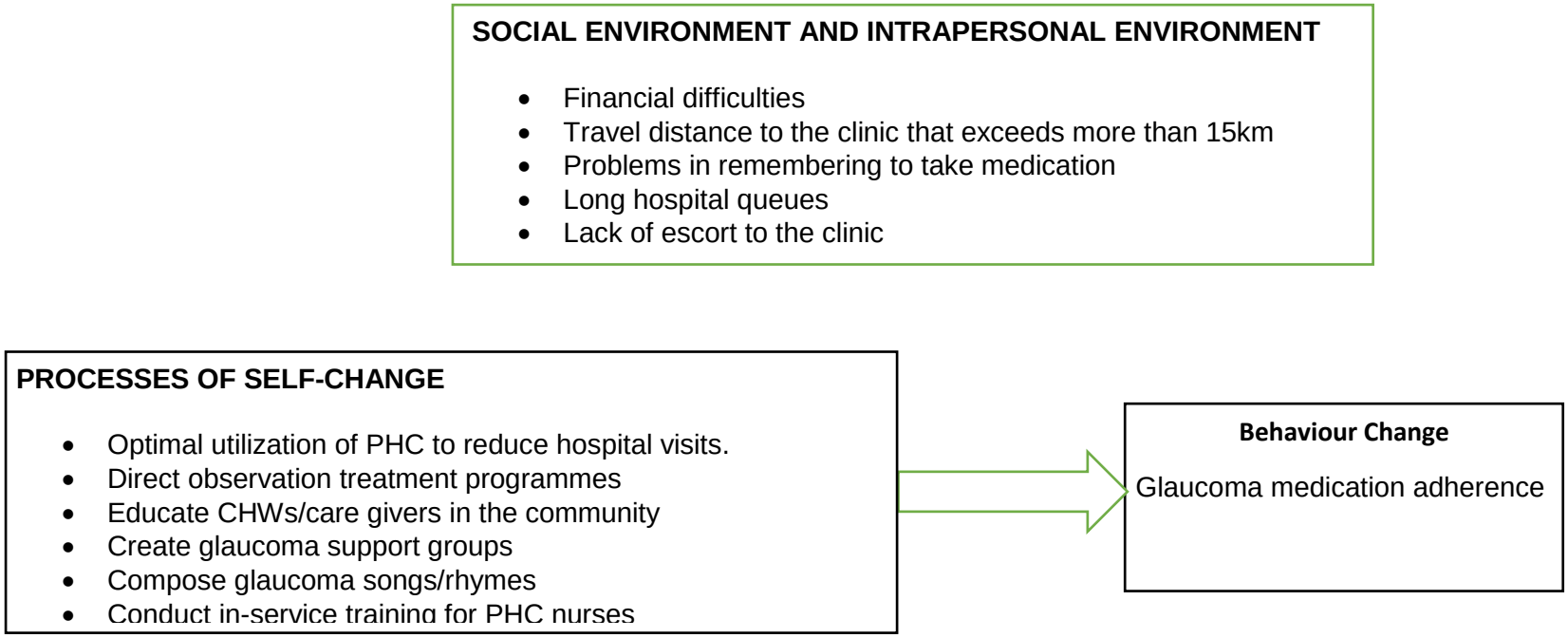


Figure 3: Adapted Conceptualization of the SAT model by Ewart (2009) to promote medication adherence among glaucoma patients

Health Belief Model theory (HBM):

This model is effective for promoting numerous positive health behaviors such as adherence to glaucoma medication. The HBM is a cognitive interpersonal approach that views humans as rational beings who behave in certain ways to minimize what they perceive as threats (for example, non-adherence) and enhance what is perceived as benefits (for example, adherence to their glaucoma medication). The HBM contains cognitive constructs that include perceived susceptibility, severity, perceived benefit, perceived barrier, and self-efficacy that predict why people take actions to control their illnesses (Kaup, Ooman & Shivalli, 2018). The model has several interactive states of belief, which collectively affect glaucoma adherence. it has core assumptions indicating what should be addressed: The HBM is likely to help glaucoma patients to be adherent and remain in care. So, patients need to be aware of the risks of getting blind if they are not adherent to their medication. It is also important for participants in the study to know the risks of nonadherence to glaucoma medication. The HBM cognitive constructs are explained as follows:

Perceived severity: This means one's opinion of how serious glaucoma and its consequences are. Unfortunately, other glaucoma patients in the study did not understand the importance of glaucoma follow-up and medication adherence. They were not aware that failure to take medications as prescribed may result in vision loss and blindness. This implies that if patients were aware that LTFU can result in serious health complications such as vision loss and blindness, they might have taken responsible health actions (remaining in care and consistently and taking glaucoma medication). This knowledge would make glaucoma patients adhere to their medications realizing that failure to do so can result in total blindness (Mansberger et al, 2013).

Perceived susceptibility refers to one's opinion of the chances of developing severe glaucoma. In this study, patients did not understand that non-adherence makes them vulnerable to glaucoma complications. They were also not aware that nonadherence to glaucoma medications causes irreversible blindness. The study participants were not fully aware of the consequences of LTFU.

Perceived benefits, refers to one's belief in the efficacy of using eye drops to reduce the risk or seriousness of the glaucoma disease. In this study, some patients were unaware of the benefit of regular follow-up and medication adherence, hence they were LTFU. In HBM, patients have a positive expectation that regular follow-up and using eye drops will lower the IOP and preserve current eyesight. Patients also understand that glaucoma medication adherence can help them reduce complications. At this stage, they further recognize that remaining in care and adhering to the medication as prescribed by the doctors result in the lowering of IOP which is the only proven way to reduce the risk of glaucoma vision loss (Robin, Kelly & Muir, 2019). Some patients understood the benefits of adherence and staying in care. They pointed out that they were aware of the positive health benefits of remaining in care. They had stopped taking their medication because of the disease burden as they already had more than two chronic conditions. In addition to knowledge of the benefits of glaucoma medications, patients should have the confidence to

remain in care and adhere to their medications. Yang et al (2020) also reported similar findings that patients with more than two chronic diseases and longer duration of chronic diseases are associated with lower medication adherence.

Perceived barriers. These include factors which an individual perceive as obstacles to the health action (Adefolalu, 2018). Most patients are aware of their barriers contributing to their LTFU. Therefore, patients may choose to adhere to the medications that will prevent vision loss and ignore the cost of long-distance to the hospital.

Self-efficacy. This refers to an individual's perception of his or her competence to successfully perform a behavior. It was added to the HBM to explain the individual differences in health behaviors (Onoruoiza, Musa, Umar & Kunle, 2015). At this point, patients are confident that regardless of the perceived barriers such as accessibility and financial cost, they will adhere to their glaucoma medications. **I**n this study, this is the vital assumption in resolving psychological barriers. No one can guarantee that glaucoma patients (especially the younger age group) can never be stigmatized and discriminated hence self-efficacy is of utmost importance. At this point, patients would be confident that regardless of the perceived barriers such as stigma and discrimination, they will adhere to the medication Some glaucoma patients in this study did not have the self-efficacy needed to remain in care and to be adherent to their medication, hence they were LTFU due to fear of stigma and discrimination.

All these core elements of HBM work together. For instance, patients need to be educated and well informed of all the assumptions for them to understand the risks of non-adherence, the benefits of adherence, and to have the self-confidence that they can adhere to their medication regardless of psychological barriers.

The statements below show that there is a need for a strategy to address all constructs of the HBM. For example, if patients perceive dropping out of care as dangerous, they are more likely to stay in care and be adherent to glaucoma medications. Below are statements that show that patients in the current study do not see their actions (defaulting from care) as risky, hence they are LTFU.

"I stopped taking my medication because I do not feel any pain in my eyes, …

I feel healthy……".

"I see no need to continue taking medication because I am using holy water from my pastor that will cleanse my eyes".

There are several studies on the efficacy of HBM on health behavior change, especially on glaucoma adherence. For instance, a New York study found that using the HBM model helped to educate glaucoma patients effectively and efficiently. Similarly, Sleath, Blalock, Covert, et al (2012) discovered that patients on two or more glaucoma medications were more likely to report multiple problems taking their eye drops than patients who are using one glaucoma medication. These authors reported that patients on more than two glaucoma medications are more likely to report having difficulty with (1) forgetfulness, (2) side effects, (3) inability to control the eye drops, (4) inconvenient dosing times. The study findings proposed that providers

should attempt to simplify patient's regimen to make it fewer eye drops. Studies for other diseases indicate that simplifying patients' medication regimens can improve medication adherence (Haynes, McDonald & Garg, 2002; Sleath et al, 2012; Costa et al, 2015; Mansberger et al, 2013) also reported that HBM could use the Glaucoma Treatment Compliance Assessment Tool (GTCAT) to measure the effectiveness of an intervention to improve glaucoma adherence.

