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EYE REMOVAL SURGERIES AT MULAGO NATIONAL REFERRAL HOSPITAL – PATTERNS AND QUALITY OF LIFE OF AFFECTED PATIENTS

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DECLARATION

I **NAIGA MAGEMBE HAWA** declare that the work in the dissertation is original and my own work and has never been presented for any academic award before either wholly or partially to any other institution.

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DEDICATION

I would like to dedicate this dissertation to my beloved family and the esteemed members of the Department of Ophthalmology. Without their unwavering support, guidance, and encouragement, this journey would have been far more challenging.

To my parents, whose love and sacrifice have been the foundation of my success, I am forever grateful. Your constant belief in me and your boundless support has fueled my determination to pursue my dreams. Your unwavering faith in my abilities has been an inspiration throughout this arduous yet rewarding process. I dedicate this dissertation to you, as a token of my deepest appreciation and admiration.

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This dissertation is a testament to the immense gratitude I hold for my family and the Department of Ophthalmology. It is their unwavering support that has propelled me forward, and it is my earnest hope that this research will contribute to the advancement of knowledge in the field and make a meaningful impact on patient care.

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The successful completion of this research dissertation is a testament to the collective efforts and unwavering support of all individuals mentioned above. I am profoundly grateful for the opportunity to collaborate with such exceptional individuals and be part of a supportive network. Our collective aspiration is to make a positive impact in the field of ophthalmology and improve the lives of individuals affected by eye health issues.

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ACRONYMS AND ABBREVIATIONS

HQROL – Health-related quality of life

HIV – Human Immunodeficiency Virus

IAC- Intra-arterial chemotherapy

IVC – Intravenous chemotherapy

MNRH – Mulago National Referral Hospital

NEI-VFQ – National Eye Institute Visual Function Questionnaire

PSS – Perceived Stress Score

PI – Primary Investigator

QOL – Quality of Life

SOMREC – School of Medicine Research Ethics Committee

SCC – Squamous cell carcinoma

SF-36 – 36 item Short Form Survey Instrument

TEM – Traditional Eye Medicine

WHO – World Health Organisation

OPERATIONAL DEFINITIONS

Eye removal surgeries are defined as surgeries that are performed to remove contents of the eye or the eye with or without periorbital tissues such that the normal functionality and morphology of the eye is disrupted for example enucleation, evisceration, and exenteration(Chan et al., 2017).

Evisceration – Surgical removal of the cornea and intraocular contents(Phan et al., 2012).

Enucleation – Surgical removal of the entire globe with or without the extraocular muscles(Batten, 1971).

Exenteration – Surgical removal of the eye and the affected orbital contents with or without the eyelids(Kasaee et al., 2019).

Patterns of eye removal surgery – In this study patterns of eye removal surgery will be defined as the type of eye removal surgeries, the indications of the eye removal surgeries, and the characteristics of patients that have undergone eye removal surgery.

Sympathetic ophthalmia - is a rare, bilateral, granulomatous uveitis caused by exposure of previously immune-privileged ocular antigens from trauma or surgery with a subsequent bilateral autoimmune response to this tissue. The injured eye or operated eye is the exciting eye and the contralateral eye is the sympathizing eye(Noyes, 1872).

Endophthalmitis – An inflammation of the inner coats of the eye, resulting from intraocular colonization of infectious agents with exudation within intraocular fluids (vitreous and aqueous)(Relhan et al., 2018).

Panophthalmitis - Acute inflammation of the eyeball involving all structures and extension of the inflammation into the orbit(Relhan et al., 2018).

Painful Blind Eye - is characterized by its chronic, gradual progression of vision loss and ocular pain(RIFFENBURGH, 1965).

Glaucoma – A group of progressive optic neuropathies characterized by an excavated appearance of the optic disc, often described as cupped, together with loss of ganglion cells and their axons and corresponding vision loss(Jackson et al., 2014).

Quality of life – This is the subjective measure of a person's ability to function physically, psychologically, and socially(Goiato et al., 2018). For this study, it was defined concerning patients who have undergone eye removal surgery as the subjective measure of the patient's health-related quality of health, perceived stress, socioeconomic status, and job separation due to disability. In this study, the quality of life assessment will include the HRQOL, perceived stress, job separation due to disability, and socioeconomic status.

Health-Related Quality of Life – This is the perception of physical and mental health of a group or individual who has a pre-existing medical condition or experience(Karimi & Brazier, 2016).

Perceived Stress - the feelings or thoughts that an individual has about how much stress they are under at a given point in time or over a given period(Cohen et al., 1983).

Job separation due to disability - action is taken to separate an employee from service when the employee is unable to perform the essential functions of the position with or without a reasonable accommodation due to medical impairment(M. L. Rasmussen et al., 2012).

ABSTRACT

Background: Eye removal surgeries are done when the eye becomes detrimental to health in cases such as trauma, tumors, infections, and more. Consequences like job loss and mental stress affect the quality of life of patients. Investigating the current patterns of eye removal surgeries and their impact on quality of life is crucial to ensure appropriate rehabilitation services are provided.

Purpose: To describe the pattern of eye removal surgeries from 2018 to 2022 and assess the quality of life of affected patients at Mulago National Referral Hospital, Uganda.

Methodology: This was a hospital-based cross-sectional study design that included 257 case files of patients who underwent eye removal surgery from 2018 to 2022 at MNRH, Uganda by consecutive sampling. The case file data was retrieved using a data collection tool. 88 patients were contacted thereafter, and their quality of life was measured using the interviewer-administered SF-36 and PSS-10 tools. Data was entered using Epidata version 4.6 and analyzed using STATA version 14.0.

Results: The study involved participants with a mean age of 30.2 years, with the under-20 age group most affected (37.4%). Evisceration (48.6%) was the primary surgery, followed by enucleation (35%) and exenteration (16.4%). The main indication was tumors (48.6%), particularly Retinoblastoma and Squamous cell carcinoma. Poor SF-36 scores in role limitations due to physical (51.1, SD=41.7) and emotional issues (47.7, SD=45.4) led to reduced quality of life (QOL). Patients with ocular prostheses had significantly better QOL ($p<0.05$) than those without. QOL declined with surgery type: evisceration, enucleation, and exenteration.

Conclusion: The causes of most indications that lead up to eye removal surgery are preventable through eye health promotion, sensitization and implementation of screening programs for ocular tumors. The poor QOL especially of patients without ocular prostheses may be improved through comprehensive post-surgical rehabilitation services that include scheduled counseling sessions and the provision of prostheses to improve patients' quality of life.

CHAPTER 1: INTRODUCTION

Eye removal surgeries are performed in ophthalmology practice when the retention of the eye is likely to pose a risk to ocular or general health, endangering the individual's life(Hita-Antón et al., 2016). Eye removal surgeries include exenteration, enucleation, and evisceration(Lavaju et al., 2015) excluding auto-enucleation and ritual enucleation(Adeoye & Onakpoya, 2007). Evisceration involves the removal of the cornea and intraocular contents, enucleation refers to the surgical removal of the entire globe while exenteration of the orbit refers to the surgical removal of the eye and the affected orbital contents with or without the eyelids(Dean, 2015).

The global and continental magnitude of eye removal surgeries is not known; however, studies conducted in various countries provide insights into the prevalence of these surgeries. In Ankara, Turkey, 123 eye removal surgeries were reported between 2000 and 2014(Koylu et al., 2015) while in St. John's Hospital, Jerusalem, 409 cases were documented over five years (Batten, 1971). In East Africa, studies include one in Kenyatta National Hospital, Kenya(2002-2012) where 282 surgeries were done over 10 years(Said, 2014), and a study done in MNRH 27 years ago (1987-1991) showed 350 surgical eye removals were done over 5 years(Adima, 1993).

The indications for eye removal surgeries vary depending on the underlying condition being treated, including trauma, tumors, infections, painful blind eyes, chronic uveitis, spontaneous intraocular hemorrhage, and anterior staphyloma(Musa et al., 2016). The pattern of indications is influenced by factors such as the level of development, sociocultural dynamics, medical facility standards, standard of living, and cultural background in each specific setting(Gyasi et al., 2009; Shapiro & Monselise, 1978). In developed countries, orbital-ocular tumors and painful blind eyes are common indications, while in developing countries, trauma and infectious origins predominate (Gyasi et al., 2009; Setlur et al., 2010). The trend of indications has shifted over time, with ocular trauma being primary in the early 20th century and malignancies in the latter part(Salvi et al., 2013). However, a study in Mulago National Referral Hospital(MNRH)-Uganda demonstrated that trauma and infections remained the predominant indications from 1987-1991(Adima, 1993).

Eye removal surgeries have a profound impact on individuals, resulting in visual loss, facial disfigurement, and emotional instability, affecting their quality of life. Emotional instability can manifest as depression, low self-esteem, employment difficulties, and coping issues(Centre

Hospitalier Universitaire de Besancon, 2022). Factors contributing to the decline in quality of life include the lack of prosthetic eye usage, loss of employment, social stigma, and poor socioeconomic status(Luangrungrot et al., 2018).

Proper education, counseling, and prosthesis fitting have been associated with better quality of life in affected patients(Adeoti et al, 2016).Therefore, comprehensive care for patients undergoing eye removal surgery should encompass emotional, social, and psychological rehabilitation(Goiato et al., 2018).

The aim of the study was to guide the understanding of the patterns of eye removal surgeries and the impact of these surgeries on the quality of life of affected patients. Understanding of this can be crucial for improving the quality of care, including preventive measures, rehabilitation of the patients at MNRH, and thus contribute to enhancing patient well-being.

1.1 PROBLEM STATEMENT

Eye removal surgery can be very traumatic in a person's life, not only physically, but also emotionally, socially, and financially and tend to negatively impact the quality of life of these individuals(Deacon, n.d.). It results in disfigurement, low self-esteem, altered identity, anxiety, depression, disproportionate growth in children, and loss of binocular vision and this could lead to limitations in or loss of employment(Chan et al., 2017; Hita-Antón et al., 2016). Loss of employment implies a reduction in the workforce, increased dependence of the patients, and possible reduction of the nation's capital(Steinmetz et al., 2021).

WHO reports that vision impairment creates a large global financial burden with annual global productivity losses of approximately US$ 411 billion(WHO, 2022). The cost of eye removal surgeries, artificial eyes, and visual rehabilitation is also an added cost to individuals and creates a financial burden(Nesemann et al., 2022). In Nigeria, 80% of the patients reported that the artificial eye cost between $9 and $17which is relatively costly for many people in a third-world country(Ayanniyi, 2008).

Somel studies have investigated the quality of life of patients who underwent eye removal surgery in different continents. In North America, Smith et al(2017) found that patients who underwent enucleation reported a significant decrease in visual function and QOL, as measured by the NEI VFQ-25(Smith et al, 2017).Adeoti in Nigeria (2014) emphasized the importance of doing more

research to assess the quality of life of patients in Africa to provide better rehabilitation services(Adeoti et al, 2016). The lack of available information on the quality of life of patients that have undergone eye removal surgery in Uganda pre-empted the need to do this study in MNRH in-order to guide the improvement of rehabilitation of these patients.

1.2 JUSTIFICATION

The United Nations 2030 Agenda for Sustainable Development Goals stipulates the inclusion of persons with disability referencing them in parts related to education, growth and employment, inequality, accessibility of human settlements as well as data collection and monitoring(Sustainable Development Goals and Disability, 2016). Disability secondary to eye removal hinders some visual functions like binocular functions and this individual may need specific adjustments for monocular vision, associated occupational adjustments, and adjusted financial needs(Kondo et al., 2013). Establishing the quality of life of patients that have had eye removal will highlight the need to provide equitable services if not yet availed, and may become the basis for advocating for improved rehabilitation like counseling, and job sourcing (especially NGO funded) for patients who have had eye removal surgery.

The WHO and IAPB also launched the "VISION 2020: The Right to Sight" in 1999 as a global initiative to provide strategic guidelines to developing countries, like Uganda, in scaling up efforts for the prevention of blindness and promoting advocacy for the right to sight hence reducing on the percentage (80%) of people who lose their sight due to preventable or curable eye conditions. The patterns of indications evolve in different societies due to advancements in medical interventions which may enable better preventive measures for certain conditions, early diagnostics, and treatment thus nullifying the need for eye removal(Musa et al., 2016). The study's findings will provide valuable insights into sustainable eye health care strategies in Uganda by revealing the extent of preventable eye removal surgeries and guiding necessary improvements in medical interventions, prevention, and rehabilitation measures.

Despite increased access to improved eye health interventions in MNRH, Uganda like anti-glaucoma drugs, advanced chemo/radiotherapeutics i.e., Intravascular chemotherapy for retinoblastoma, better diagnostics, little is known of their impact on the outcome of the ocular morbidities that may affect the pattern of eye removal surgery.

1.3 RESEARCH QUESTIONS

1. What are the patterns of eye removal surgeries among affected patients at Mulago National Referral Hospital?

2. What is the quality of life of adult patients that have undergone eye removal surgery at Mulago National Referral Hospital?

1.4 STUDY OBJECTIVES

1.4.1 GENERAL OBJECTIVE

To determine the patterns and quality of life of patients that have undergone eye removal surgery at Mulago National Referral Hospital.

1.4.2 SPECIFIC OBJECTIVES

1. To describe the patterns of eye removal surgeries among affected patients at Mulago National Referral Hospital.
2. To describe the quality of life of adult patients that have undergone eye removal surgery at Mulago National Referral Hospital.