The results of this study show that due to their lack of education about the benefits of glaucoma medications, patients do not understand how medication can help them control their intraocular pressure, slow disease progression, and reduce vision loss leading to better health outcome and lower health care cost. They also lack the understanding of the negative consequences of medication non-adherence and dropping out of care. However, the responses in this study also show that belief/knowledge alone is not enough. Rather, patients should also have the confidence to be adherent regardless of barriers experienced. For instance, some patients who understood glaucoma medication benefits and believed in the positive health outcome of the medication were non-adherent because of fear of being stigmatized and discriminated. While studies demonstrated that beliefs about benefits/effectiveness of glaucoma medication predicted high adherence and absence of beliefs predicted non-adherence, it is important to instill more than knowledge about the benefits of glaucoma adherence; patients need motivation in building their confidence to adhere to their glaucoma medication and remain in care. The figure below proposes the HBM strategy to strengthen the eye care follow-up and treatment adherence amongst glaucoma patients.

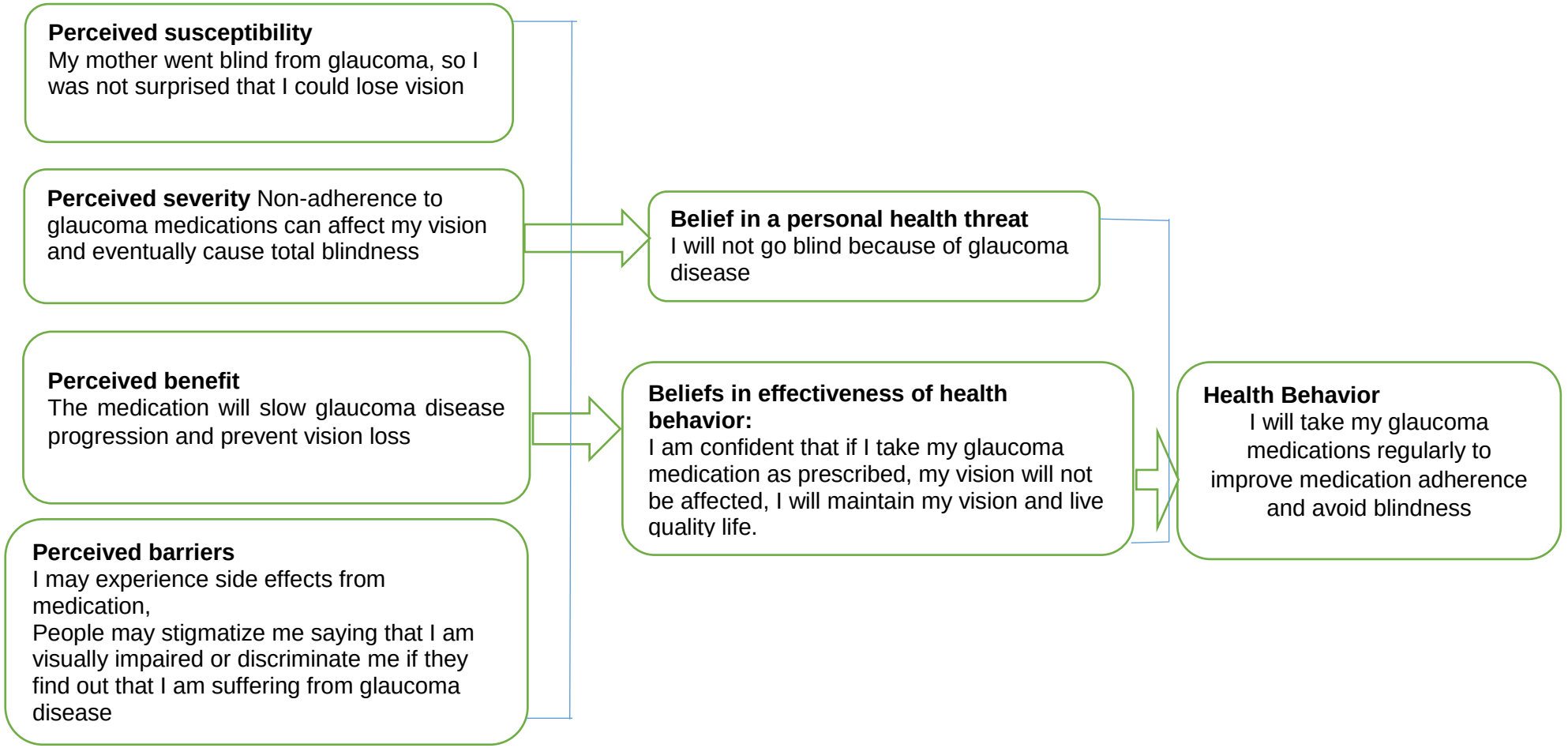
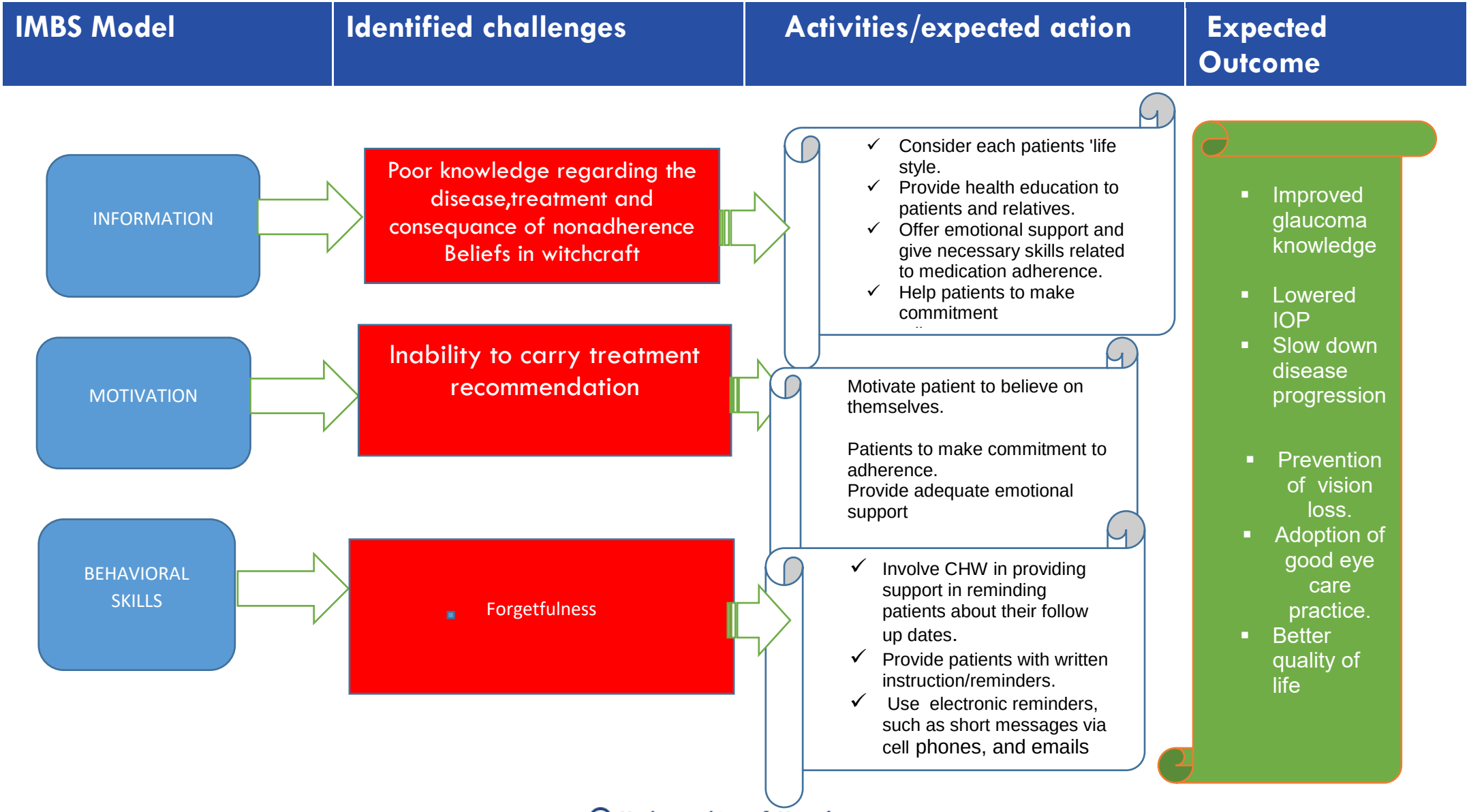


Figure 4. Adapted HBM model adapted by Hochbaum et al (1950) to promote positive health behaviors among glaucoma patients.

.

PROPOSED STRATEGY

The three chapters revealed knowledge gaps that informed the development of strategy guided by various theories intended to strengthen the eye care follow-up amongst glaucoma patients as is described in figure 1 and figure 2



Model	Identified challenges	Activities/expected action	Expected Outcome
SOCIAL COGNITIVE THEORY	Unavailability of medication Negative staff attitude inability to drive oneself •Failure to understand treatment regime	✓ Improved provider-patient relationship. ✓ Make use of lift club ✓ create support group for different age groups	Educate patient on the negative effects of non-adherence Educate the patient to continuously overcome challenges
SOCIAL ACTION THEORY	Long distance to the clinic Financial constraints • Problems in remembering to take medication• Lack of escort to the clinic	✓ Glaucoma treatment to be supplied by the local clinic ✓ Stable glaucoma patients to be given less frequent follow-up appointments	Improved Glaucoma medication adherence and follow up care
HEALTH BELIEF MODEL	Fear of stigmatization and discrimination Fear of getting blind	✓ Educate patient on the negative effects of non-adherence ✓ Educate them to overcome challenges Continuously	Patients may have the self-confidence to adhere to their medication

Implications and recommendations of the proposed strategy in the Vhembe District health care facilities

The strategy proposed in this study may improve the retention of glaucoma patients in care in all health facilities in the Vhembe District of Limpopo Province. This will promote good health outcomes such as lowering IOP and prevent or slow down further vision loss that can result in blindness, and ultimately reduce the rate of glaucoma LTFU. The findings of the study revealed factors that contribute to nonadherence in patients with glaucoma. Patients outlined various reasons that contribute to their glaucoma loss to follow-up. These included: inadequate knowledge regarding the disease itself, the perception that compliance to medications and follow-up is less important, forgetfulness, financial difficulties, lack of an escort to the clinic, travel distance from home to the clinic exceeding more than 15 km, long hospital queues and the belief that glaucoma is caused by witchcraft or evil spirit, difficulty in getting time off to attend hospital and shortage of medication.

The study found that the degree of vision loss is associated with increased glaucoma nonadherence. Similarly, the study concurs with other studies that were conducted mostly in sub-Saharan Africa (Abdull *et al*, 2012; Thompson *et al,* 2015). The proposed strategy can be used or adapted by any health facility since it shows how glaucoma interventions strategy can be integrated into glaucoma guidelines and policies of the hospitals. Furthermore, the study also revealed that glaucoma can be controlled and vision loss prevented with regular follow-up clinic visits and using effective medications. The study suggests that patients should be informed about the advantages and disadvantages of glaucoma loss to follow-up. The Vhembe District Department of Health should provide Mobile Clinic vehicles for easy access by glaucoma patients who stay far from health facilities. Campaigns to enhance public eye awareness on glaucoma diseases should be conducted to improve the effectiveness of health promotion and prevent vision loss. All this could significantly improve the quality of life for patients and their families. This will also reduce national expenditure by the health care services and increase productivity of the country's economy.

The study suggests that the Department of Health in Limpopo ensures that policies are reviewed to re-dress the issue of accessibility and affordability so that glaucoma patients can get their medications from health care facilities closest to their homes. Moreover, specific intervention theories were applied to develop a strategy that would help health care facilities in the Vhembe District to retain patients in care and strengthen glaucoma follow-up adherence. The models include: Information Motivation Behavior Skills Model (IMB) to address patient barriers; Social Cognitive Theory (SCT) to address system barriers; Social Action Theory (SAT) that addresses structural barriers; and lastly the Health Belief Model (HBM) which addresses psychosocial barriers. Taking into account the results of the current study and literature on the effectiveness of various psychological models in health behavior change, the developed strategy outlines the need to strengthen information, motivation, behavioral skills, and social support for patients to remain in care and adhere to their glaucoma medications. The proposed strategy will be shared with District Managers and hospitals of Vhembe District with the hope that they will improve patients' health outcomes when implemented. However, the validation of the strategy was not possible in the context of the current study because there is no known similar study conducted in the Limpopo Province and in Vhembe District. Validation can only be done if similar studies have been conducted under similar conditions. Therefore,

change of attitude, knowledge, and skills development requires extensive education and practice. Then, a retrospective cohort study might be suitable at a later stage to get improved results than the previous ones.

Conclusion

This chapter presented the proposed strategies that might be useful in strengthening eye care follow-up amongst glaucoma patients in the Vhembe district of Limpopo Province. Different psychological models were outlined and used in guiding this strategy that might reduce the rate of glaucoma LTFU if correctly applied. It provides useful information about strategies that might improve glaucoma follow-up care and glaucoma medication adherence. If these strategies are effectively implemented, rates of glaucoma LTFU might be reduced and improvement of medication adherence in the hospitals/clinics of the Limpopo Province observed. However, the proposed strategy in the current study is not cast a stone. There is a need to observe that each patient is an individual and may not necessarily be served best by the proposed strategy. The strategy would be used most effectively if health care service facilities draw up their procedures and protocols based on the conceptualized and contextualized circumstances.

Reference list

Abdull, M.M., Gilbert, C.C. and Evans, J. Primary open-angle glaucoma in northern Nigeria: stage at presentation and acceptance of treatment. *Ophthalmology*, 2015;15(1), p.111.

Adio AO, Onua AA. Economic burden of glaucoma in Rivers State, Nigeria. *Clinical Ophthalmology* (Auckland, NZ). 2012; 6:2023.

Aghedo AV, Tlou B, Mahomed S. Knowledge, attitudes and self-care practices of patients with glaucoma in uThungulu in KwaZulu-Natal. *African Vision and Eye Health*. 2018 Feb 26;77(1):1-6.

Al-Mulla AH, Al-Thafar AK, Hussain MA, Ali SI, Al-Dossary SK. Knowledge, attitude and practice toward diabetic retinopathy and retinal examination among diabetic population in Al-Hasa Region, Saudi Arabia: A cross-sectional study. Age. 2017 Jul 1;35(116):24-.

Batiha AM, ALBashtawy M. Attitudes and practices of health science students regarding blood donation. *International Journal of Advanced Nursing Studies*. 2016 Jan 1;5(1):81.

Bedasso K, Bedaso A, Feyera F, Gebeyehu A, Yohannis Z. Prevalence of common mental disorders and associated factors among people with glaucoma attending outpatient clinic at Menelik II Referral Hospital, Addis Ababa, Ethiopia. PloS one. 2016;11(9).

Bleijenberg, N., Janneke, M., Trappenburg, J.C., Ettema, R.G., Sino, C.G., Heim, N., Hafsteindóttir, T.B., Richards, D.A. and Schuurmans, M.J., 2018. Increasing value and reducing waste by optimizing the development of complex interventions: Enriching the development phase of the Medical Research Council (MRC) Framework. *International Journal of Nursing Studies*, *79*, pp.86-93.

Bonner, S., Zimmerman, B.J., Evans, D., Irigoyen, M., Resnick, D. and Mellins, R.B., 2002. An individualized intervention to improve asthma management among urban Latino and African-American families. *Journal of Asthma*, *39*(2), pp.167-179.

DeVellis, B.M. and DeVellis, R.F., 2001. Self-efficacy and health. Handbook of health psychology, pp.235-247.

Ehiemua, U.R.A., 2014. *Reasons for poor adherence to Antiretroviral Therapy (ART) by young female (15-24 years) HIV/AIDS patients in Oshakati district* (Doctoral dissertation, Stellenbosch: Stellenbosch University).

Fudemberg SJ, Lee B, Waisbourd M, Murphy RA, Dai Y, Leiby BE, Hark LA. Factors contributing to nonadherence to follow-up appointments in a resident glaucoma clinic versus primary eye care clinic. Patient preference and adherence. 2016; 10:19.

Kaup S, Oomman SS, Shivalli S. Determinants of medication adherence to topical ocular hypotensive and application of health belief model among glaucoma patients visiting a tertiary care hospital in coastal Karnataka, India. *Indian Journal of Ophthalmology*. 2018 Aug 1;66(8):1229-30.

Kyari F, Adekoya B, Abdull MM, Mohammed AS, Garba F. The current status of glaucoma and glaucoma care in sub-Saharan Africa. *The Asia-Pacific Journal of Ophthalmology*. 2018 Nov 1;7(6):375-86.

Lee BW, Sathyan P, John RK, Singh K, Robin AL. Predictors of and barriers associated with poor follow-up in patients with glaucoma in South India. *Archives of Ophthalmology*. 2008 Oct 13;126(10):1448-54.