1.5 CONCEPTUAL FRAMEWORK

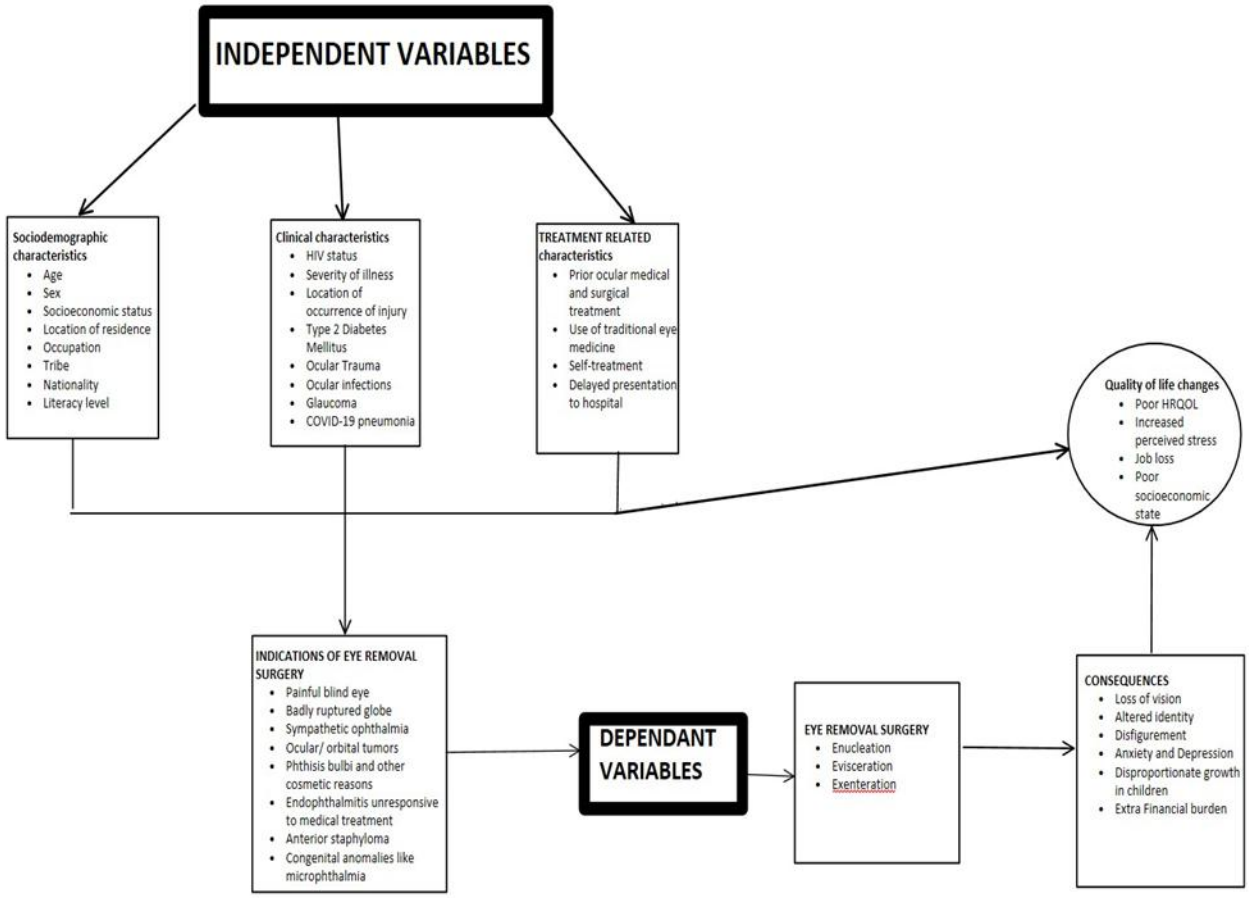


Figure 1: A conceptual framework showing the patterns of eye removal and the factors affecting the QOL of these patients adapted from the literature review

1.5.1 Narrative of a conceptual framework of Eye Removal Surgery

Patients that have eye removal surgery have several characteristics contributing to the outcome of eye removal surgery. The clinical, sociodemographic, and treatment-related characteristics may affect the type of surgery that is done for eye removal and as well affect the quality of life of the patients that have undergone eye removal surgery.

1.6 SCOPE OF THE STUDY

The study focused on the patterns of eye removal surgery and the quality of life of the affected patients. The patterns included the types of eye removal surgery done,

indications of the surgery, and the characteristics of patients that had eye removal surgery.

The quality of life of affected patients was the primary outcome.

The quality of life of patients that underwent eye removal surgery involved the following variables:

Independent variables

The independent variables were the factors that had an association with the quality of life of the affected patients as below;

- Sociodemographic factors like age, sex, socioeconomic status, location of residence, occupation, nationality, tribe, and literacy level
- Clinical factors like HIV status, Type 2 DM, the severity of illness, location of occurrence of injury, ocular trauma, ocular infections, neoplasms, glaucoma, and COVID-19 pneumonia.
- Treatment-related factors like prior medical and surgical treatment, use of TEM, self-treatment, and delayed presentation to the hospital.
- Type of surgery done as well as the use of the implant or prosthesis during the surgery.
- Indications of the eye removal surgery

Dependent variables

The primary outcome was the **quality of life** of patients that underwent eye removal surgery.

CHAPTER 2: LITERATURE REVIEW

2.1 BACKGROUND OF EYE REMOVAL SURGERIES

Eye removal surgeries can be defined as surgeries that are performed to remove contents of the eye or the eye with or without periorbital tissues such that the normal functionality and morphology of the eye are disrupted. There are 3 main types of eye removal surgeries that include evisceration, enucleation, and exenteration(Musa et al., 2016). Evisceration removes only the cornea and contents of the eye, leaving the white part of the eye (the sclera) and the eye muscles intact(Honavar & Rao, 2019). Enucleation involves the removal of the eye, including the globe, but leaving the rest of the orbital contents in place while exenteration is the removal of the entire orbital contents and surrounding structures often including the eyelids(Mukona, 2019).

Enucleation is the oldest known operation in ophthalmology with descriptions of this procedure seen in Chinese literature as early as 2600 BC(Moshfeghi et al., 2000). In the 1500s the surgical removal of an eye was first reported called extirpation(Sami et al., 2007) and later in 1817, Bear introduced evisceration when he removed the remaining intraocular contents of an eye following an expulsive hemorrhage(Black et al., 2012). Noyes, 50 years later, then described evisceration for the management of intraocular infection(Noyes, 1872), and in 1884 Mules described the placement of a hollow glass sphere into the eviscerated cavity as an implant(Mules, 1885). Exenteration was first described by Bartisch in 1583(Bartisch, 1996) while the first report of modern total exenteration in the early 20th century was published by Golovine(Golovine, 1909) with one of the largest historical series of orbital exenteration being published in 1989 by the Mayo clinic(Bartley et al., 1989).

One of the earliest published data on eye removal surgeries in Africa was in 1970 by Davanger in MNRH eye department that described the causes of enucleation in Uganda(Davanger, 1970) and then later in 1988, Kaimbo published a study that described the causes of enucleation in a tertiary hospital in Harare, Zaire(Kaimbo, 1988).

These surgeries have evolved with several modifications for example exenteration modifications like lid-sparing techniques, retention of the conjunctiva, and preservation of the periorbita have been introduced to aid in facial rehabilitation(Kasaee et al., 2019). The evolution in surgical techniques may have also led to the evolution in the indications over time in different societies.

2.2 MAGNITUDE OF EYE REMOVAL SURGERIES

The global prevalence of eye removal surgeries as a group of surgeries or individually is currently not available however different regions in the world have shown a varying prevalence of eye removal surgeries.

Chan showed that in Canada from 2003 to 2017, 87% of the 713 patients who had eye removal surgeries came from peripheral centers, and of those removed 60% were enucleations, 39% were eviscerations and 1% were exenteration(Chan et al., 2017). In comparison, Rasmussen showed that from 1996 to 2003, 345 patients had eye removal surgeries, out of 3 million people that attended the Rigshospitale hospital in Denmark with 51% being eviscerations, 45% enucleations, and 4% exenterations(M. L. R. Rasmussen et al., 2010). Thus showing that in Canada mostly enucleations were performed versus Denmark where mostly eviscerations were performed and with both countries having a very low number of exenterations performed.

Gaton et al in Tel Aviv, Israel from 1981 to 2007 showed that a total of 206 (74%) eviscerations and 73 (26%) enucleations were performed with the relative rates of performance of the two procedures similar from 1981-1990 and 1991-2000(Gaton et al., 2008). Gaton et al's findings differed from Lavaju et al's in Nepal (2008 to 2013) that showed 52.3% of the 88 eye removal surgeries to be enucleations, followed by eviscerations at 34.1% then exenterations at 13.6%(Lavaju et al., 2015). Similar to the comparison between Canada and Denmark, Israel had eviscerations as the most commonly performed procedure while Nepal had enucleations as the most commonly performed procedure further reinforcing the variations in types of surgeries preferred in different settings.

The prevalence of eviscerations and enucleations varies in different settings due to the risk of sympathetic ophthalmia which continues to be a contentious issue although evisceration has gained popularity over enucleation as it provides superior functional and cosmetic results versus enucleation(Phan et al., 2012). A study done in Washington over 20 years showed that from the first to the second decade between 1990 to 2009 there was a marked decrease in the number of enucleations and an increase in the total number of eviscerations, with no evidence of sympathetic ophthalmia in any post-evisceration case which made evisceration a safer and quicker alternative to enucleation(Yousuf et al., 2012).

Hansen et al in Denmark also showed a significant decrease ($p<0.001$) in the number of enucleations from 358 in 1975-76 to 214 in 1995-96 which corresponded to the equivalent increase in the number of eviscerations from 5 in 1975-76 to 83 in 1995-96. The decrease in enucleations was also attributed to the reduction in the number of glaucoma-related enucleations from 32.7% in 1975-76 to 15% in 1995-96(Hansen et al., 1999). Zheng and Wu in New York, USA, also recommended evisceration over enucleation especially in cases of reliable patient follow-up due to the low incidence of sympathetic ophthalmia(Zheng & Wu, 2013).

In Africa, several studies have been done in different parts of the continent, especially in Western Africa and they also show the varying occurrence of the different types of eye removal surgeries. In West Africa, about 3 different studies were done to study the prevalence and pattern of these eye removal surgeries. Enock's study in Edo State, Nigeria, showed that 6.96 % of the patients that had eye surgeries had eye removal surgeries with 34(80.95%) eviscerated and 8(19.05%) enucleated(Enock et al., 2008). Another study in Kwara State, Nigeria, also showed similar findings as in Edo state with a prevalence of 8.9% eye removal surgeries done in 5 years, 82.1% being eviscerations, 16.4% enucleations and 1.5% exenterations(Olatunji et al., 2011). Unlike in Edo and Kwara states, Eze et al in Enugu state, Nigeria showed an increased performance of exenterations (11.3%) from 1994 to 2003(Eze et al., 2007; Olatunji et al., 2011). Eviscerations were still the most performed in the Enugu state at 55.7% and 33% were enucleations(Eze et al., 2007). The reason for the increase in exenterations was not known.

The earliest known study done in Uganda, East Africa in 1970 showed that from 1963 to 1967, 207 enucleations were done (Davanger, 1970). In comparison to Adima's study, over 5 years from 1987 to 1991, 350 eyes were removed 170 enucleations were done followed by 169 eviscerations and 11 exenterations(Adima, 1993).

Overall the most commonly performed eye removal surgery in most African countries was eviscerations which corresponded to research done in Nigeria and Gambia as well(Steele et al., 2015). However both of the studies done in Uganda showed enucleations to be the most common surgery contrary to findings in most African countries and this was attributed to the fear of sympathetic ophthalmia with performing eviscerations(Adima, 1993; Davanger, 1970). Unlike other countries, in Harare Zimbabwe, exenterations were performed more at 39.7% compared to enucleations at 14.9%, although eviscerations were still the most commonly performed at

46.13%(Mukona, 2019). The large amount of exenterations was attributed to the hinderances in management of ocular malignancies like delayed presentation(Mukona, 2019).

2.3 INDICATIONS FOR EYE REMOVAL SURGERIES

Eye removal surgeries are the most drastic options for the management of eye diseases or injuries and are only done as a last resort to avoid inflicting any further damage on the patient. It is a very difficult decision to make to remove a patient's eye, but it may be necessary for severe ocular infections unresponsive to medical treatment, severe eye injury with no visual potential and to treat intraocular malignancies (Musa et al., 2016). The indications for the surgeries may comprise infective and non-infective causes(Mukona, 2019).

The indications for eye removal surgeries are similar globally but the prevalence of the different ocular morbidities necessitating these procedures differs from place to place(Musa et al., 2016). The patterns of eye diseases in different parts of the world can be approximated by analyzing the different causes of these eye removal surgeries thus giving information on the relative frequency of different pathological conditions(Davanger, 1970). The prevalence and burden of several ocular morbidities may not be documented yet but the eye removals done due to these conditions are well documented and this information can give an insight into the burden of most of these conditions(Adima, 1993). The prevalence of eye removal surgeries due to a certain cause can also be a reflection of the level of sophistication in the management of these diseases(Batten, 1971). The common indications of eye removal surgeries include trauma, tumors, painful blind eye, panophthalmitis, and disfiguring blind eye for example phthisis bulbi, end-stage glaucoma, and corneal disease(Davanger, 1970).

Obuchowska in Poland showed the most often indication for eye removal surgery to be trauma followed by intraocular tumors, secondary glaucoma, phthisis bulbi, and cosmetically disfigured eyes(Obuchowska et al., 2005). The pattern of the indications varied slightly from the findings in Denmark which is more developed than Poland. In Denmark, Rasmussen found that the most common indication was a painful blind eye, followed by neoplasm, infection, unsalvageable injury, disfiguring blind eye, and prevention of sympathetic ophthalmia(M. L. R. Rasmussen, 2010).

Ocular tumors especially the malignant type may also commonly lead to eye removal as a means of management to preserve an individual's life(Hita-Antón et al., 2016). Günalp et al in Turkey(1963 to 1993) showed that 429 cases had exenteration due to malignant tumors with secondary tumors infiltrating from the sinuses being the most common indication(Günalp et al., 1996). The primary orbital tumors associated with exenteration in Turkey were rhabdomyosarcomas (35), neurogenic tumors(9), fibrocystic tumors(2), melanocytic tumors(1), vascular tumors(2) and 1 teratoma(Günalp et al., 1996). Bartley et al in the Mayo Clinic, USA, also found that of the 102 patients that had exenteration done, 100 of them were due to neoplastic disorders and the most commonly associated neoplasms were squamous cell carcinoma, BCC, and melanoma which constituted 70% of all the neoplasms(Bartley et al., 1989).

SCC has also been commonly implicated, and Tunc et al in San Francisco showed that 61% of the patients with intraepithelial and invasive SCC underwent enucleation or exenterations(Tunc et al., 1999). African countries especially those in Sub-saharan Africa are even at an increased risk of SCC as an indication of eye removal surgery due to the increased exposure to common risk factors like HIV/AIDS, HPV, allergic conjunctivitis, and exposure to solar UV radiation(Gichuhi & Sagoo, 2016).

Hime et al found that in a tertiary hospital in Brazil, ocular melanoma (35.4%) and retinoblastoma (31.1%) were the most common indications of eye removal surgeries with other indications being endophthalmitis (6.3%), non-specific ocular inflammation (4.1%), SCC (3.6%), panophthalmitis (3.4%) and phthisis bulbi(1.2%) and noted that alternative treatment would have been effective in limiting the need of eye removal in some of the malignancy cases if not for the socioeconomic constraints in the public center(Hime et al., 2017). Vemuganti et al from India, which has a similar socioeconomic background to Brazil, also showed that tumors contributed to 49% of the eye removal surgeries done, followed by staphylomas, acute injury, absolute glaucoma, painful blind eye, and phthisis bulbi(Vemuganti et al., 2001). Vegumanti et al also noticed staphyloma to be more prevalent in the low socio-economic group with a history of childhood trauma(Vemuganti et al., 2001).

In Africa, the indications among the different countries are mostly similar with the commonest cause usually being trauma as in Haile & Alemayehu's study in Ethiopia where the most common causes of eye removal were traumatic globe rupture(33%), followed by malignancy, corneal

staphyloma and panophthalmitis(Haile & Alemayehu, 1995). These findings were similar to Olatunji's study in Nigeria which showed that the most common indication was trauma(38.8%), infection(21.3%), anterior staphyloma, tumor, and painful blind eye(Olatunji et al., 2011), implying that there is need for attention to the prevention of ocular trauma, especially in children(Jiang et al., 2019).

However, findings from Gyasi et al's research in Ghana slightly differed from those in Ethiopia and Nigeria and showed the most common indications for eye removal surgeries to be panophthalmitis/ endophthalmitis followed by ocular injuries(Gyasi et al., 2009).

In 1970 a study done in MNRH, Uganda that focused mainly on the causes of enucleation showed at the time that the most common causes were trauma(51%), Corneal disease(18%), painful blind eye(9%), malignant tumor(7%), panophthalmitis(6%), glaucoma(6%), phthisis bulbi(3%) and trauma was found to be most common because, at the time, eye injuries were commonly sustained during the war by civilians and soldiers and due to the poor transportation facilities the delayed reporting to hospital by days or weeks led to complications that rendered the eye unsalvageable(Davanger, 1970).

A study done in Zimbabwe showed that 45% of the patients who had eye removal surgeries were due to ocular squamous neoplasia with the prevalence higher in females than males(Mukona, 2019). Davanger also showed that 5 of the 207 patients who had their eyes removed were due to SCC and Adima also noted that 1.7% of patients had their eyes removed due to SCC(Adima, 1993; Davanger, 1970)A study was done in Uganda in 2000 also found that there had been a large increase in the incidence of conjunctival SCC(Wabinga et al., 2000) and this may also lead to an increase in SCC-related eye removal.

Numerous countries in Africa have shown retinoblastoma to be related to eye removal surgeries, especially enucleations in children. The delay in the presentation of these children and associated hindrances in treatment especially due to poor financial status leads to a lot of children presenting with advanced-stage disease including fungating growth and metastases that will need eye removal(Adeoye & Onakpoya, 2007). A In Nigeria, several studies that have been done have shown retinoblastoma to be the commonest cause of eye removal in children for example a study done in Ile-Ife showed that 87.2% of eye removal surgeries done due to retinoblastoma-related complications(Adeoye & Onakpoya, 2007).

The study done by Davanger in MNRH also showed that 50% of the enucleations done due to malignant tumors were found to be retinoblastoma and Adima's study, also done in MNRH 20 years later, showed that 56 children had their eyes removed due to retinoblastoma(Adima, 1993; Davanger, 1970). Adima queried if the increase in the number of enucleations was due to increased awareness or increased health service delivery(Adima, 1993). Therefore with modern treatment modalities that may hinder eye removals like IVC, IAC, TTT, and cryotherapy for the treatment of retinoblastoma(Ancona-Lezama et al., 2020), it would be helpful to assess the number of eye removal surgeries that are currently due to retinoblastoma and that can help us ascertain the morbidity of the disease currently in Mulago National Referral Hospital.

Corneal disease-related eye removal surgeries in Uganda occurred due to poor health-seeking behavior of people with corneal ulcers, trachoma complicated by entropion and trichiasis, and corneal resistance reduced to bacterial infection due to malnutrition(Davanger, 1970). This trend may be different now since there has been marked improvement in the health care systems in the country and a reduction in the prevalence of trachoma due to the Trachoma Initiative that provided up to 27,000 sight-saving surgeries over the last four years(Kolaczinski et al., 2007). Although current corneal-related illnesses may be due to the HIV endemic in the country(Ateenyi-Agaba, 1995).

In comparison to the study done by Davanger in 1970, Adima in 1993 showed that trauma(35.43%) was still the commonest cause of eye removal surgery, followed by malignancy(18.87%), ocular infection(17.14%), Staphyloma(9.43%), painful blind eye, phthisis bulbi and then glaucoma(Adima, 1993). The persistent associations of high incidences of eye removal surgeries in Uganda in both studies were attributed to the several incidences of political instability in the country at the time and multiple injuries were sustained secondary to physical violence as well as fire arms injury in the war zones(Adima, 1993; Davanger, 1970)

Currently, in Uganda, there is a general improvement in the socioeconomic status from 56.4% of people below the poverty line in 1993 to 19.7% in 2013, which may lead to a change in the prevalence and patterns of the different indications of eye removal surgeries(Adima, 1993; Owori, 2020).

Microbial keratitis resulting in loss of the eye typically may occur in patients who are elderly with preexisting poor visual acuity that presents with severe infections due to virulent organisms or

delayed treatment in developed countries(Cruz et al., 1998) while in countries like Uganda, the microbial keratitis leading up to eye removal surgeries is common in the age group of 20-40 years of age probably due to associated HIV pandemic, application of TEM and poor health seeking behavior (Adima, 1993).

Regardless of the pattern of the indications, most studies seemed to find that most of the indications were preventable and needed serious preventive strategies to reverse the trend of indications of eye removal surgeries(Gyasi et al., 2009).

This study was used to determine the current patterns of indications that lead to the different eye removal surgeries in comparison to the previous studies done by Davanger(1970) and Adima(1993) and this information may be used to assess the trend of the effectiveness of the eye health care systems in the country over the years and guide the evolution of Mulago National Referral Hospital into a center that provides more comprehensive, specialized and preventive eye health care.

2.4 CHARACTERISTICS OF PATIENTS THAT HAVE UNDERGONE EYE REMOVAL SURGERIES

Eye removal surgeries are performed as a result of specific indications as the end-stage along the path of a complicated disease, or the primary treatment in trauma and neoplasm that commonly follows late presentation for care(Eballé et al., 2011).

2.4.1 SOCIODEMOGRAPHIC CHARACTERISTICS

Age of Patient

The mean age of occurrence of these eye removal surgeries varies in different parts of the world with associated variations in the indications and eye removal surgeries done in the different age groups.

The age range most affected in Yazid, Iran, Asia was found to be 20 to 50 years old with 30.4% of those cases attributed to the goal of prevention of sympathetic ophthalmia(Oveisi et al., 2014). The age group above 50 years in Yazid, Iran was second to the age group of 20 to 50 years old and unlike the latter age group, the commonest cause of eye removal surgeries in this age group was due to painful blind eye associated with glaucoma, trauma, uveitis, and keratopathy(Oveisi et al., 2014). However, another study done in Tel Aviv, Israel, Asia from 1981 to 2007 showed that the

mean age for people who had eye removal surgery was above 55 years old(Gaton et al., 2008) which contrasted with the one done in Iran and another study done in Palestine that also showed an average age of 35 years being most afflicted with eye removal surgeries(Keenan & Sargent, 2011).

In Zimbabwe, the average age group with the highest number of eye removal surgeries done was between 21-30 years with the less than 10 years age group having the lowest prevalence(Mukona, 2019). Eye removal surgeries are thought to be most common in the above 20 years age group because this is the active age group where trauma-related injury to the eye occurs frequently(Eze et al., 2007). Furthermore, another study done in India showed that of the 150 patients(151 eyes) that had enucleation done in a tertiary care hospital from 1995 to 1998, 85.2% of them were children under the age of 15 years. This high predilection for children below 15 years of age which contrasts with most studies is mostly due to the high percentage of children that were enucleated due to retinoblastoma, other suspected tumors, and associated staphylomas(Vemuganti et al., 2001). It was in this study that it was noted that, despite the incidence of enucleation declining in most other parts of the world, there was not much change in India over the past two decades as evidenced by a large number of enucleations still being done in children secondary to retinoblastoma(Vemuganti et al., 2001).

The two studies done earlier also had varying results when it came to age range. Davanger reported that enucleations were mostly done in the age group of 30-39 years of age while Adima's study found the age group of 0 to 9 years to have the highest prevalence of eye removal surgeries. Davanger attributed the high prevalence of eye removal surgeries in the 30-39 years age group due to the high risk of exposure to traumatic eye injury versus Dr. Adima who attributed the high prevalence of eye removal in the age group of 0-9 years of age to the high incidence of retinoblastoma and malignant tumors(Adima, 1993; Davanger, 1970).

Therefore the average age of occurrence of eye removal surgeries does vary in different parts of the world and as well as noted variations in the indications for these surgeries in the different age groups. The noted variations in the age group even at a national level after different periods make it imperative to assess after 27 years the current trend regarding the prevalence of eye removal surgeries in the different age groups(Adima, 1993; Davanger, 1970).

Sex of patient

Numerous studies showed that eye removal surgeries were more common in males than females for example in Ethiopia the M: F ratio was 2.2:1(Haile & Alemayehu, 1995), in Zaire the M: F ratio was 1.2:1(Kaimbo, 1988), in Lagos, Nigeria the M: F ratio was 2:1(Musa et al., 2016), in Iran M: F ratio was 2.1:1(Oveisi et al., 2014). In these countries, the indication for eye removal in the male age group was traumatic injury and this is of major concern because a majority of the circumstances that lead to the injury were largely avoidable(Musa et al., 2016). The type of activity that men usually also engaged in was thought to predispose them more to traumatic eye injury compared to women(Oveisi et al., 2014).

The most frequent injury type in males is work-related injuries (49.7%), whereas the most frequent injury type in females is home-related injuries as shown by a study done in China(Wu et al., 2020).

In addition, there was a coherent high M: F ratio in Davanger's(1.8:1) and Adima's(2.11:1) that was attributed in both studies to the exposure of the male species to more hazardous activities and tendencies to violence more among men than women(Adima, 1993; Davanger, 1970). There may be a decrease in the M: F ratio difference since there has been a period of political stability all over the country over the last 20 years and other associated factors like the increase in opportunities for women that were previously only accorded to men thus women are exposed to similar occupational hazards.

Socioeconomic status of the patient

Socioeconomic status has been shown to predispose some patients to certain risks that may lead to eye removal surgeries. The privilege of belonging to a higher socioeconomic status results in a lower risk of visual impairment or blindness compared to those in the lowest socioeconomic group(Nesemann et al., 2022).

For example, Vemuganti et al noted that the group with non-tumor indications of eye removal surgeries was mostly due to anterior staphyloma (25.2%)(Vemuganti et al., 2001). In his study, he noted that countries with similar socioeconomic standing like Ethiopia (11%) had similar prevalence of anterior staphylomas, and he also noted that the anterior staphyloma was more common in the non-paying patients attending the general outpatient clinic versus the paying patients(Vemuganti et al., 2001). The predisposing factors to the pathogenesis of the anterior staphyloma apart from trauma were also thought to be nutritional factors, chicken pox, measles,

infections, ignorance on the part of the patient, increased tolerance of glaucoma symptoms, and improper or inadequate treatment on the onset of the disease process probably due to financial restraints(Vemuganti et al., 2001).

Meanwhile, studies in the developed world have identified neoplasm and painful blind eyes as the leading indications for surgical removal of the eyes(Adeoye & Onakpoya, 2007). This was shown clearly by a study done at Rigshospitalet, Denmark for which the most frequent indications for eye removal surgeries were painful blind eye (37%) and neoplasm (34%)(M. L. R. Rasmussen, 2010).

The low socioeconomic status was also associated with reduced immunity to bacterial corneal infections especially secondary to malnutrition among the children and difficult accessibility to health centers in Davanger's study. Adima debated whether the increased corneal infections were associated with the low socioeconomic status in the country, since he argued that the availability of eye health care services had become more accessible(Adima, 1993; Davanger, 1970). The disagreement between these two studies creates a dilemma that may be answered by the assessment of the socioeconomic characteristics of people that had eye removal surgery.

Occupation of the patient

As most eye removal surgeries are attributed to traumatic injury of the eye, several occupational risks can lead to unsalvageable eye damage and the need for removal.

Several studies on different continents have shown that laborers are more prone to traumatic eye injury versus those with white-collar jobs(Oveisi et al., 2014). For example in Yazd, Iran the study done showed the more frequent rate of surgery was amongst the range of 20-50 years (53.9%) 21.6% of whom were laborers and 18.6% were housekeepers(Oveisi et al., 2014)Men are even considered more at risk because they tend to engage in occupations that constitute a considerable risk to ocular safety(Adeoye & Onakpoya, 2007).

Another study done in Nigeria showed that farmers (n=23; 21.7%) had a higher risk of eye removal surgery incidence compared to civil servants (n=10; 9.4%) due to their engagement in injury-prone agricultural activities(Eze et al., 2007).

Another 20 years study in China from 1999 to 2008, showed that of the 1818 globes removed, the most frequent injury type was work-related injuries, followed by injuries due to outdoor

recreational activities, violence-related injuries, and home-related injuries either by metals, nails, scissors, or needles(Wu et al., 2020).