Mansberger SL, Sheppler CR, McClure TM, VanAlstine CL, Swanson IL, Stoumbos Z, Lambert WE. Psychometrics of a new questionnaire to assess glaucoma adherence: The Glaucoma Treatment Compliance Assessment Tool (an American Ophthalmological Society thesis). Transactions of the American Ophthalmological Society. 2013 Sep; 111:1.

Mbadugha, C.A. and Onakoya, A.O., 2014. The awareness, perceptions and experiences of primary open angle glaucoma patients in Lagos Nigeria. *Scientific reports*, *4*(1), pp.1-6.

Movahedinejad T, Adib-Hajbaghery M. Adherence to treatment in patients with open-angle glaucoma and its related factors. *Electronic Physician*. 2016 Sep;8(9):2954.

Nayak, B., Gupta, S., Kumar, G., Dada, T., Gupta, V. and Sihota, R., 2015. Socioeconomics of long-term glaucoma therapy in India. *Indian Journal of Ophthalmology*, 63(1), p.20.

Newman-Casey PA, Robin AL, Blachley T, Farris K, Heisler M, Resnicow K, Lee PP. The most common barriers to glaucoma medication adherence: a cross-sectional survey. *Ophthalmology*. 2015 Jul 1;122(7):1308-16.

Njenga LN. *Determinants of Non-adherence to Long Term Therapy with Prescription Medicines in Adult Patients Attending Medical Outpatient Clinic at Mbagathi Hospital* (Doctoral dissertation, University of Nairobi).

Onoruoiza SI, Musa A, Umar BD, Kunle YS. Using health beliefs model as an intervention to non-compliance with hypertension information among hypertensive patient. Int Organ Sci Res J Human Soc Sci. 2015;20(9):11-6.

Parsons JT, Rosof E, Mustanski B. Medication adherence mediates the relationship between adherence self-efficacy and biological assessments of HIV health among those with alcohol use disorders. AIDS and Behavior. 2008 Jan 1;12(1):95-103.

Quaranta L, Riva I, Gerardi C, Oddone F, Floriano I, Konstas AG. Quality of life in glaucoma: a review of the literature. Advances in therapy. 2016 Jun 1;33(6):959-81.

Reynolds WM. Reynolds adolescent depression scale. The Corsini Encyclopedia of Psychology. 2010 Jan 30:1

Robin AL, Muir KW. Medication adherence in patients with ocular hypertension or glaucoma. *Expert Review of Ophthalmology*. 2019 Sep 3;14(4-5):199-210.

Rumelt S, Schreib S. Why Do Patients with Controlled Glaucoma Continue to Lose Their Vision. Causes and Coping with Visual Impairment and Blindness, IntechOpen, London. 2018 Sep 19:23-32.

Simoni, J.M., Pearson, C.R., Pantalone, D.W., Marks, G. and Crepaz, N., 2006. Efficacy of interventions in improving highly active antiretroviral therapy adherence and HIV-1 RNA viral load: a meta-analytic review of randomized controlled trials. *Journal of Acquired Immune Deficiency Syndromes (1999)*, *43*(0 1), p. S23.

Sleath, B., Blalock, S.J., Carpenter, D.M., Sayner, R., Muir, K.W., Slota, C., Lawrence, S.D., Giangiacomo, A.L., Hartnett, M.E., Tudor, G. and Goldsmith, J.A., 2015. Ophthalmologist–patient communication, self-efficacy, and glaucoma medication adherence. *Ophthalmology*, 122(4), pp.748-754.

Tadesse F, Mulugeta A. Compliance to topical anti-glaucoma medication among glaucoma patients at Menelik II Tertiary Hospital, Addis Ababa, *Ethiopia. thiop. J. Health Dev*. 2015 Jan 1;29(1):32-6.

Tamrat L, Gessesse GW, Gelaw Y. Adherence to topical glaucoma medications in Ethiopian patients. *Middle East African Journal of Ophthalmology*. 2015 Jan;22(1):59.

Thompson AC, Thompson MO, Young DL, Lin RC, Sanislo SR, Moshfeghi DM, Singh K. Barriers to follow-up and strategies to improve adherence to appointments for care of chronic eye diseases. *Investigative Ophthalmology & Visual Science*. 2015 Jul 1;56(8):4324-31.

Tripathi S, Gupta S, Arora V. Socio-demographic determinants of glaucoma medications compliance: a North Indian cross-sectional study. *Indian J Clin Exp Ophthalmol*. 2017 Jan;3(1):53-6.

Yang, C., Hui, Z., Zeng, D., Liu, L., and Lee, D.T.F., 2020. Examining and adapting the information–motivation–behavioral skills model of medication adherence among community-dwelling older patients with multimorbid: protocol for a cross-sectional study. *BMJ Open*, *10*(3), p. e033431.

CHAPTER 6

General Discussion, Strengths and Limitations, Recommendations and Conclusions

General Discussion, Strengths and Limitations, Recommendations and Conclusions

The thesis consists of five chapters, which resulted in the development of a glaucoma intervention strategy presented in Chapter 5. Chapter 6 presents the concluding remarks on the study discusses the strengths and limitations of the study and offers recommendations that emanate from the study's findings.

The study developed an intervention strategy to strengthen eye care follow-up among glaucoma patients in the Vhembe District of Limpopo Province. The following objectives were achieved to meet the aim of the study: A systematic review to strengthen eye care follow-up among glaucoma patients in the Limpopo Province. The study was conducted in two phases; phase 1A and Phase 1B. Phase 1A was a survey to increase the ***understanding of reasons for loss to follow-up among glaucoma patients in rural hospitals of Limpopo Province, South Africa*** and phase 1B employed the qualitative method and an article titled ***"Challenges Contributing to Loss to Follow-up as Experienced by Glaucoma Patients in the Vhembe District of Limpopo Province, South Africa"*** was subsequently published***.*** The following is a summary of key findings concerning the objectives of the study:

As part of assessment requirements of the development of an intervention strategy, **Chapter 2** of the study was published in *The Open Public Health Journal* (2020) as ***"Systematic Literature Review on strengthening Eye Care Follow-Up among Glaucoma Patients in Limpopo Province.*** The systematic literature review analyzed the intervention strategies used to ensure that glaucoma patients remain in care within health care facilities. Several techniques have been employed worldwide to detect non-adherence to glaucoma follow-up care (Joseph & Pasquale, 2017; Lee, Murakami, Duncan., et al, 2013; Tamrat, Gessesse & Gelaw, 2015). Efforts have been made to design and evaluate various interventions to improve glaucoma adherence with mixed achievements. Intervention strategies include: patient education sessions; written information; medication reminders; eye drop administration training, and individualized adherence plans.

Several countries have identified the importance of conducting educational intervention strategies for improving health risk behavior among glaucoma patients. Out of seven articles that met the inclusion criteria, only four were randomized controlled trials (RCTs) and the remaining three were observational studies. Most studies (7/11) were conducted in developed countries such as the United States of America, Canada, South Korea, and Australia, while only one was conducted in sub-Saharan Africa, Nigeria. Of the four RCTs, three showed an improvement in medication adherence after using educational interventions

while three of the observational studies confirmed an improvement in adherence after using motivational interviewing, but showed no significant improvement in adherence with educational interventions.

Chapter 3 was published in the Journal of African Vision and Eye Health (AVEH) (2020) with the title "***"Loss to follow-up amongst glaucoma patients in selected hospitals of the Limpopo Province, South Africa***". Quantitative analysis was conducted amongst 429 glaucoma patients from the selected hospitals. The study findings revealed that non-adherence to scheduled follow-up appointments among glaucoma patients in rural hospitals was still prevalent. However, factors varied due to every person's unique experience. In this study, respondents showed inadequate knowledge about glaucoma disease and its management. Most glaucoma patients did not know that glaucoma needed regular follow-ups like any other chronic disease such as diabetes and hypertension. This was attributed to the fact that glaucoma is asymptomatic. Similar findings were confirmed by Zhao, Fu, Li, Li, and Lou (2015) and Demirtaş, Dağtekin, Önsüz, T al (2018) who reported that glaucoma patients were not aware that they needed regular eye examinations.