2.4.2 CLINICAL CHARACTERISTICS

HIV serostatus

A study done in Botswana showed that 48.5% of patients that were diagnosed with squamous cell carcinoma of the eye were also HIV positive, 0.9% and 1.3% of whom had eviscerations and enucleation done respectively(Steele et al., 2015). Another study done in Zimbabwe showed ocular squamous neoplasia as the most common indication of eye removal surgery in the age group of 21-40 years which was attributed to the fact that this is the most sexually active age group and more at risk of HIV and AIDS conditions(Mukona, 2019).

In Uganda, among the 48 patients that were found to have conjunctival tumors in Mulago National Referral Hospital, 75% were HIV seropositive and the recent epidemic of conjunctival tumors was largely due to the epidemic of HIV infection(Ateenyi-Agaba, 1995). HIV seropositive patients are still at risk of eye removal surgeries secondary to squamous cell carcinoma since preventive interventions are not yet identified through HIV research to focus on the treatment of this tumor(Gichuhi & Irlam, 2007).

HIV seropositive children are also predisposed to incidences of sporadic anterior staphyloma and corneal perforation that may lead to eye removal surgery(Ezegwui et al., 2012). The occurrence of spontaneous ulcerative keratitis in HIV/AIDS patients secondary to *Capnocytophaga* species, *Candida* species, *S.a* and *P.a* may also put seropositive patients at an increased risk of eye removal surgery(Aristimuño et al., 1993).

The two studies that have been done in Mulago National Referral Hospital did not at the time assess for the association between HIV and the prevalence of eye removal surgeries. This is because the study done by Davanger(1970) was before the discovery of HIV in the country while Adima's study was done amid the HIV pandemic in the country when the disease had not been well understood and very high levels of stigma hindered these patients from seeking health care or disclosing their status in the health center(Adima, 1993).

Severity of illness

Indications of eye removal surgery like endophthalmitis have devastating sequelae that can result in blindness and even loss of an eye(Lu et al., 2016). The latter is also dependant on the origin of inoculation with endogenous endophthalmitis and endophthalmitis secondary to corneal ulcers having the highest risk of the need for evisceration or enucleation(Jiang et al., 2019). This is because the progression of an infectious corneal ulcer to endophthalmitis could be attributed to delayed diagnosis and treatment, a delay in culture results, the use of topical steroids, a pre-existing ocular pathology, a previous ocular surgery, dementia, nursing home residential care, lack of understanding of the severity of the condition, and/or poor adherence to treatment and probable high virulence of microbes that lead to severe corneal ulcer related endophthalmitis(Lugo Merly et al., 2022).

The choice of evisceration or enucleation in ocular tumors may also indicate the severity of the tumors for example a study done in Turkey showed that most patients with retinoblastoma had enucleation except for those who displayed massive proptosis, ocular damage, and blindness at initial presentation and underwent exenteration(Günalp et al., 1996).

Location of occurrence of injury to the eye

Traumatic injuries to the eye can occur either at the place of work, at home, at school, or on the road(Oum et al., 2004). Most eye injuries usually occur at work(Cao et al., 2012) with the most affected workers being in manufacturing followed by construction, agriculture, and service industry(Cai & Zhang, 2015). Penetrating ocular injury and intraocular foreign bodies especially metallic bodies are some of the more severe forms of presentation of work-based ocular trauma that may lead to eye removal surgeries(Oum et al., 2004).

Traumatic eye injuries sustained due to road traffic accidents are associated with midfacial fractures and ruptured globe that may lead to the need for eye removal surgeries(Fomete et al., 2021). There has however been a reduction in the incidence of penetrating ocular injuries in vehicle users since the introduction of the seat belt(Wykes, 1988).

Another study done in India in 2017 showed that most incidences of ocular trauma occurred during casual activities done at home(41.7%) followed by sports-related(16.8%), then agriculture-related(14.6%) accidents, and the findings in this research were mostly attributed to lack of home safety measures(Shukla et al., 2017).

The majority of the circumstances of trauma sustained at home, work, school, or on the road are largely avoidable and unnecessary if appropriate measures are taken(Musa et al., 2016). However no study has been able to show which location of injury ie work-based, home-based, school-based, or road-based is more associated with injuries that are more likely to lead to eye removal surgeries. Adima also noted that most of the injuries occurred in children while they were playing at school and in adults as they were in their gardens working or in motor accidents(Adima, 1993).

Diabetes Mellitus

In most countries in the world, there has been an increase in the prevalence of type 2 diabetes mellitus due to the increase in the sedentary lifestyle including poor nutrition all over the world(Sun et al., 2022). Type 2 Diabetes Mellitus can lead to immunosuppression of a patient when sub-optimally controlled and may also hinder good immune response to medical therapy(Mack et al., 2022).

A study done in Thailand to assess corneal ulcers leading to evisceration or enucleation in a tertiary eye care center with clinical and microbiology characteristics also found that 13% of the patients who had corneal ulcers that progressed to need enucleations and eviscerations were type 2 diabetes mellitus patients(Hongyok & Leelaprute, 2016).

The presence of type 2 diabetes mellitus was not elicited in the previous studies done by Davanger and Adima while this study showed the relation of type 2 diabetes mellitus in patients who have had eye removal surgery

Ocular trauma

Ocular trauma is a leading cause of significant visual impairment and loss of an eye(Adima, 1993) and worldwide it is a neglected disorder contrary to the extent of public health problems it creates(Leonard, 2019). Eye removal surgeries secondary to ocular trauma can be avoided by prompt diagnosis and appropriate treatment thus limiting sight-threatening sequelae(Hardy, 1996).

Ocular trauma can cause damage to all parts of the eye including the cornea, angle, lens, macula, and peripheral retina but early treatment can prevent potential severe loss of vision(Giovinazzo, 1987). Ocular trauma can be classified into open globe and closed-globe injuries which can then further be divided into contusion and lamellar lacerations for the latter(Kuhn et al., 2004). Closed

globe injuries can also be further classified into globe rupture, and laceration with laceration being sub-divided into penetrating, perforating, and IOFB(Kuhn et al., 2004).

A study done in Saudi Arabia showed that of 110 patients that underwent evisceration and enucleation, 35% were due to traumatic injury to the eye while 65% were not associated with traumatic events with the leading mechanism of injury being metallic nail injuries(Al-Dahmash et al., 2017). Another study done in Nepal also established that of the 67 cases that had evisceration, 55.2% of them were due to trauma and its subsequent sequelae(Limbu et al., 2009).

The previous studies done by both Adima and Davenger also emphasize the cohesive relationship between eye removal surgeries and ocular trauma and show that most patients had their eyes removed either due to ocular trauma or due to its sequelae like endophthalmitis, painful blind eye, etc.(Adima, 1993; Davanger, 1970). Therefore the relevance of the association between ocular trauma and eye removal surgeries was investigated since the limited information on the social and economic consequences of ocular trauma already suggests significant financial and social resources are spent on medical care rehabilitation(Kobusingye & Lett, 2000).

Ocular infection

Ocular infections and inflammation are major eye health problem and their sequelae like corneoscleral perforation, metastatic spread via the bloodstream, and endophthalmitis/panophthalmitis may lead to eye removal surgeries(Adima, 1993).

Ocular infections have been evolving over the years due to the increased use of antibiotics and genetic transformation of the pathogens to gain resistance thus creating 3 time-periods of endophthalmitis i.e the pre-antimicrobial era, the predominantly systemic antimicrobial era, and the current intravitreal antimicrobial era(Relhan et al., 2018).

Endophthalmitis may occur after ocular surgeries, trauma, or from a systemic infection and the seriousness of this condition requires prompt recognition and treatment to avoid eye removal surgery(Lemley & Han, 2007). A study done in MNRH to study the external ocular surface bacterial isolates and their antimicrobial susceptibility patterns among pre-operative cataract patients in 2013 showed the presence of MRSA and MRS in 27.6% and 31.9% respectively which may lead to an increased risk of post-operative endophthalmitis(Mshangila et al., 2013).

In sub-Saharan Africa, the co-existence of HIV infection also creates an added disadvantage as it increases the risk of infections like CMV retinitis and herpetic keratitis that are difficult to treat, especially in a limited resource setting(Schaftenaar et al., 2014).

In most African countries, ocular infection sequelae contribute significantly to the indications of eye removal surgeries. In Lagos Univeristy Teaching Hospital Nigeria, a study showed that 18.4% of the patients had their eyes removed due to ocular infection(Musa et al., 2016). Another study done in Ethiopia also showed that 11% of the people whose eyes were removed were due to panophthalmitis(Haile & Alemayehu, 1995).

Davanger found that 38 cases had enucleation due to perforating corneal ulcers secondary to late presentation of patients with corneal infections, trachoma, and corneal resistance to bacterial infection probably due to malnutrition(Davanger, 1970). Adima also found that 95 eyes were removed secondary to endophthalmitis/ panophthalmitis and it was noted that intraocular infections usually occurred in people with low socio-economic status and low personal hygiene(Adima, 1993).

Currently in Uganda, the number of people suffering from trachoma infection has decreased dramatically after Sightsavers and its partners implemented the WHO SAFE strategy, and the attribution of corneal perforation due to Trachoma as recognized by Davanger may have reduced. Furthermore, the resistance profile of the pathogens has changed since 1993 when Adima's research was done and the morbidity of ocular infections has also changed which may easily be elicited by ascertaining the eye removal surgeries attributed to ocular infections.

Glaucoma

Chronic open-angle glaucoma, the commonest type in Uganda, can cause surgical removal of the eye(Adima, 1993). Numerous studies have shown a correlation between glaucoma and eye removal surgeries. The advancement in medical therapies has led to a decrease in eye removal surgeries for example there has been a decline in the number of enucleations between 1975 and 1995 due to the decrease in the number of glaucoma-related enucleations(Hita-Antón et al., 2016).

A study done in India over 60 years, noted that glaucoma had a steady decrease as a risk factor for eye removal over the years(Setlur et al., 2010). In this study, it was noted that the eyes removed

surgically in the 1950s vs 2000s were 34% vs 0% and this was attributed to improved medical and surgical treatment of glaucoma that lead to the end-stage eye disease(Setlur et al., 2010).

In Uganda, the study done by Davanger showed that 5.8% of the enucleations done were due to glaucoma-related complications and he attributed this to poor health-seeking behavior(Davanger, 1970). In a later study done by Adima, the eye removals done secondary to glaucoma complications accounted for about 1% which showed a marked decrease from Davanger's study and therefore improved management of glaucoma(Adima, 1993).

This study ascertained if the management of glaucoma has improved even further and is related less to eye removal surgeries in Mulago National referral Hospital.

2.4.3 TREATMENT RELATED CHARACTERISTICS

Use of Traditional Eye Medicine

Significant associations have been shown between the use of TEM and eye removal surgeries(Jaya & Masanganise, 2014). Mild trauma to the eye that may have healed easily with adequate treatment may progress to corneal ulcers and panopthalmitis due to the harmful use of TEM and a study done in Gambia showed that 80% of patients who underwent enucleation or evisceration gave a history of having used TEM(Dawodu & Faal, 2000).

Another study done in Uganda showed that TEM users had a poorer clinical presentation and outcomes of microbial keratitis(Arunga, Asiimwe, et al., 2019) and this led to larger risks or poor outcomes that may lead to eye removal surgery(Arunga, Asiimwe, et al., 2019).

The use of TEM delays the initiation of appropriate treatment as well as causes undesirable effects on the eye like masking the primary pathology, leading to infections and/or corneal scarring(Dawodu & Faal, 2000). In Nigeria, another study showed that 47.6% of the patients whose ocular injury resulted in eye removal surgery were due to the use of traditional eye medicine(Enock et al., 2008).

In Adima's study, he also realized that 10 of the 350 eyes removed had a history of the application of traditional eye medicine(Adima, 1993). This study also looked at the use of TEM in patients that had eye removal surgery at MNRH.

Prior Ocular Medical and Surgical Treatment

The initiation of medical and surgical treatments for very severe corneal infections or ulcers may not be sufficient to hinder the loss of an eye(Hongyok & Leelaprute, 2016). The low knowledge among health workers and the poor capacity of the health facilities to diagnose the management of microbial keratitis can lead to delays in appropriate treatment and the need for eye removal surgery(Arunga, Kyomugasho, et al., 2019). Indications like endophthalmitis, painful blind eye, and glaucoma may also be unresponsive to treatment and lead to the need for eye removal surgery(Koylu et al., 2015).

Resistance to a particular antibiotic, anti-fungal or antiviral eye drops may lead to progression of the corneal infections and the need for eye removal surgery for example a study done in Switzerland showed that most strains of bacteria were resistant to fluoroquinolones, aminoglycosides, cefazolin, chloramphenicol, polymyxin-B, fusidic acid, bacitracin and therefore associated with poor clinical outcome like eye removal surgery(Schaefer et al., 2001).

Patients also tend to visit multiple health facilities which may be associated with poor adherence to treatment due to the increased cost of treatment thus increasing the risk of complications of microbial keratitis and eye removal surgery(Arunga, Kintoki, et al., 2019).

Post-surgical endophthalmitis may also occur as an adverse side effect of intraocular surgeries like cataract surgery and glaucoma surgery and if managed poorly may lead to eye removal surgery(Gyasi et al., 2009).

Self-Treatment

Patients who may sustain corneal ulcers secondary to trauma or organic objects are usually more inclined to self-treat and therefore lead to the progression of an ulceration that may eventually lead to eye removal(Hongyok & Leelaprute, 2016). A study in Nigeria showed that 9.5% of the patients who had eyes removed had initially used topical corticosteroids before presentation to the hospital(Enock et al., 2008).

In Adima's study, he found an incidence of medical health personnel who developed corneoscleral rupture secondary to severe intra-ocular infection because they had self-prescribed topical corticosteroids(Adima, 1993).

Delayed presentation to the hospital

The periodicity of illness or ailment of the eye without presentation to the hospital may premeditate the poor outcome of any interventions and therefore the need for eye removal surgery(Davanger, 1970). In a tertiary eye care facility in Enugu state, Nigeria, it was shown that the incidence of eye removal was highest among farmers obviously due to the engagement in injury-prone agricultural activities with associated difficulty in accessibility to tertiary eye care centers from there remote areas thus presenting late after the secondary infection has set in and the eye is damaged beyond salvage(Eze et al., 2007). Enock et al also noted that 95.2% presented to the hospital after 1 week after the onset of ocular lesions that eventually ended with eye removal surgeries(Enock et al., 2008).

Albeit most studies show that delayed presentation of the patient to the eye care center leads to increased risk of eye removal surgery. A clinicopathologic study of enucleated globes to determine how and why the indications for enucleation have changed over time in Doheny Eye Institute in Los Angeles over 60 years showed that the absolute number of enucleations secondary to neoplasms has not decreased over time despite the improved referral patterns(Setlur et al., 2010).

In addition to the school of thought that delayed presentation to the hospital contributes to an increased risk of eye removal surgeries, Davanger et al showed that the condition of the injured eye became worse because most of the patients did not go to the hospital for proper treatment until many days or weeks after the accident in 1970(Davanger, 1970). The early detection and management of ocular malignancies and infections were also emphasized as one of the interventions that may lead to a reduction in the need for these eye removal surgeries(Adima, 1993). Difficult accessibility to health facilities or non-availability of free health care services to the less economically productive may precipitate late presentation thus eye removal surgery(Musa et al., 2016).

In conclusion, the increased availability of regional referral facilities from 5 in 1993 to approximately 20 in 2022 may increase the accessibility of eye health care services and therefore the study of delayed presentation to hospitals concerning eye removal surgeries may indicate whether the improved accessibility to these health centers has markedly decreased the time from occurrence of symptoms to medical intervention.

2.56 QUALITY OF LIFE

2.5.1 CONSEQUENCES OF EYE REMOVAL SURGERY

Loss of Vision

Apart from the loss of vision secondary to the loss of an eye, some patients may also have an ocular co-morbidity in the fellow eye and therefore have enhanced difficulties with peripheral vision or distance judgments (Morgan-Warren et al., 2013).

The loss of binocular vision with a reduced field of vision and depth perception implies job limitations that may destabilize the individual's financial standing(Ayanniyi, 2008).

Altered identity and Disfigurement.

Removal of an eye is associated with a perceived facial disfigurement that is undesirable and henceforth poor self-esteem making the psychological trauma more taunting than the physical disability (Jordan and Klapper 2012).

Even with the rehabilitation of anophthalmic sockets/orbits that is provided by the ophthalmologist and ocularist to ensure anophthalmic cosmesis, a study done in Nigeria showed that 47% of the patients that received anophthalmic cosmesis still showed regret about losing their eye, 2 patients were depressed and only 1 patient was satisfied with the outcome of the anophthalmic cosmesis (Ayanniyi, 2008).

In Manchester, United Kingdom a study showed that only 30 of 69 patients had exenterations done and therefore the rest of the patients were left with disfigurement(Kasaee et al., 2019). Another study that assessed the social challenges of cancer patients with orbitofacial disfigurement found that patients who had eye removal surgeries were more uncomfortable in situations where normal patients would have been comfortable(Bonanno et al., 2010).

Extra Financial Burden

WHO also reports that vision impairment creates a large global financial burden with annual global productivity losses of approximately US$ 411 billion. The cost of eye removal surgeries, artificial eyes, and low vision rehabilitation is also an added cost to the individuals and creates a financial burden(WHO, 2022).

In Nigeria, 80% of the patients reported that the artificial eye cost between $9 and $17 while 20% procured it for less than $9 which is still relatively costly for people in a third-world country(Ayanniyi, 2008).

2.5.2 EFFECTS OF EYE REMOVAL SURGERY ON QUALITY OF LIFE OF AFFECTED PATIENTS

Quality of life is defined as the individuals' perceptions of their position in life in the context of the culture and value systems in which they live and concerning their goals, expectations, standards, and concerns (WHOQOLGroup, 1996). This definition shows that QOL refers to a subjective evaluation that is embedded in a cultural, social, and environmental context. The concept of QOL has a broad range of factors within it including a person's physical health, psychological state, personal beliefs, social relationships, and their relationship to salient features of their environment.

QOL can be subdivided into specific parameters that create a wholesome assessment of the quality of life i.e. HRQOL, perceived stress, job separation due to disability, and socioeconomic status(M. L. R. Rasmussen, 2010). The terms QOL and HRQOL are at times used interchangeably but it is important to note that, unlike QOL, HRQOL only focuses on the way someone's health status empirically affects their QOL(Karimi & Brazier, 2016). The study of HRQOL is important in guiding patient management and policy development(Guyatt et al., 1993).

Removal of an eye not only implies that someone has lost a part of their body or face but even more intricately they have lost a part of their likeness and maybe even a part of their personality(M. L. R. Rasmussen, 2010). The implied impact on the general well-being of a patient that has an eye surgically removed is foreseen but rarely measured to provide efficacious solutions to the shortcomings and therefore maintain or improve the quality of life of this patient(Ahn et al., 2010; Kondo et al., 2013).

Eye removal surgery can have a significant impact on an individual's HRQOL which may be worse than the general population (Ahn et al., 2010; Chia et al., 2004). A study done in Brazil found that patients who underwent eye removal surgery reported lower scores in several dimensions of HRQOL, including physical functioning, role limitations due to physical health, and social functioning(Schellini et al., 2015). Another study done by Kondo et al reported that monocular patients had equivalent general physical and mental HRQOL to binocular patients despite the

surgical removal of one eye but the reduced vision-specific HRQOL of monocular patients on the NEI VFQ indicated reasonable residual visual deficits even after prolonged monocular status(Kondo et al., 2013). A study done by Rasmussen also showed that the indication related to the removal of eye surgery affected the HRQOL, that is to say, he found that patients with trauma were found to have a better HRQOL compared to those who had eye removal surgery secondary to cancer and this was attributed to the short intervention time from disease infliction to the removal of the eye(M. L. R. Rasmussen et al., 2010).

Perceived stress for patients that experience eye removal surgery is significant and various studies have shown relevant correlations of increase in perceived stress of these patients(Cohen et al., 1983). A study done by Horgan et al found that patients experienced high levels of anxiety and depression before eye removal surgery and that the surgery itself was a significant source of stress(Wagner et al., 2012). The high perceived stress in these patients (M. L. Rasmussen et al., 2012)is supplemented by the anxiety, depression, and poor self-image that these individuals experience(Linberg et al., 1988). Research has also shown that the perceived stress may be related to the type of surgery done for example patients who have undergone evisceration had a lower median in dimensions of SF-36 and more perceived stress (M. L. R. Rasmussen et al., 2012).

Eye removal surgery can lead to job separation due to disability, as visual impairment can impact an individual's ability to perform certain tasks. Research has shown that a significant proportion of patients who underwent eye removal surgery reported that their work had been impacted by this condition(Schellini et al., 2015). A study done by Coday et al showed that there was unexpected change or loss of employment due to the loss of an eye and this was highly attributed to the fact that 91% of the patients had no formal training to help them adapt(Coday et al., 2002). Another study showed that 25% of patients who underwent eye removal surgery retired or changed to part-time jobs and 39.5% stopped participating in leisure activities due to the loss of an eye(M. L. R. Rasmussen, 2010).

Socio-economic status (SES) can either impact the outcomes of patients who undergo eye removal surgery or be impacted by the loss of an eye. A study done by Bekibele et al found that patients with lower SES were more likely to experience delays in seeking medical care for eye conditions, which may impact the timing and outcomes of eye removal surgery(Bekibele & Gureje, 2008).

The study of HRQOL in patients who have had eye removal surgery in Africa is deficient however, there are a few studies that have investigated the impact of visual impairment on HRQOL. For example, a study done by Oye et al in Nigeria found that visual impairment was associated with poorer HRQOL outcomes, particularly in the physical and social functioning domains. Another study done in South Africa showed that there was an improvement in the visual-related QOL in terms of general functioning, psychosocial impact, and vision symptoms domains in patients who had visual impairment due to cataracts and underwent surgery to restore vision(Zitha & Rampersad, 2020).

While the above studies are not specific to patients who have had eye removal surgery, they provide some insight into the potential impact of visual impairment on HRQOL in African populations. Given the lack of specific research on HRQOL in patients who have had eye removal surgery in Africa, there is a need for further research to better understand the unique challenges and experiences of this population.

2.5.3 Tools used for QOL assessment.

The SF-36 (Short Form 36 Health Survey) and PSS (Perceived Stress Scale) are two commonly used measures in healthcare research to assess health-related quality of life and stress levels, respectively(Trentham-Dietz et al., 2008).

The SF-36 tool is an instrument used to measure HRQOL(Trentham-Dietz et al., 2008; Varma et al., 2006). SF-36 is a set of generic, coherent, and easily administered quality-of-life measures. These measures rely upon either patient self-reporting or interviewer administration and have been widely used. It contains 36 items measuring 8 dimensions of health and well-being namely: **PF** for Physical Functioning, **RP** for Role limitations due to the Problem, **BP** for Bodily Pain, **GH** for General Health perceptions, **VT** for Vitality, **SF** for social functioning, **RE** for Role limitations due to emotional problems, **MH** for Mental Health.

Each of the dimensions is scored from 0 (worst possible health state) to 100(best possible health state). This tool has been used in various ophthalmological studies and has been found useful for collecting data from older patients as well as visually impaired patients(Chia et al., 2004; Varma et al., 2006).

The SF-36 is a self-reported or interviewer-administered questionnaire and has been extensively tested for reliability and validity and has demonstrated good psychometric properties. The SF-36 has shown good internal consistency, with Cronbach's alpha coefficients ranging from 0.6 to 0.96 for different domains. Test-retest reliability has been demonstrated with intraclass correlation coefficients ranging from 0.6 to 0.9. The SF-36 has also demonstrated good validity through construct, convergent and discriminant validity tests. The Cronbach's alpha coefficient of SF-36 tool for our study for the different dimensions ranged from 0.6 to 0.96 except for social functioning which was 0.342.

The PSS is a self-reported questionnaire that consists of 10 items and measures the degree to which a person perceives their life as stressful. It assesses the degree to which situations in one's life are perceived as stressful and the level of perceived control over those situations. In the context of researching the quality of life (QOL) among patients who have undergone eye removal surgery in Uganda, the inclusion of the Perceived Stress Scale (PSS) as a measurement tool holds significant merit. Previous studies have underscored the pivotal role of perceived stress in influencing the overall well-being and QOL of individuals facing health-related challenges (Cohen & Janicki-Deverts, 2012; Schwarzer & Taubert, 2002).

Eye removal surgery can engender psychological and emotional stress due to both the physical changes resulting from the surgery and the potential impact on self-esteem and body image (Corkin et al., 2017; Finger, 2008). By integrating the PSS into this study, a comprehensive evaluation of the patients' subjective perception of stress was attained, illuminating its potential connections with various dimensions of QOL, such as psychological well-being, physical functioning, and social interactions. Such an approach aligns with the notion that the interplay between stress and QOL is intricate and multifaceted, warranting a nuanced investigation that transcends the mere assessment of surgical outcomes (Bokhari et al., 2020; Taylor et al., 2010). Consequently, the incorporation of the PSS as a key measurement tool not only enriched the depth of understanding regarding the experiences of these patients but also facilitated the identification of potential intervention strategies aimed at enhancing their QOL through targeted stress management approaches.

The PSS typically contains items that are scored on a Likert-type scale, where respondents rate how often they have felt a certain way in the past month. The responses are often anchored by statements like "0 = Never" to "4 = Very often". The total PSS score is calculated by summing up

the scores from each item. The total score can range from 0 to a maximum value that depends on the number of items in the scale (usually between 0 and 40).

Interpreting PSS scores generally involves understanding the level of perceived stress that an individual is experiencing based on their total score. Here's a general guide to interpreting PSS scores: Low Perceived Stress: Scores between 0 and a certain threshold (e.g., 13) are often considered indicative of low perceived stress. This suggests that the individual perceives their stress levels as relatively low and manageable. Moderate Perceived Stress: Scores between the low and high thresholds (e.g., 14 to 26) suggest a moderate level of perceived stress. This indicates that the individual experiences a moderate amount of stress in their life, which could be related to various factors but is not overly severe. High Perceived Stress: Scores above a certain threshold (e.g., 27 or higher) are often considered indicative of high perceived stress. This suggests that the individual perceives their stress levels as relatively high and may be struggling to cope with the demands of their life.

The PSS has been shown to have good psychometric properties, including high internal consistency with Cronbach's alpha coefficients ranging from 0.65 to 0.91 and good test-retest reliability with intraclass correlation coefficients ranging from 0.6 to 0.9. The PSS has also demonstrated good validity, including construct validity, discriminant validity, and predictive validity. Overall, both the SF-36 and PSS have demonstrated good reliability and validity, and they are widely used in healthcare research to assess health-related quality of life and stress levels, respectively.

In conclusion, the literature suggests that HRQOL, perceived stress, job separation due to disability, and SES are all important factors to consider in patients who have undergone eye removal surgery. The study investigated the QOL of affected patients and this could have important implications for improving the quality of life and social and economic outcomes for this population.

CHAPTER 3: METHODOLOGY

3.1 STUDY DESIGN

This was a hospital-based cross-sectional descriptive study.

3.2 STUDY PERIOD

The study was conducted from 30th May 2023 to 30th June 2023.

3.3 STUDY SETTING

This study was conducted at the Records and Eye department in Mulago National Referral Hospital located in Kawempe division in Uganda's capital city, Kampala. Mulago National Referral Hospital is a public hospital. Mulago National Referral Hospital has an eye department that comprises an eye clinic, theatre, and eye ward.

The eye clinic is open from Monday to Friday except on public holidays. Different days are for different specialty clinics i.e., Monday- Paediatric ophthalmology, Tuesday-Oculoplastic, and Neuroophthalmology, Wednesday-Glaucoma, Thursday- Retina, and Friday for General patients. The eye clinic received an average of 100 patients per day and opened from 7:30 am to 6:00 pm to attend to patients. The oculoplastic section of the eye department offered reconstructive surgeries to disfigured anophthalmic patients and therefore many who had eye removal surgery attended the oculoplastic clinic for these services.