Respondents indicated that they sometimes forget to administer their eye drops. This is one of the barriers contributing to glaucoma medication non-adherence. This finding is in line with the study by Olthoff, Hoevenaars, van den Borne, Webers, Schouten (2009) and Carvalho, Marques, Oliveira., *et al* (2015) who indicated that patients felt that there is no direct advantage from the eye drops if they forget their treatment since there is no immediate disability from the disease. Other patients' reasons were conflicting beliefs such as traditional and religious beliefs. These patients assumed that glaucoma is caused by witchcraft or evil spirits thus, they consulted traditional healers and religious prophets for prayers and cleansing. These patients resort to traditional eye medication (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 poor access to eye care and belief in divine healing contributed to most patients trusting in TEM and the use of holy water (Morse, 2015; Khandekar, Chauhan, Yasir, Al-Zobidi, Judaibi, Edward,2019; Achigbu & Achigbu, 2017). The study found that most patients were LTFU because of financial difficulties. They did not have transport money and hospital fees. Patients also complained about the long distance they traveled to the hospitals which in some cases exceeded 15 km. There were similar findings studies conducted elsewhere (Newman-Casey, Robin, Blachley, Farris, Heisler, Resnicow, Lee, 2015; Momoh, Bunce, Oko-oboh, Gilbert, 2018; Foreman, Keel, van Wijngaarden, et al, 2018).

C**hapter 4** was also published in *The Open Public Health Journal* (2020) with the title ***"Challenges Contributing to Loss to Follow-up as Experienced by Glaucoma Patients in the Vhembe District of Limpopo Province, South Africa".*** The section was conducted qualitatively to get detailed information from patients identified as glaucoma LTFU during the quantitative study. The key findings that emanated from the qualitative data collection were mostly system-related factors such as the negative attitude of the hospital workers, shortage of glaucoma medications, long waiting time, and long queues. The problem of poor communication between patients and health care providers was also highlighted. This is in line with other similar studies conducted globally (Hahn, 2009; Morse, 2015; Bassett, Coleman, Giddy, et al, 2017). Other findings revealed by patients which contribute to glaucoma LTFU are lack of escort and family support, difficulty in getting time off, and the issue of stigma and discrimination. Similar findings were experienced by other patients who suffered from other chronic diseases like HIV and AIDS and those attending maternal health (Bogart, Naigino, Maistrellis, et al, 2016; Ganle JK, Otupiri E, Obeng B, Edusie AK, Ankomah A, Adanu, 2016).

Chapter 5(a) was also published in the Journal of African Vision and Eye Health (AVEH) (2020) with the title "***Application of an information-motivation-behavioural skills model to strengthen eye care follow-up amongst glaucoma patients"***. The study employed a cross-sectional survey distribution method. The study was conducted amongst glaucoma patients who were 18 years and older at one of the specialized eye Hospital in the Limpopo province, South Africa. The study found that glaucoma patients need more information about their condition. Moreover, the findings showed that information, motivation and behavioural skills are interrelated. The study also revealed that strategies to improve adherence to glaucoma medication are likely to be effective when they include multiple components such as educating the patient and their family members. Therefore, these findings suggest that the application of the IMBSM might improve glaucoma patients' adherence.

Chapter 5(b) proposed the outline of the strategy based on the findings (Chapter 2-4), literature review and theoretical framework. The chapter begins by describing the purpose and rationale for the strategy. The most used theories are the Health Belief Model (HBM); Social Cognitive Theory (SCT); Information Motivation Behavior Skill Model (IMB) and the Social Action Theory (SAT). These theories have been tested and used effectively in health behavior change programs worldwide (Chang, Choi, Kim, and Song, 2014). These theories can improve medication adherence and contribute to the development of effective interventions in the strengthening of glaucoma eye care in the Limpopo Province.

The study conducted by Sleath et al (2016) in North Carolina (USA) revealed that there is an association between patients with higher glaucoma medication adherence self-efficacy and outcome expectations. Patients with higher glaucoma adherence self-efficacy were found to be more clearly adherent in using their medications. Correspondingly, studies in HIV, diabetes, asthma, and depression have reported positive associations between self-efficacy and medication adherence especially where SCT has been applied (Bonner Zimmerman, Evans, et al, 2002; Parson, Rosof & Mustanski, 2008; Sleath et al, 2012).

STRENGTHS AND LIMITATIONS OF THE STUDY

Strengths

Systematic literature reviews that follow scientific principles and procedures that allow for a more objective appraisal of the evidence than traditional narrative reviews was conducted. This revealed a gap in knowledge when it comes to strategy to strengthen eye care follow up among glaucoma patients in South Africa.

Unlike the traditional approach for writing a thesis, the current study followed the modern approach for presenting chapters in article format. To date, three chapters (2, 3, and 4) have been published in peer-reviewed journals and chapter 5 is currently under review.

The proposed strategy provides useful information for improving glaucoma care and glaucoma medication adherence through strengthening patient education, establishing family support, and effective primary health care services to serve disadvantaged communities.

Limitations

Empirical data was drawn from Vhembe district in Limpopo Province, and therefore findings can only be transferable within the district. Another limitation was that validation of the study findings was not done because there was no other similar study that was conducted in the province with which to benchmark its effectiveness for changing glaucoma patients' risk behaviours that contribute to LTFU.Validation of the study will be done during the post doctoral study when the implementations of the study will be evaluated.

It is in this light that a cohort study should be conducted to evaluate the effectiveness of the strategy proposed in this study. Finally, the study findings cannot be generalized to the whole population, but only to the Vhembe District, since the study was limited to this district. This study included research from published works in English between January 2009 and January 2019 in a systematic review of five databases. There could be other studies published outside this timeframe in other languages and databases that could have been

missed by the researcher. Those potentially overlooked studies might have impacted the findings of this study. Moreover, the study was restricted to patients with established glaucoma presenting themselves at hospitals that only provide glaucoma services.

Recommendations

To implement the proposed strategy for strengthening follow-up care amongst glaucoma patients, the following recommendations are made:

Recommendations to the patients and family members and community health workers

The literature and the current study findings suggest that there is a need for educating patients and their family members about the importance of glaucoma follow-up and medication adherence because most of patients in this study were LTFU. Therefore, glaucoma patients should be informed about the importance of glaucoma disclosure to maximize their likelihood of getting social support from family members and friends, for all age groups. Patients should be taught about the complications that might arise from glaucoma non-adherence such as permanent blindness. Glaucoma patients should have someone to remind them to take medications. Songs with glaucoma lyrics should be composed to enhance knowledge about the disease.

Also, previous studies confirm the findings of this study that glaucoma patients lack support from family members and have financial difficulty. It is therefore recommended that patients be encouraged to use public transport such as buses, as this is cheaper than private cars. Patients are advised to form support groups to motivate each other. Furthermore, family members are encouraged to go and refill treatment on behalf of their relatives who suffer from glaucoma. Community members who are glaucoma patients themselves should act as role models to other glaucoma patients in the same community. It was observed from the study findings that one of the reasons for medication non-adherence amongst glaucoma patients was forgetfulness. It is therefore recommended that health care providers should use M-health (using electronic interventions such as mobile phones, emails, and SMS) to remind the patients. It is also recommended that community health care workers (CHWs) should do direct observation treatment (DOT) to glaucoma patients like they do with any other chronic patients during home visits. Patients should be assisted to remember eye drops by incorporating them into their routine cues such as brushing of teeth, morning tea, and administration of other chronic medications. Besides, advise Patients who work should be advised to consider keeping an extra bottle of medication at their workplace.

The study also established that lack of escort is one of the causes of LTFU. Most patients cannot access health care facilities on their own because of aging and poor vision.

Therefore, it is recommended that family members should be involved in the care of their relatives and give support.

Recommendation to PHC and eye care health practitioners (ECHP)

Study findings revealed that hospital staff display a negative attitude towards glaucoma patients. Therefore, hospital staff must be provided with continuous in-service training concerning work ethics and communication. Findings also showed that patients lack adequate knowledge about glaucoma and its management. Consequently, it is recommended that health care providers, especially eye care staff offer enhanced counseling to glaucoma patients, particularly those with advanced disease, to address management options, goals, treatment compliance as well as patients' expectations and challenges. ECHP should tailor education to each patient's level of understanding.

Furthermore, health care providers should strengthen media campaigns and education during awareness months to enhance public education. The study findings also established that patients complained about medication shortages because eye clinics do not function over the weekend and on holidays. Therefore, it is recommended that ophthalmic services should open for 24 hours to provide services for those patients who have difficulty getting time off work. ECHP should continuously remind glaucoma patients to inform the hospital staff when they swap clinics to continue with care in another health facility. Hospital staff should also be informed when a glaucoma patient dies to avoid having an inaccurate LTFU rate. It was also observed that other patients still practice traditional and spiritual glaucoma treatment methods. Therefore, it is recommended to educate glaucoma patients, traditional leaders, and community members on the consequences of using traditional eye medicine (TEM). Written information or pamphlets to impart knowledge to the patients and the whole community at large should be distributed.

Recommendations for the Department of Health (DOH)

Glaucoma patients travel for more than 15 km to access hospitals. This makes it difficult for glaucoma patients to adhere to their eye appointment due to financial difficulties and other barriers. Therefore, it is recommended that the Vhembe District Department of Health provide mobile clinics for easy access by patients who stay far away from the health facilities. It is also recommended that glaucoma eye care services be provided at Primary Health Care facilities for easy accessibility by glaucoma patients. This is likely to improve adherence and follow-up. Patients complained about long waiting times and long queues at hospital. It is recommended that the department of health provide training to all staff about record-keeping and filing systems to avoid long waiting time. Glaucoma patients should pay

less for their checkup since most of them have financial difficulties. Patients should also be provided with medication to last more than two months to minimize clinic visits and reduce transport costs.

Recommendations for further research

This study recommends other pivotal areas for further research. Based on the findings, it was noted that it would be helpful to assess the staff's knowledge of glaucoma through further research since this has a direct impact on the information that patients receive from health facilities. Qualitative research involving both eye care workers and selected patients will provide clarity on various aspects of glaucoma. It would be interesting to conduct a study after the implementation and evaluation of the proposed strategy and determine its effectiveness. The following areas can be researched: Evaluation of the intervention strategy and making necessary adjustments; experiences of glaucoma patients' primary caregivers. Moreover, research on the experiences of glaucoma family members and the development of a program of action could expand the understanding of glaucoma care and management in communities.

Conclusion

This chapter summarized the findings of the study as outlined in Chapter Three to Four. It also provided conclusions of the study and made recommendations to all stakeholders. This study reveals that achieving adherence to glaucoma medication is a demanding matter for the public health services in Limpopo. The findings also point out important areas where improvement is necessary. If the proposed strategies are implemented, there might be a drop in the LTFU rate and glaucoma medication adherence in the hospitals of the Vhembe District. A follow up study reviewing the effectiveness on the implementation of intervention strategies should be conducted. Remarkably, there have been no known published studies in the South African literature that uses several intervention models to guide the intervention which address specific barriers that contribute to glaucoma LTFU. Therefore, the current study addresses an important health issue and contributes new statistics from the rural Vhembe District. It is believed that the implementation of this intervention strategy will benefit the glaucoma patients not only from the Vhembe district but throughout the Limpopo Province.

REFERENCES.

Achigbu, E.O. and Achigbu, K.I., 2017. Traditional eye medicine use among ophthalmic patients attending a secondary health care center in Southeast Nigeria. *Port Harcourt Medical Journal*, 11(2), p.79.

Bassett, I.V., Coleman, S.M., Giddy, J., Bogart, L.M., Chaisson, C.E., Ross, D., Flash, M.J., Govender, T., Walensky, R.P., Freedberg, K.A. and Losina, E., 2017. Barriers to care and 1-year mortality among newly diagnosed HIV-infected people in Durban, South Africa. *Journal of acquired immune deficiency syndromes (1999)*, 74(4), p.432.

Bogart, L.M., Naigino, R., Maistrellis, E., Wagner, G.J., Musoke, W., Mukasa, B., Jumamil, R. and Wanyenze, R.K., 2016. Barriers to linkage to HIV care in Ugandan fisher folk communities: a qualitative analysis. *AIDS and Behavior*, *20*(10), pp.2464-2476.

Bonner, S., Zimmerman, B.J., Evans, D., Irigoyen, M., Resnick, D., and Mellins, R.B., 2002. An individualized intervention to improve asthma management among urban Latino and African-American families. *Journal of Asthma*, 39(2), pp.167-179.

Carvalho, I.M., Marques, C.S., Oliveira, R.S., Coelho, P.B., Costa, P.C. and Ferreira, D.C., 2015. Sustained drug release by contact lenses for glaucoma treatment—a review. Journal of Controlled Release, 202, pp.76-82

Chang, S.J., Choi, S., Kim, S., Song, M. (2014). Intervention strategies based on Information-Motivation-Behavioral Skills Model for Health Behavior Change: A Systematic Review. *Korean Society of Nursing Science, 8*, 172- 181.

Demirtaş, Z., Dağtekin, G., Önsüz, M.F., Soysal, A., Yıldırım, N. and Metintaş, S., 2018. Validity and reliability of the glaucoma knowledge level questionnaire. *Turkish journal of ophthalmology*, 48(3), p.115.

Foreman, J., Keel, S., van Wijngaarden, P., Bourne, R.A., Wormald, R., Crowston, J., Taylor, H.R. and Dirani, M., 2018. Prevalence and causes of visual loss among the Indigenous peoples of the world: a systematic review. *JAMA ophthalmology*, 136(5), pp.567-580.

Ganle, J.K., Otupiri, E., Obeng, B., Edusie, A.K., Ankomah, A. and Adanu, R., 2016. Challenges women with disability face in accessing and using maternal healthcare services in Ghana: a qualitative study. *PloS one*, *11*(6), p.e0158361.

Hahn, S.R., 2009. Patient-centred communication to assess and enhance patient adherence to glaucoma medication. *Ophthalmology*, 116(11), pp. S37-S42.

Joseph, A. and Pasquale, L.R., 2017, January. Attributes associated with adherence to glaucoma medical therapy and its effects on glaucoma outcomes: an evidence-based review and potential strategies to improve adherence. In *Seminars in Ophthalmology* 32, (1), pp. 86-90. Taylor & Francis.

Khandekar, R., Jaffer, M.A., Al Raisi, A., Zutshi, R., Mahabaleshwar, M., Shah, R. and Choudhury, A.H., 2008. Oman Eye Study 2005: prevalence and determinants of glaucoma.

Kraukamp, P.2013.*Factors associated with late presentation of glaucoma*: A study in black South African Population.

Lee, B.W., Murakami, Y., Duncan, M.T., Kao, A.A., Huang, J.Y., Lin, S. and Singh, K., 2013. Patient-related and system-related barriers to glaucoma follow-up in a county hospital population. *Investigative ophthalmology & visual science*, 54 (10), pp.6542-6548.

Momoh, R.O., Bunce, C., Oko-oboh, G.A. and Gilbert, C.E., 2018. Advanced glaucoma at presentation is associated with poor follow-up among glaucoma patients attending a tertiary eye facility in Southern Nigeria. *Ophthalmic epidemiology*, *25*(3), pp.266-272

Morse, A.R., 2015. Improving medication adherence to reduce vision loss in patients with glaucoma: low hanging fruit? *Ophthalmology*, 122(7), pp.1280-1282.

Newman-Casey, P.A., Robin, A.L., Blachley, T., Farris, K., Heisler, M., Resnicow, K. and Lee, P.P., 2015. The most common barriers to glaucoma medication adherence: a cross-sectional survey. *Ophthalmology*,122(7), pp.1308-1316.

Olthoff, C. M. G., Hoevenaars, J. G.M.M., Van den Borne, B. W., Webers, C. A. B &Schouten, J. S. A. G.2009.Prevalence and determinants of non-adherence to topical hypotensive treatment in Dutch glaucoma patients. *Graefs Arch Clin Exp Ophthalmol* .247:235-243.

Parsons, J.T., Rosof, E. and Mustanski, B., 2008. Medication adherence mediates the relationship between adherence self-efficacy and biological assessments of HIV health among those with alcohol use disorders. *AIDS and Behavior*, 12(1), pp.95-103.

Sleath, B., Carpenter, D.M., Blalock, S.J., Davis, S.A., Hickson, R.P., Lee, C., Ferreri, S.P., Scott, J.E., Rodebaugh, L.B. and Cummings, D.M., 2016. Development of a new diabetes medication self-efficacy scale and its association with both reported problems in using diabetes medications and self-reported adherence. *Patient preference and adherence*, *10*, p.1003.

Sleath, B., Blalock, S.J., Stone, J.L., Skinner, A.C., Covert, D., Muir, K. and Robin, A.L., 2012. Validation of a short version of the glaucoma medication self-efficacy questionnaire. *British Journal of Ophthalmology*, 96(2), pp.258-262.

Tamrat, L., Gessesse, G.W. and Gelaw, Y., 2015. Adherence to topical glaucoma medications in Ethiopian patients. *Middle East African journal of ophthalmology*, *22*(1), p.59.

Tenkir, A., Solomon, B., Deribew, A. 2010. Glaucoma awareness among people attending ophthalmic outreach services in Southwestern Ethiopia. *BMC Ophthalmol*; 10:17.

Zhao, Y., Fu, J.L., Li, Y.L., Li, P. and Lou, F.L., 2015. Epidemiology and clinical characteristics of patients with glaucoma: An analysis of hospital data between 2003 and 2012. *Indian Journal of Ophthalmology*, *63*(11), p.825.