The eye ward is located on the first floor, Block A of Mulago National Referral Hospital, and accommodated a maximum of 50 patients, both male and female. The eye ward admitted approximately 4 patients per month that underwent eye removal surgery as per the ward and theatre registry records. The patients were admitted through the eye clinic, the accident, and the emergency or transferred from other wards in the hospital.

The Main Eye Theatre in MNRH is located on the first floor of Block B and operated from Monday to Thursday from 8:00 am to 5:00 pm. As per the theatre records, 305 eye removal surgeries had been done from the period of January 2018 to December 2022.

3.4 POPULATION

3.4.1 Target Population

All patients who had eye removal surgery in the central region of Uganda.

3.4.2 Accessible Population

All patients that had eye removal surgery at Mulago National Referral Hospital from 1st January 2018 to 31st, December 2022.

3.5 ELIGIBILITY CRITERIA

3.5.1 Inclusion Criteria

For objective 1

- Patients who underwent eye removal surgery in the Eye theatre at Mulago National Referral Hospital and whose records included the following information as below;
    - A front sheet that contained the patient demographics, date of admission, and date of discharge/ death
    - A copy of the consent form for treatment and amputation
    - Clerking notes
    - Operation notes
    - Pre-operative and post-operative notes
- Patients of all ages were included.

For objective 2

- For the assessment of the quality of life, only case files of patients who were 18 years and older at the time of the study were used to contact patients to participate in that part of the study.
- Patients who consented to participate in the study.

3.5.2 Exclusion Criteria

For objective 2

1. Patients who were mentally unstable at the time of the study may not have been able to give viable responses to the questionnaire.
2. Patients who were still undergoing recovery from the surgery i.e
    - Within 6 weeks of evisceration
    - Within 8 weeks of enucleation
    - Within 2 to 3 months of exenteration

3.6 SAMPLE SIZE ESTIMATION

Sample Size Calculation

For Objective 1

An estimated number of 4 patients underwent eye removal in MNRH which translated to 240 patients in 5 years (from the MNRH Eye Department Records).

Consecutive sampling was used whereby all case files that met the inclusion criteria were included in the study. Even though all case files of patients who had eye removal were intended to be recruited into the study, some files that did not meet the inclusion criteria were not used. Some files were also untraceable since the records department was not yet digitally transferred.

To achieve a sample size that enabled me to achieve my objective 1, I referred to Said's study in Kenyatta National Hospital as a reference and used the sample size calculation below to get a minimum sample size...

$$n' = \frac{NZ^2P(1-P)}{d^2(N-1) + Z^2P(1-P)}$$

Where

n' = Sample size for the study

N = Size of the population = **240** (estimated number of patients who have undergone eye removal according to the MNRH theatre registry book from 2018 to 2022)

Z=statistic for 95% level of confidence

P=estimated prevalence of the most common eye removal indication which was orbital tumors as per Said's study in Kenyatta National Hospital which is = **42.35%** (Said, 2014) d = Margin of error = **5%**

n = **116** case files will be used

To account for a 10% non-response rate, we needed to recruit a minimum sample size of **130** case files.

For Objective 2

The calculation was based on the study done by (M. L. Rasmussen et al., 2012) which assessed the quality of life of patients that had eye removal surgery in comparison to the general population. We used Rasmussen et al's study because it used similar tools (SF-36 and PSS) that we used in our study.

The mean score of the continuous outcome variable, HRQOL, was reported and the formula for determining the mean of a characteristic was used:

$$N = \frac{Z^2 \alpha/2 S^2}{d^2}$$

- S is the standard deviation of the mean HRQOL specifically social functioning which was 24.1.
- Z was 1.96 which corresponded to the set confidence level of 95%
- swathe precision set at 6 (based on 7% of 84.7[the mean of social functioning])
- Based on the above values, the minimum sample size was **N** = **61 patients**

The sample sizes for objective 2 were less than those of objective 1 because only patients 18 years old and above were included and those however some of those patients that would have been

eligiblehad died or were unreachable with the contacts retrieved from the case files or relocated, others were not willing to participate in the study.

3.7 SAMPLING TECHNIQUE

For objective 1

Case files were retrieved by consecutive sampling. A list of all the names and hospital case file numbers of all patients that underwent enucleation, evisceration, and exenteration of one or both eyes from 1st January 2018 to 31st, December 2022 were extracted through physical checks of the case files from the records department and correlation with the theatre lists, theatre registry and eye ward registry in Mulago National Referral Hospital.

The list that was created was then used to retrieve all case files that met the inclusion criteria consecutively from 31st, December 2022 to 1st January 2018.

For objective 2

Purposive sampling was used to select patients who participated in this part of the study. After the case files of patients that met the inclusion criteria were sorted out, contacts of patients that were retrieved from the files were used to reach the eligible patients. As per the exclusion criteria, patients that were mentally unstable and showed tendencies of abnormal speech or behavior were excluded. Patients that were reachable and consented to participate were then recruited into the study.

3.8 STUDY VARIABLES

3.8.1 Dependant variables

Quality of life was derived from the assessment of the 8 different dimensions of HRQOL using the SF-36 tool and the perceived stress using PSS scores. Eye removal surgery was the primary outcome in this study.

3.8.2 Independent variables

- **Sociodemographic factors;** Age, sex, socioeconomic status, location of residence, occupation, nationality, tribe, and literacy level

- **Clinical factors;** HIV status, Type 2 DM, the severity of illness, location of occurrence of injury, ocular trauma, ocular infections, neoplasms, glaucoma, and COVID-19 pneumonia
- **Treatment factors**; prior medical and surgical treatment, use of TEM, self-treatment, and delayed presentation to the hospital. Type of surgery done as well as the use of the implant or prosthesis during the surgery.
- Indications of the eye removal surgery

3.9 DATA COLLECTION

3.9.1 Data Collection Tools

For objective 1

The study used an electronic data extraction tool which was filled in by the PI. The PI deduced the information required to fill in the data extraction tool (See Appendix 2) from the patient case files.

A data extraction tool was used to collect the following information:

- Patient demographics
- Consent to procedure and treatment
- Admission and consent to the admission form
- History including:
    - Presenting complaint
    - History of presenting complaint
    - Review of other systems
    - Past Ocular History
    - Past Medical History
    - Past Surgical History
    - Family Social History
- Examination including:
    - General examination
    - Systemic examination
    - Detailed ocular examination
- Investigations including post/pre-operative histology results if available.

- Diagnosis
- Indication of eye removal surgery
- Type of eye surgery done
- Post-operative notes to look for proof of prosthesis fitting

For Objective 2

A questionnaire was used to extract data concerning the HRQOL, perceived stress, job separation due to disability, and socioeconomic position.

The questionnaire included the RAND SF-36 tool, the PSS tool, and other questions as described below:

- **Job Separation due to disability** was assessed using a questionnaire that comprised of two questions that assessed the correlation of separation from the job due to the eye removal surgery as used by the study done by Rasmussen et al in Denmark(M. L. Rasmussen et al., 2012). This inquired if the change in employment was due to the surgery or not.
- The socioeconomic status was measured with 1 question in the questionnaire that asked about their occupation. This question inquired about the current employment status of the patient.
- Two questions were used to address leisure activities and assess whether there was any limitation to the patient's leisure activities. These asked about if the patient still participated in their leisure activities and the second question asked if the surgery had impacted their leisure activity in terms of time spent in leisure activities.

3.10 DATA COLLECTION PROCEDURE

I generated a list of all the names and hospital case file numbers of patients that underwent enucleation, evisceration, and exenteration of one or both eyes from 31st, December 2022 to 1st January 2018. The list was created by physical checks and correlation of in-patient numbers and names of patients that underwent eye removal surgery in the study period from the theatre lists, theatre registry, and eye ward registry in Mulago National Referral Hospital.

For objective 1

The list generated was used to access and retrieve the case files from the Records department in MNRH .Case files that met the inclusion criteria were picked for study objective 1 and given a code number as given in order of selection of the files starting with 001 then 002, 003…….

Names of patients were only used to retrieve the case files and the list on which they were listed was kept only by the P. I to ensure confidentiality.

After a code number was generated for the data extraction tool, the PI then went ahead to read through the case file and deduce the information needed to fill in the data extraction tool. All sections in the data extraction tool were responded to. The information was filled into an electronic data extraction tool in Epidata version 4.0.

For objective 2

The case files used to study objectives 1 retained the earlier assigned codes and were sorted to separate those belonging to patients that are 18 years old and above at the time of the study. Case files of patients that were reported dead by means of a death declaration form attached to the file were excluded. The contacts available in the case files were used to reach out to patients by means of phone calls. The P.I. and 2 research assistants made calls to the patients and gave them information about the study.

After consent was received, the patient was asked to come to the eye department in MNRH. For the patients who declined a physical session, the questionnaire was filled in over the phone.

The scores in the different dimensions of the SF-36 tool were generated from the SF-36 tool guide and the PSS score from the PSS tool guide.

3.11 DATA MANAGEMENT AND ANALYSIS

For Objective 1

Data collected was entered by the PI into electronic Epi Data Version 4.6 and checked for completeness and accuracy. Thereafter, data was exported to STATA version 14.0 for analysis.

Univariately, data was summarized using descriptive texts and summarizing tables or charts. Categorical variables were summarized into frequencies and percentages whereas continuous variables were summarized using the standard deviation or median (25th and 75th quartiles).

For Objective 2

The data was interpreted as per the respective assessment tools provided for the different tools used that is, the SF-36 interpretation tool and PSS interpretation tools to formulate quantitative data.

The quantitative data was entered by the PI into electronic Epi Data Version 4.6 and was checked for completeness and accuracy. Thereafter, data was exported to STATA version 14.0 for analysis.

Data cleaning was done by checking for missing values, outliers, and any data entry errors.

We conducted a sub-group analysis and examined the patterns and quality of life (QoL) among patients who had undergone eye removal surgeries in MNRH. By stratifying the data based on specific characteristics, such as age, gender, or underlying eye condition, we explored potential variations and factors that influenced QOL outcomes within this patient population. This sub-group analysis provided a deeper understanding of the nuances and heterogeneity within the sample and enhanced the interpretation of the overall findings.

Data was extracted using Epidata® version 4.6 and it was then exported to Stata 14.2 for analysis. Continuous variables were summarized as means and standard deviations while categorical variables were summarized as frequencies and percentages. The outcome variable of the type of surgery done was also summarized into frequencies and percentages.

The perceived stress score (PSS-10) was calculated by scoring the responses to the 10-item questionnaire. The responses never, almost, sometimes, fairly often, and very often were scored 0,1,2,3 and 4 respectively as per the Likert scale. The PSS score was then obtained by summing across all items. The higher the PSS score the more stress a patient had.

The SF-36 survey for quality of care was scored according to RAND health care guidelines(RAND, 2023). All items were scored so that a high score defines a more favorable health state, each score ranging from 0 to 100. The items were then averaged and categorized into 8 aspects of quality of life. These were: **PF** for Physical Functioning, **RP** for Role limitations due

to the Physical problem, **BP** for Bodily Pain, **GH** for General Health, **VT** for Vitality, **SF** for social functioning, **RE** for Role limitations due to Emotional problems, **MH** for Mental Health

In bivariate analysis, the type of surgery was compared across other variables using chi-squared. The means of PSS and quality of life scores were compared across categories of different variables by using ANOVA.

3.12 QUALITY ASSURANCE AND CONTROL

For Objective 1

The standard data extraction tool was pretested on 15 case files to find out whether the data extraction tool collects all the necessary information with efficiency and effectiveness. The screening standard data extraction tool was reviewed by an independent ophthalmologist not part of the study that ensured reliability.

The study tools were kept under lock and key and only accessible to the P. I ensured that there was no breach of confidentiality.

To minimize errors during the process of data collection,

1. All case files were reviewed by the primary investigator.
2. All final diagnoses used as the indication to perform eye removal surgery were confirmed and filled in by the PI.
3. The data extraction tool was filled in and checked for completeness after a case file review by the PI.
4. The code number is what was used as a reference to the information attained from the case file and this ensured patient confidentiality and avoided the use of the patients' names.
5. Crosschecks of some data extraction tools were done by the supervisors randomly to ensure the appropriate collection of information.

For Objective 2

The tools used for the assessment of the quality of life are already standardized globally and acknowledged so there was no need to pretest them. The PI adequately trained and supervised the

2 research assistants for 2 days to ensure the correct use of the data collection tools and adherence to the ethical principles.

The questionnaires administered by the research assistants were crosschecked by the P.I before confirmation of complete administration of the questionnaire.

The questionnaires that were filled were also randomly checked by the supervisor to ensure proper administration of the questionnaires.

The SF-36 has been shown in numerous studies to have a high internal consistency when Cronbach's alpha coefficient ranges from 0.60 to 0.96 across all domains in a sample of patients as shown by Meng et al(Q & et, 2019). In our study, Cronbach's alpha for the SF-36 tools dimensions ranged from 0.619-0.926, and this showed a high internal consistency, except for the social functioning dimension which was 0.342. The PSS-10 tool has also shown good psychometric properties with Cronbach's alpha coefficient of 0.65 to 0.91 and for this study, ours was 0.677. (Liu D, 2020).

3.13 ETHICAL CONSIDERATIONS

Permission to do the research was sought from the Makerere University Department of Ophthalmology.

Ethical approval was sought from the School of Medicine Research and Ethics Committee (SOMREC) of Makerere University.

Administrative clearance was sought from MNRH Research and Ethics Committee to access the case files from the Records Department of MNRH and to administer the questionnaires to patients of the hospital.

Permission for waiver of consent from participants whose case files were used in the study of objective 1 was sought from the SOMREC Makerere School of Medicine as the previous proof of consent to medical and surgical intervention had been stipulated and this was used as a guide that patient was compliant to confidential use of their information.

All case files were only included in the study with proof of prior consent or assent (where applicable) given by either the patient or parent before initiation of treatment. Participants'

anonymity was guaranteed on the questionnaires to ensure confidentiality by using alternative identification like study numbers.

For objective 2, participants were enrolled after informed consent and were allowed to withdraw from the study as and when they wished to.

The participants for objective 2 were interviewed from Mulago National Referral Hospital, however, if the participants couldn't come to the hospital, the questionnaires were administered over the phone after they had given their verbal consent.

The study tools were kept under lock and key and only accessible to the research team to ensure that there was no breach of confidentiality.

3.15 DISSEMINATION OF RESULTS

Study results will be disseminated to the Department of Ophthalmology at Makerere University, Sir Albert Cook Medical Library in Mulago, the School of Graduate Studies at Makerere University, the Ministry of Health, Uganda, and international peer review Medical Journals. I also intend to present results at conferences at national and international levels whenever the opportunity arises.

CHAPTER 4: RESULTS

4.1 Introduction

This study aimed to determine the patterns of eye removal surgeries and the quality of life of affected patients at Mulago National Referral Hospital. The records from the theatre, in-patient, and outpatient registers showed that **305** eye removal surgeries had been done over the study period time. However, **257 case files** were used to study objective 1(Figure 2) and **88 patients were** recruited to study QOL (Figure 2).

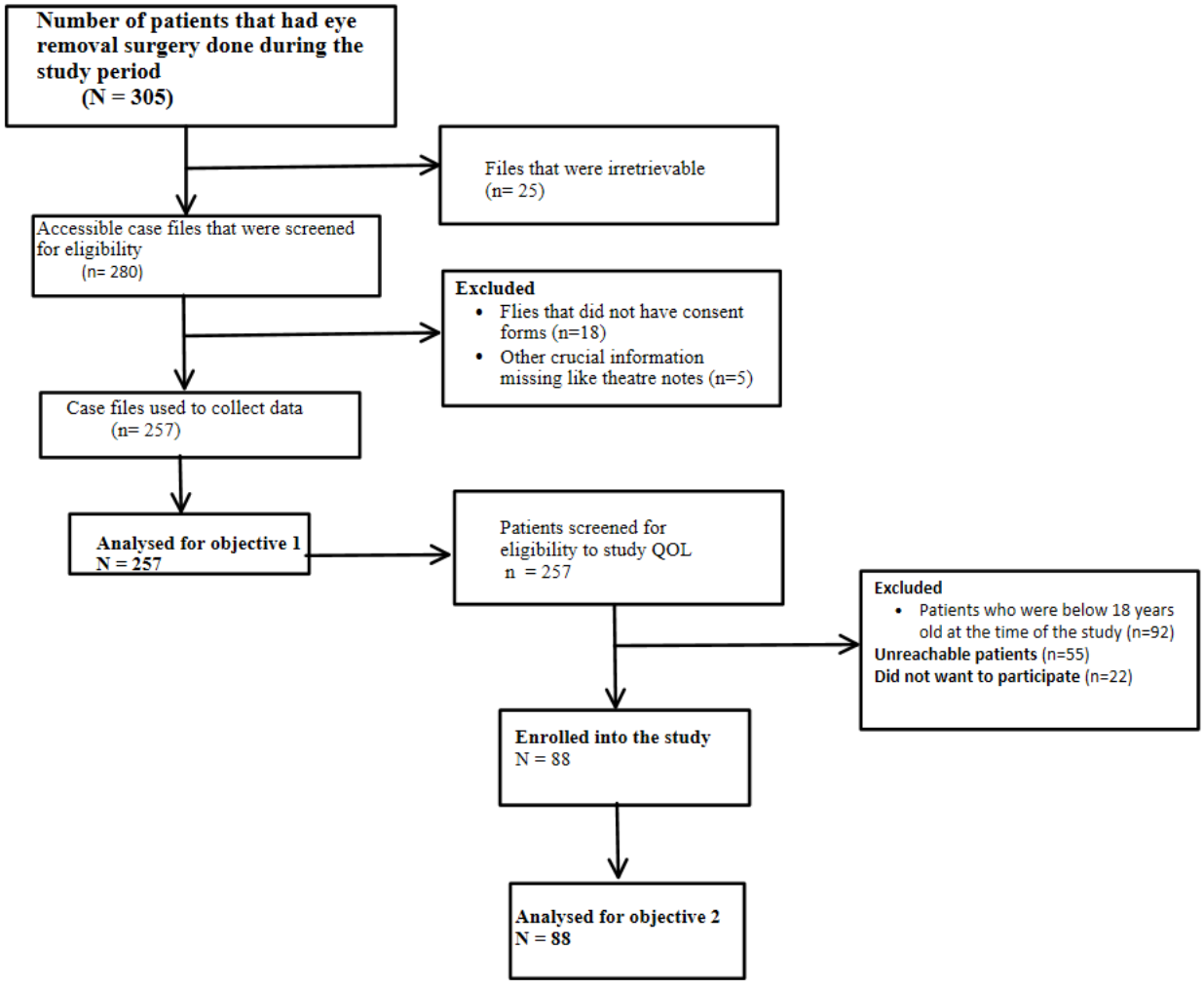


***Figure 2*: The Study Flow Diagra**

4.2 Patterns of eye removal surgeries in Mulago National Referral Hospital

Baseline characteristics of affected patients

The majority of the patients were less than 20 years of age (37.4%, n= 96), with the mean age of patients being 30.2 years (SD=22.5).The youngest patient was 4 months old and the oldest was 90 years old. The most affected sex was male (57.2%, n=147) at a M: F ratio of 1.3:1 as shown in **Table 1.**

Table 1: Sociodemographic characteristics of patients that had eye removal surgery done at Mulago National Referral Hospital

Variable	Measure	Frequency N=257	Percentage
Age of patient, mean(SD)	30.2(22.5)		
Age groups			
<20 years		96	37.4
20-39 years		80	31.1
40-59years		54	21.0
≥ 60 years		27	10.5
Sex			
Male		147	57.2
Female		110	42.8
Tribe			
Bantu		196	76.3
Nilotic		26	10.1
Hamites		20	7.8
Unknown		15	5.8
Nationality			
Ugandan		226	87.9
Non- Ugandan		31	12.1

The highest percentage of the patients came from urban areas (72.8%, n=187). Children (33.1%, n=85), followed by unemployed (17.1%, n=44) and motorists (12.0%, n=31), were the groups of occupation most affected as shown in **Table 2.**

Table 2: Sociodemographic characteristics of patients that had eye removal surgery done at Mulago National Referral Hospital

Variable	Measure	Frequency N=257	Percentage
Residence			
Urban		187	72.8
Rural		70	27.2
Occupation of patient			
Child		85	33.1
School going		43	16.7
Non-school going		42	16.3
Unemployed		44	17.1
Vendors		36	14.0
Motorist		31	12.0
Agricultural workers		28	10.9
Industrial/construction workers		17	6.7
Office worker		16	6.2
Level of education			
None		79	30.7
Primary		84	32.7
Secondary		73	28.4
Tertiary		21	8.2
Referral status			
Self-referral		183	71.2
Hospital referral		71	28.8

Clinical characteristics of affected patients

Most of the patients reported to the hospital within 1 month to 3 months (**Table 3**) of initial symptoms. Some patients reported a history of ocular trauma (28%, n=72), with most injuries taking place on the road (**Table 3**). **Table 3** also shows the mechanisms of injury with penetrating injury (67.6%, n=48) being more common than blunt force trauma (32.4%, n=23).

Table 3: Duration of symptoms and history of ocular trauma

Variable	**Frequency**	**Percentage**
Duration of symptoms	**n= 257**	
< 2 weeks	**59**	**23**
2weeks – 1 month	**54**	**21**
1 month – 3months	**82**	**32**
> 3 months	**62**	**24**
History of trauma to the eye	**n=257**	
Yes	72	28
No	185	72
Location of the patient at the time of injury	**n=72**	
Work	23	31.9
Home	13	18.1
School	3	4.2
Road	33	45.8
Mechanism of injury	**n=71**	
Blunt force injury	23	32.4
Penetrating injury	48	67.6

Chronic corneal ulcer was the most common ocular disease reported in the history of the patients followed by glaucoma and then uveitis in **Table 4** below.

Some of the patients were also found to have a history of HIV (21%, n=54) and diabetes mellitus Type-2 (6.2%, n=16) (**Table 4**). As shown in Table 5, 14% (n=36) of the patients reported to be HIV positive were on HAART treatment.

Table 4:Patients with history of HIV, Type 2 DM treatment, and chronic ocular disease

Variable	Frequency	Percentage %
HIV negative	**203(n=257)**	**79**
HIV positive	**54(n=257)**	**21**
On HAART	36	14
<2 weeks	4	1.5
>2weeks	32	12.5
HAART naïve	17	6.6
Unknown	1	0.4
DM	**16(n=257)**	**6.2**
On medication	6	2.3
Defaults on medication	6	2.3
Not on medication	4	1.6
Patients with history of ocular disease	**n=61**	
Chronic corneal ulcer	27	44.3
Glaucoma	12	19.7
Uveitis	6	9.8
Others[1]	16	26.2

HAART – Human Active Anti-Retroviral Therapy, **1 Others include chronic allergic and bacterial conjunctivitis**

Treatment-related characteristics of patients that had eye removal surgeries.

The results, as in **Table 5**, showed that 24.9% (n=64) of the patients that had eye removal surgery had self-medicated with the majority using topical anti-biotic eye drops (14%, n=36) and topical corticosteroids (7.8%, n=20). **Table 5** also shows patients who had a history of use of prescribed medication (34.2%, n=88) with the most used drug being a topical antibiotic (22.6%, n=58). 30.7% (n=79) of the patients had used TEM and the highest percentage of those that used TEM was for longer than 2 weeks (23.3%, n=60) (**Table 5**).

Table 5:Treatment-related characteristics of patients that had eye removal surgeries

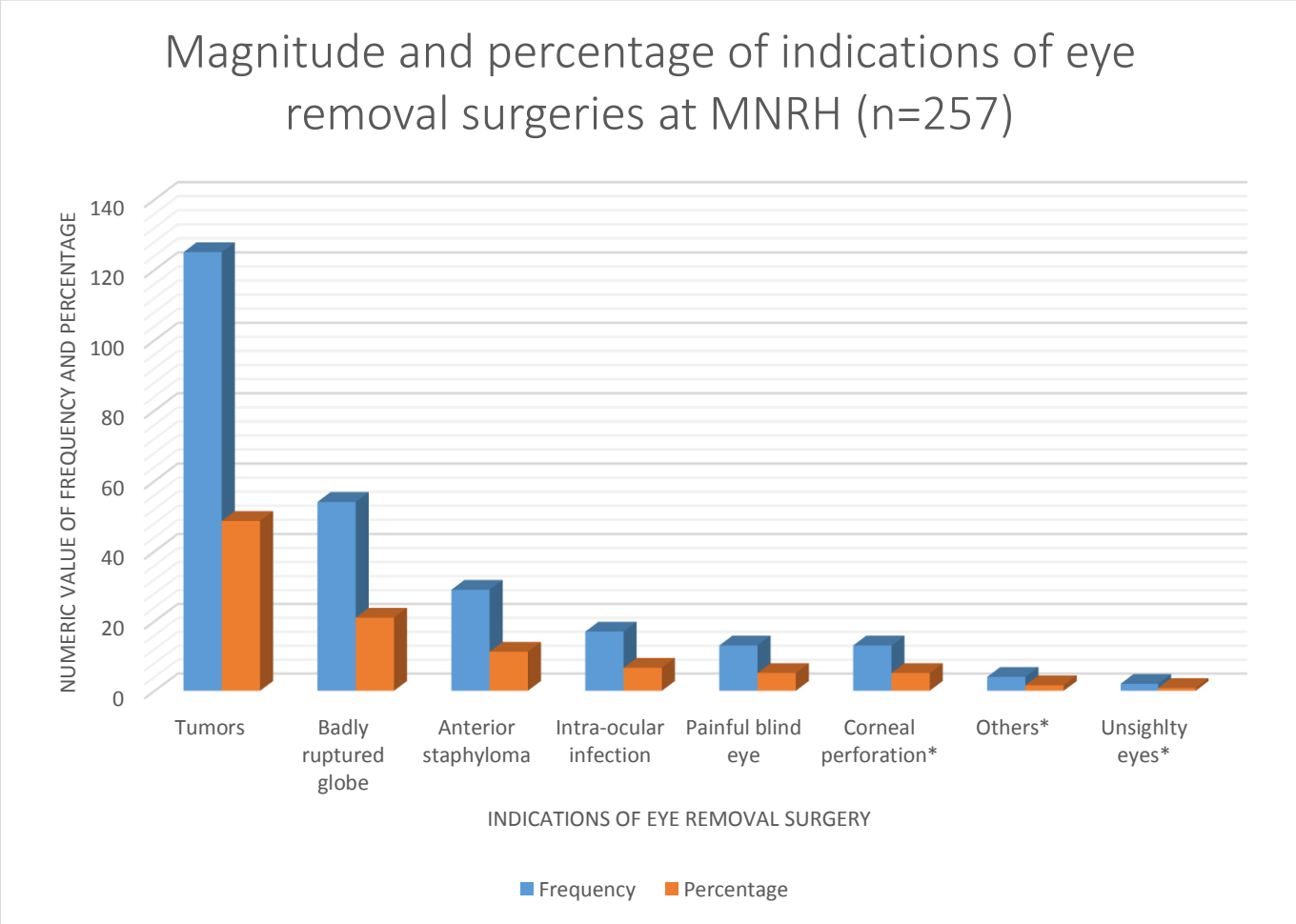
Variable	Frequency(n=257)	Percentage
Use of TEM*	79	30.7
<2 weeks	19	7.4
>2weeks	60	23.3
Prescribed medication	88	34.2
Antibiotic ED*****	58	22.6
Anti-glaucoma ED	17	6.6
Analgesic ED	12	4.7
Topical CCS*****	1	0.4
Self-treatment	64	24.9
Antibiotic ED	36	14
Topical CCS	20	7.8
Analgesic ED	5	1.9
Anti-glaucoma ED	3	1.2

***TEM – Traditional eye medicine, CCS – corticosteroids, ED – eye drops**

Indications of eye removal surgeries

The most common indications for eye removal surgery were tumors (48.6%, n=125) followed by badly ruptured globe (21%, n=54), with other indications listed in **Figure 3**.