ANNEXURE 1: QUESTIONNAIRE FOR GLAUCOMA PATIENTS

INSTRUCTIONS:

Do not write your name in the questionnaire.

Complete the following items by ticking the appropriate response and by writing a short response where necessary.

Give your most honest response for each question.

Complete the questionnaire in black ballpoint pen.

SECTION A: SOCIO- DEMOGRAPHIC CHARACTERISTICS

1	Gender	Male	1
		Female	2

2	Age in years	18-24years	1
		25-54years	2
		55-64years	3
		65 and over	4

3	Marital status	Never married	1
		Married	2
4.	What is your highest level of education?	Never attended school	1
		Primary education	2
		Secondary education	3
		Tertiary/college	4

5.	Employment status	Employed	1
		Unemployed	2

6.	What is your religious affiliation?	Christianity	1
		Non-Christian	2

7.	Duration of glaucoma in years	1-3years	1
		4-6years	2

		7years and above	3
8	Is there any history of glaucoma in any of your family members?	No	1
			2

SECTION B: KNOWLEDGE REGARDING GLAUCOMA DISEASE and SOURCE OF INFORMATION

9.Are you aware of the disease "glaucoma"?

Yes	1
No	2

10.If yes, what is your source of information?

Health Care providers	1
Relative and friends suffering from glaucoma	2
Media (TV, radio, health magazine, pamphlets	3

11. What is your understanding of glaucoma?

High pressure in the eye,	1
Disease that is caused by witchcraft/evil spirit	2
Disease that runs in the family	3
I don't Know	4

12. Glaucoma is a treatable disease?

Yes	1
No	2

13. Glaucoma patient requires lifelong treatment

Yes	1
No	2

14. Most patients with glaucoma have no symptoms

Yes	1
No	2

15. Vision loss in glaucoma is permanent

Yes	**1**
No	**2**

16. Glaucoma patients require follow-up care

Yes	**1**
No	**2**

17. If left untreated, glaucoma can lead to blindness.

Yes	**1**
No	**2**

18.Have you been done glaucoma surgery?

Yes	**1**
No	**2**

19.What type of glaucoma surgery (If patient cannot recall, it was found from the medical file)

Trabeculectomy	1
Laser therapy	2
Peripheral iridectomy	3

20.What treatment are you on? (it can be gathered from the medical records)

Eye drops	**1**
Oral medication	**2**

21. Are you aware that Glaucoma requires lifelong treatment?

Yes	**1**
No	**2**

Section C: Practices regarding Glaucoma Disease

22.Where do you prefer to collect your glaucoma medications from?

Hospital eye clinic	1
Primary health care clinic	2
Private pharmacy	3

23.On average, how many doses do you miss per week?

None	**1**
1-2	**2**
3-5	**3**
More than 5	**4**

What difficulties do you have when taking your medications?

24. Drug related

Lack of knowledge	1
Forgetfulness	2
Denial	3
No specific reasons	4

25.Incidental

Medical /physical illness	**1**
Public holiday	**2**

26.Financial barriers

Transportation cost	1
Outpatient fees	2

27.What type of transportation do you use to come to the clinic and return home

Private car/taxi	1
Bus	2
Walking	3

28.Distance travelled between the clinic and your home

Less than 5km	**1**
More than 15km	**2**

29.How long does it take you to travel to the clinic?

Less than 2hours	**1**
>=2hours	**2**

30.Do you require an escort to help you come to the clinic?

Yes	**1**
No	**2**

31. How difficult is it for you or your escort to take time away from home or work to come for your glaucoma follow up?

Easy	1
Difficult	2

32.How is the support from your family members

Good	1
Poor	2

SECTION D: Attitudes and Beliefs towards Glaucoma Disease

	Statement	**Agree**	**Strongly agree**	**Disagree**	**Strongly disagree**
33	I see no benefit in taking glaucoma medication regularly				
34	I don't want people to know that I suffer from glaucoma disease				
35	I felt very bad when I was diagnosed with glaucoma				
36	I believe that glaucoma is the disease of the aged				
37	I feel comfortable when doctors prescribe more than two eye medication to use				
38	I believe that using eye drops can worsen my condition				
39	Glaucoma is a disease of the aged				
40	Regular glaucoma follow-up is important				

SECTION E. ENVIRONMENTAL DETERMINATS CONTRIBUTING TO LOSS TO FOLLOW UP

Tick only one (1) response per statement by putting an X in the box of your chosen response

42. Unfriendly hospital staff

Yes	1
No	2

43. Long waiting time at the clinic/hospital

Yes	1
No	2

44. Unavailability of glaucoma medication

Yes	1
No	2

45.Eye clinic that does not operate on weekends/afterhours

Yes	1
No	2

ANNEXURE 2: INTERVIEW GUIDE FOR LTFU GLAUCOMA PATIENTS

Section A: Sociodemographic

Age in years as at last birthday .....

Gender

Female ……

Male ……

What is your highest level of education?

(1) Never attended school

(2) Primary education

(3) Secondary education

(4) Tertiary/College

Marital status

(1) Unmarried

(2) Married

Employment status

(1) Employed

(2) Unemployed

Means of transport to eye clinic ……..

Time taken to reach clinic from home (hrs)…….

Distance travelled to the clinic from home……..

Section B

How was it for you when attending/ accessing the glaucoma eye care services at this hospital?

Kindly share with me the challenges that you have experienced and the support that you have received when accessing glaucoma eye care services.

ANNAXURE 3 : INFORMATION SHEET

Title of the Research Study **"Intervention strategies to strengthen eye care follow-up among glaucoma patient in selected district hospitals of Limpopo province, South Africa**

Principal Investigator/s/ researcher: Ms S E Tshivhase, PHDPH student

Co-Investigator/s/supervisor/s : Prof.Tshitangano T G,

: Senior Prof Dean Khoza L B

Brief Introduction and Purpose of the Study: This is a research project that will be conducted for the degree of Doctor of philosophy in the Public Health (PHDPH) at the selected hospitals of Limpopo Province. The project aims to develop **Intervention strategies to strengthen eye care follow-up among glaucoma patient in selected district hospitals of Limpopo province, South Africa**.

Outline of the Procedures: In this study, you will be required to complete a questionnaire to solicit information regarding factors contributing to loss to follow up and strategies to can prevent it among glaucoma patients. You will be expected to complete all applicable questions in full and independently. The whole procedure may last between 40 and 60 minutes. There will not be any follow-up done once the completion of questionnaire has taken place.

Risks or Discomforts to the Participant: No discomfort will be instilled as there will be no administration of any treatment nor experiment

Benefit: There will be recommendation to improve on the intervention strategies to strengthen eye care follow up among glaucoma patients and reduce risks of visual loss. As a participant, you will not benefit directly from this study, however, the information received from you and the findings of the study may assist in strengthening eye care follow up among glaucoma patients. The health department will come up with strategies that will assist glaucoma patients to remain in care. The results will be published for other eye care health care workers to use as evidenced based nursing.

Reason/s why the Participant May Be Withdrawn from the Study: Participant will be allowed to withdraw from the study anytime they feel so and feels uncomfortable to continue, there will be no punishment for withdrawal

Remuneration: You will not receive monetary or any other form of remuneration by choosing to participate in this study

Costs of the Study: ***No*** You will not be expected to cover any cost related to the study.

Confidentiality: The researcher will ensure that all the information you provide in this study will be kept confidential. Your identity will not be revealed as you will not be required to write your name on the questionnaire. In addition, your identifying information will not be linked to you.

Research-related Injury: There are no foreseeable research-related injury in this study. No compensation as this study is for personal professional and academic advancement.

Researcher: Tshivhase S E cell no 082 441 59595

Promoter: Dr T G Tshitangano cell no 082 448 4111

Core – Promoter: Sen Prof Khoza L B Cell 072 402 9168

You can contact the University Research Ethics Committee Secretariat on 015 962 9058. Complaints can be reported to the Director: Research and Innovation, Prof GE Ekosse on 015 962 8313 or Georges Ivo.Ekosse@univen.ac.za

ANNEXURE 4 : CONSENT FORM

Statement of Agreement to Participate in the Research Study:

- I hereby confirm that I have been informed by the researcher, (*Tshivhase S E)*about the nature, conduct, benefits and risks of this study - Research Ethics Clearance Number: **SHS/18/PH/0111** _,
- I have also received, read and understood the above written information (*Participant Letter of Information*) regarding the study.
- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerized system by the researcher.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.
- I understand that significant new findings developed during the course of this research which may relate to my participation will be made available to me.

Full Name of Participant

Signature

Date……

I, Tshivhase S E herewith confirm that the above participant has been fully Informed ...about the nature, conduct and risks of the above study.

Full Name of Researcher: Tshivhase Shonisani

Signature**……**

Date**……..**

Full Name of Witness (If applicable)

……..

Signature**……**

Date……

ANNEXURE 5:ETHICAL CLEARENCE FROM RESEARCH AND INNOVATION OFFICE

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mrs SE Tshivhase

Student No:
11523912

PROJECT TITLE: **Intervention strategies to strengthen eye care follow-up among glaucoma patient in selected district hospitals of Limpopo Province, South Africa.**

PROJECT NO: **SHS/18/PH/35/0111**

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Dr TG Tshitangano	University of Venda	Promoter
Snr Prof LB Khoza	University of Venda	Co - Promoter
Mrs SE Tshivhase	University of Venda	Investigator – Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: November 2018
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: .....
Name of the Chairperson of the Committee: Senior Prof. G.E. Ekosse

University of Venda
PRIVATE BAG X5050, THOHOYANDOU, 0950λ LIMPOPO PROVINCEλ SOUTH AFRICA
TELEPHONE (015) 962 8504/8313 FAX (015) 962 9060
"A quality driven financially sustainable, rural-based Comprehensive University"

UNIVERSITY OF VENDA
DIRECTOR
RESEARCH AND INNOVATION
2018 -11- 02
Private Bag X5050
Thohoyandou 0950

ANNEXURE 6: PROVINCIAL GOVERNMENT PERMISSION LETTER

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 6650) Ref: **LP_2018**

Tshivhase SE
University of Venda

Greetings,

RE: Intervention strategies to strengthen eye care follow-up among glaucoma patient in selected district hospitals of Limpopo Province, South Africa

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

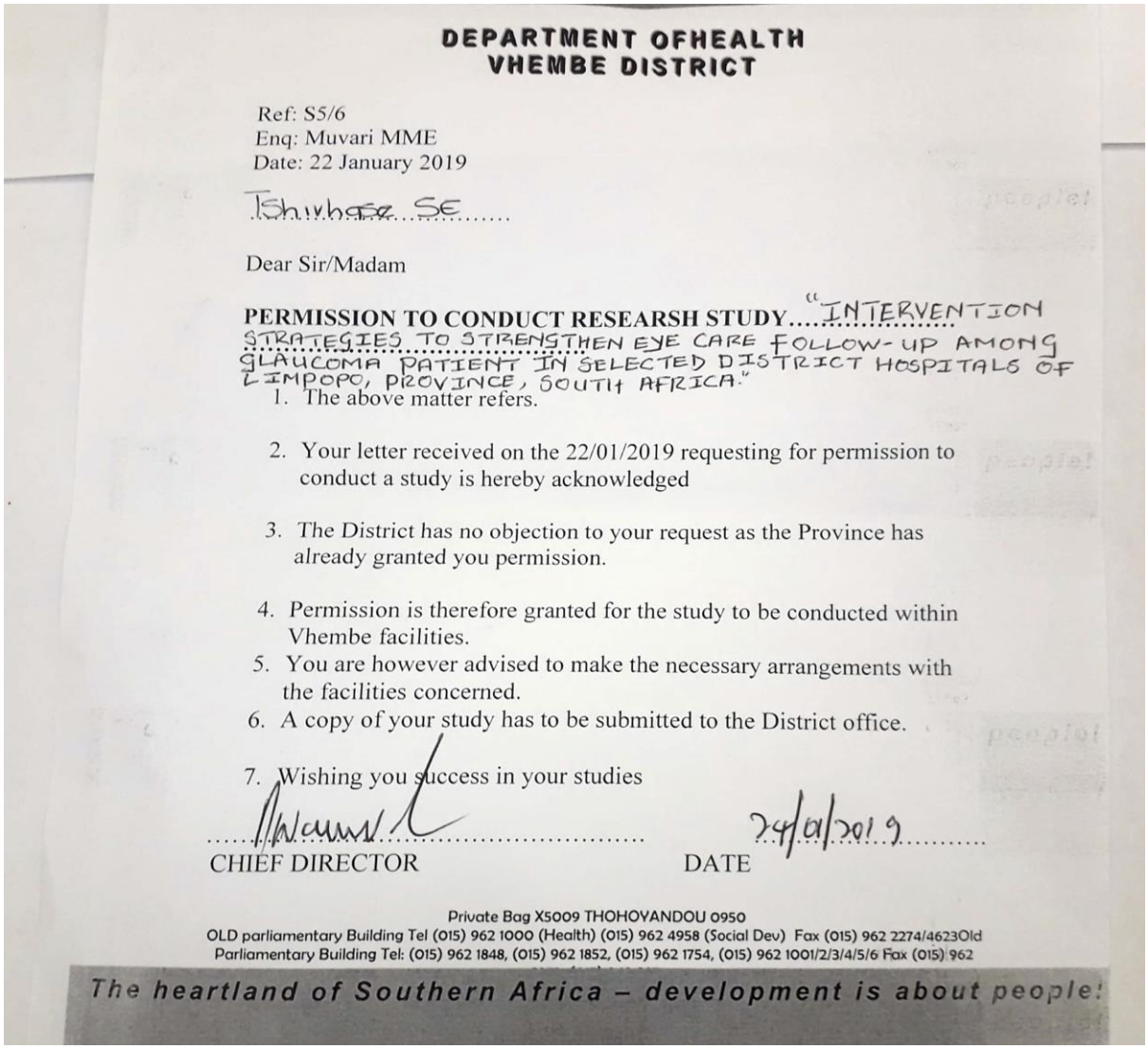
Head of Department

20-12-2018
Date

Private Bag X9302 Polokwane
Fidel Castro Ruz House, 18 College Street. Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.
Website: http/www.limpopo.gov.za

The heartland of Southern Africa – Development is about people!

ANNEXURE 7:DISTRICT PERMISSION LETTER



DEPARTMENT OFHEALTH
VHEMBE DISTRICT

Ref: S5/6
Enq: Muvari MME
Date: 22 January 2019

Tshivhase SE

Dear Sir/Madam

PERMISSION TO CONDUCT RESEARSH STUDY....."INTERVENTION STRATEGIES TO STRENGTHEN EYE CARE FOLLOW-UP AMONG GLAUCOMA PATIENT IN SELECTED DISTRICT HOSPITALS OF LIMPOPO, PROVINCE, SOUTH AFRICA."

1. The above matter refers.
2. Your letter received on the 22/01/2019 requesting for permission to conduct a study is hereby acknowledged
3. The District has no objection to your request as the Province has already granted you permission.
4. Permission is therefore granted for the study to be conducted within Vhembe facilities.
5. You are however advised to make the necessary arrangements with the facilities concerned.
6. A copy of your study has to be submitted to the District office.
7. Wishing you success in your studies

.....
CHIEF DIRECTOR

24/01/2019
DATE

Private Bag X5009 THOHOYANDOU 0950
OLD parliamentary Building Tel (015) 962 1000 (Health) (015) 962 4958 (Social Dev) Fax (015) 962 2274/4623Old
Parliamentary Building Tel: (015) 962 1848, (015) 962 1852, (015) 962 1754, (015) 962 1001/2/3/4/5/6 Fax (015) 962

The heartland of Southern Africa – development is about people!

ANNEXURE 8: HOSPITAL PERMISSION LETTER

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH
ELIM HOSPITAL

21-02-2019

Ref: S5/3/2
Enq: Makondo A.T
Date: 2019.02.21

To: Ms. Tshivhase S.E
University of Venda

CC: Acting Deputy Director: Risk Management Services: Mr. Matsheka N.J
CC: Acting Assistant Director: Quality Assurance: Ms. Sinthumule V.V

RE: APPLICATION FOR PERMISSION TO CONDUCT RESEARCH: INTERVENTION STRATEGIES TO STRENGTHEN EYE CARE FOLLOW UP AMONG GLAUCOMA PATIENTS.

1. The above matter bears reference.
2. Receipt of your application letter requesting to conduct research dated 31st January 2019 together with the approval from the Provincial and District offices is hereby acknowledged with thanks.
3. You are hereby granted permission to access the hospital to conduct the research as requested.
4. When collecting the data, you are kindly advised to liaise with Mr Matsheka: Acting Deputy Director: Risk Management Services regarding issues of information security and the patient's rights.
5. Your urgent attention is always appreciated.

.....
CHIEF EXECUTIVE OFFICER

21/02/2019
DATE

P/Bag X312, Elim Hospital, 0960
Tel (015)556 3201/2/3/4/5, Fax (015)556 3160,
The heartland of Southern Africa - development is about people
RESTRICTED