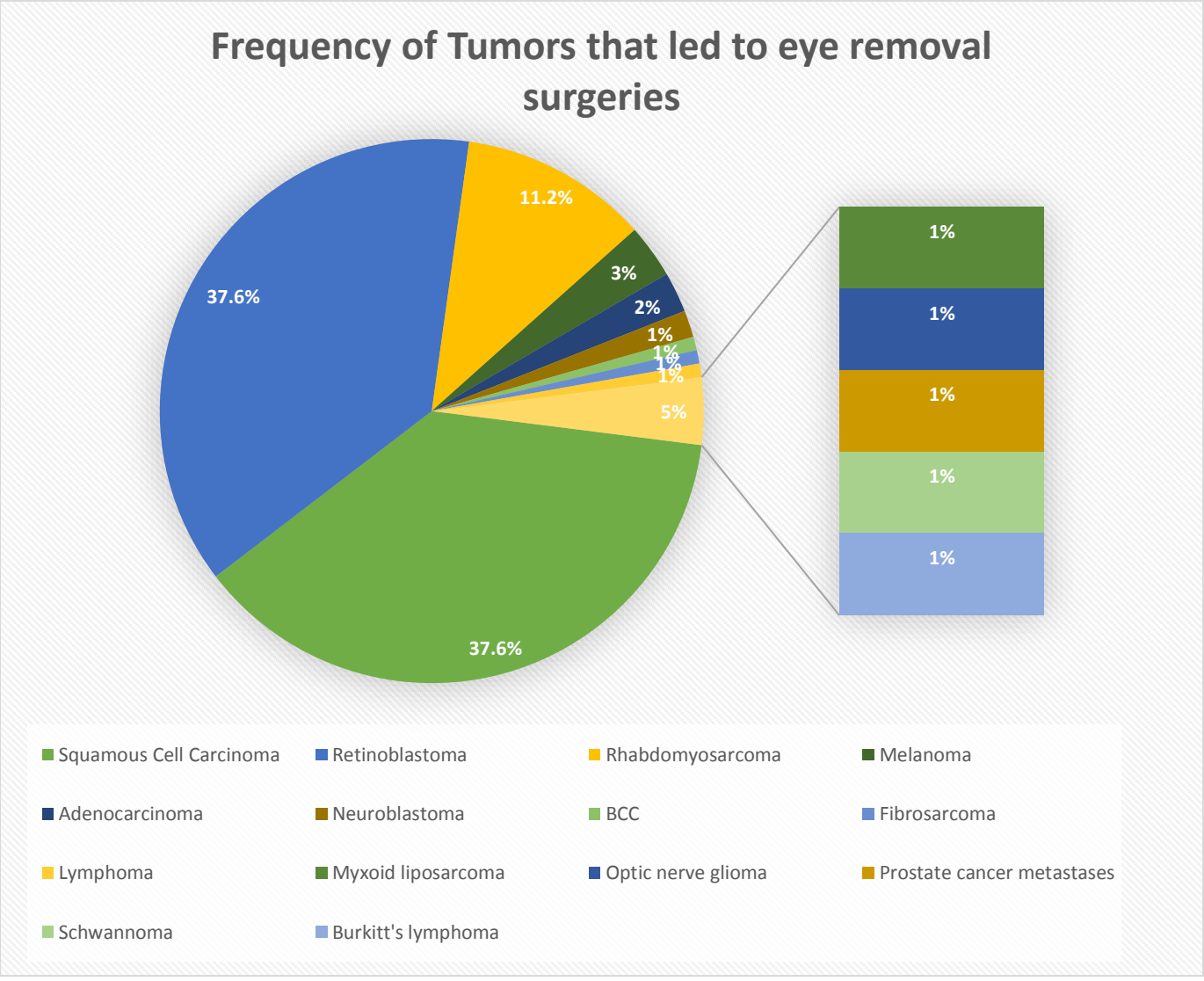
Figure 3: Indications of eye removal surgeries at Mulago National Referral Hospital



***Corneal perforation that is not directly as a result of trauma , Others include 1 corneal abscess, 1 intraocular foreign body, 1 severe stem cell deficiency, 1 attempt to prevent sympathetic ophthalmia, Unsightly eyes included 1 congenital microphthalmia, and 1 phthisis bulbi**

Squamous Cell Carcinoma and Retinoblastoma were the most common tumors that led to eye removal surgeries in **Figure 4**. Other tumors like Rhabdomyosarcoma, melanoma, adenocarcinoma, and neuroblastoma were also responsible for eye removal surgeries (**Figure 4**).

Figure 4:Tumor indications of eye removal surgeries at Mulago National Referral Hospital



Types of Eye Removal Surgery done

257 eye removal surgeries were done for 251 patients since 3 patients had both eyes removed. All the patients that had both eyes removed were below 18 years of age and 2 of them had both eyes removed due to retinoblastoma while the other 1 was due to bilateral anterior staphyloma with impending rupture secondary to bilateral Mooren's ulcer. The most common type of eye removal

surgery done was evisceration followed by enucleation and then exenteration as shown in **Table** 6.

Table 6:Types of eye removal surgeries done

Type of eye removal surgery	Frequency(n=257)	Percentage
Evisceration	125	48.6
Enucleation*	90	35
Basic Enucleation	20	7.8
Modified enucleation	36	14.0
Extended enucleation	34	13.2
Exenteration	42	16.4
Lid sparing exenteration	26	10.1
Non-lid sparing exenteration	16	6.3

***The type of surgery done was derived from what was labeled as a procedure done in the theatre notes rather than being derived from the actual steps of the procedures done due to multiple variations, especially with enucleation.**

An implant was used in 46.7 % (n=120) of the patients, 50.1% (n=130) did not get an implant and the rest were unknown (**Figure 5**).

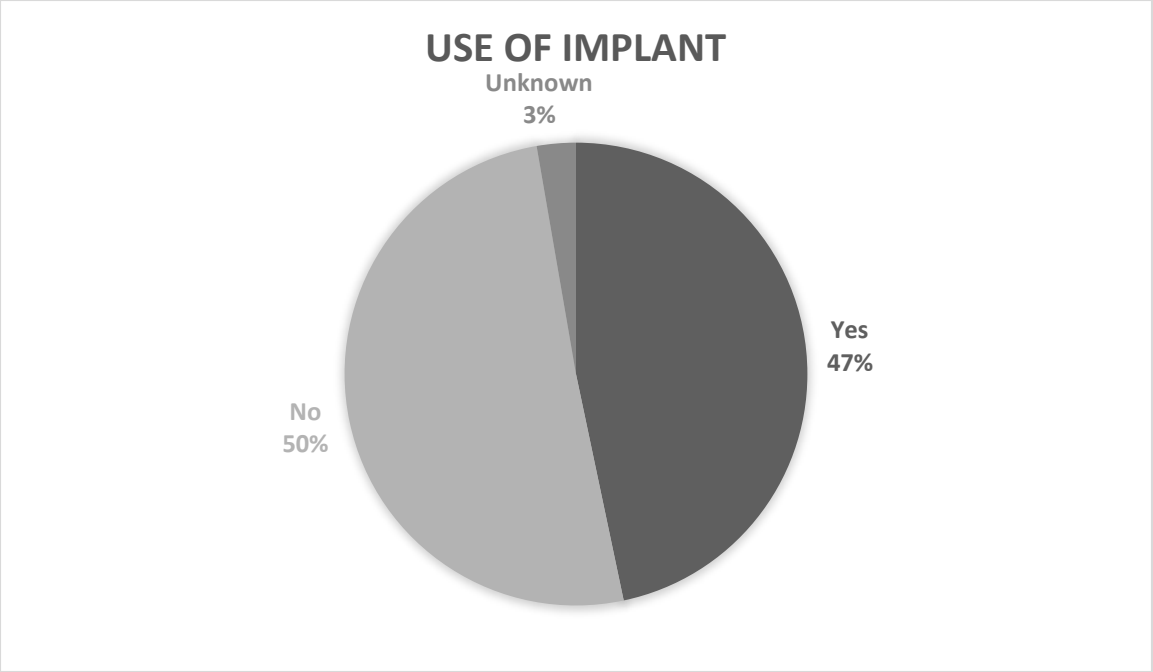


Figure 5: Number of patients for whom an implant was used during surgery

Out of a total of 257 patients, 98 (38.1%) received a prosthesis. Among those 98 patients, 53.1% (n=52) had enucleation surgery, while the remaining patients underwent evisceration surgery. None of the patients who had exenteration surgery received a prosthesis as shown in **Table 7** below.

Table 7:Prosthesis use in eye removal surgery

Surgery done	Frequency (N=98)	Percentage
Evisceration	52	53.1
Enucleation	46	46.9
Exenteration	0	0

Socio-demographic characteristics of sex, age, and level of education had significant p-values (<0.05) regarding the type of surgery done in the different characteristics. More males had evisceration surgery while more females had enucleation surgery as shown in **Table 8**. The highest number of enucleations were done in the age group below 20 years and most eviscerations were

done in the age group of 40-59 years (**Table 8**). The area of residence by the type of surgery done however was not statistically significant.

Table 8:Socio-demographic characteristics of patients by types of eye removal surgeries done.

Socio-demographic characteristic	Evisceration n(%)	Enucleation n(%)	Exenteration n(%)	Chi-square p-value
Age				**<0.001**
<20 years	28(29.2)	56(58.3)	12(12.5)	
20-39 years	52(65)	16(20)	12(15)	
40-59 years	30(55.6)	13(24.1)	11(23.4)	
≥ 60 years	14(51.9)	6(22.2)	7(25.9)	
Residence				0.629
Rural	33(47.1)	27(38.6)	10(14.3)	
Urban	91(48.7)	64(34.2)	32(17.1)	
Level of Education				**<0.001**
None	23(29.1)	47(59.5)	9(11.4)	
Primary	38(45.2)	26(31)	20(23.8)	
Secondary	45(61.6)	15(20.5)	13(17.8)	
Tertiary	18(85.7)	3(14.3)	0(0)	

The clinical characteristics of patients showed that the number of patients that had enucleation and exenteration significantly increased with the longer duration of symptoms ($p<0.05$) and the number of patients that had evisceration significantly lessened ($p<0.001$) with longer duration of symptoms (**Table 9**). The positive HIV status ($p=0.142$) and positive DM status($p=0.918$) were statistically insignificant when it came to the type of eye removal surgery done.

Table 9:Clinical characteristics of patients by types of eye removal surgeries

Clinical characteristic	Evisceration Freq (%)	Enucleation Freq (%)	Exenteration Freq (%)	Chi-square p-value
Duration of presenting complaint				**<0.001**
<2 weeks	53(88.3)	5(8.3)	2(3.4)	
2weeks – 1month	25(47.2)	19(35.8)	9(17)	
1month-3months	25(30.9)	43(53.1)	13(16)	
Above 3months	21(33.3)	24(38.1)	18(28.6)	
History of trauma to the eye	63(87.5)	7(9.7)	2(2.8)	**<0.001**
HIV status				0.142
Positive	19(35.1)	21(38.9)	14(25.9)	
Negative	100(49.5)	73(36.1)	29(14.4)	
Unknown	1(100)	0(0)	0(0)	
Type 2 DM				0.918
Positive	8(50)	5(31.3)	3(18.7)	
Negative	113(47.3)	86(36.1)	39(16.4)	

The patients that had evisceration surgery have a history of shorter periods of TEM use than those who had exenteration and enucleation as shown in **Table 10** with a significant p-value of 0.017.

Table 10:Treatment-related characteristics of patients by types of eye removal surgeries

Treatment-related characteristic	Evisceration Freq (%)	Enucleation Freq (%)	Exenteration Freq (%)	Chi-square p-value
Period of use of TEM				**0.017**
<2 weeks	10(52.6)	8(42.1)	1(5.3)	
2weeks – 1month	15(41.7)	14(38.9)	7(19.4)	
1month-3months	16(76.2)	2(9.5)	3(14.3)	
Above 3months	0(0)	1(33.3)	2(66.7)	

The patient characteristics like age, sex, occupation, and the frequency of indications of eye removal surgeries at MNRH also had statistically significant findings as shown in **Table 11**. The badly ruptured globe indication was more common between the age group of 20-40 years old ($p<0.001$) and tumors were more common in the age of less than 20 years ($p<0.001$) (**Table 11**). Motorists had the highest frequency (74.2%, n=23) of badly ruptured globes as an indication of eye removal surgery ($p<0.001$).

Table 11:Characteristics of patients by indications of eye removal surgeries in Mulago National Referral Hospital

Variable	Badly ruptured globe Freq (%)	Painful Blind eye Freq (%)	Tumors Freq (%)	Intraocular infection Freq (%)	Anterior staphyloma Freq (%)	Corneal* perforation Freq (%)	P-value
Age							**<0.001**
<20 years	8(12.3)	2(2.1)	65(68.4)	9(9.5)	7(7.4)	4(4.2)	
20 to 39	30(38.5)	4(5.1)	25(32.1)	5(6.4)	9(11.5)	5(6.4)	
40 to 59	13(24.5)	4(7.5)	22(41.5)	1(1.9)	10(18.9)	3(5.7)	
60 plus	3(11.1)	3(11.1)	13(48.1)	2(7.4)	3(11.1)	1(3.7)	
Sex							**0.009**
Male	40(27.2)	8(5.4)	57(38.8)	12(8.2)	18(12.2)	9(6.1)	
Female	14(12.7)	5(4.5)	68(61.8)	5(4.5)	11(10)	4(3.6)	
Occupation of patient							**<0.001**
Motorist	23(74.2)	2(6.5)	1(3.2)	1(3.2)	2(6.5)	2(6.5)	
Industrial / construction workers	5(29.4)	1(5.9)	7(41.2)	0(0)	1(5.9)	3(17.6)	
Agricultural workers	3(10.7)	2(7.1)	12(42.9)	4(14.3)	5(17.9)	2(7.1)	
Office work	5(31.3)	2(12.5)	4(25)	0(0)	4(25)	0(0)	
Unemployed	6(14.6)	4(9.8)	20(46.3)	1(2.4)	5(12.2)	3(7.3)	
Non-school going children	0(0)	0(0)	38(90.5)	2(4.8)	2(4.8)	0(0)	
School-going children	4(7)	1(2.3)	24(55.8)	7(16.3)	5(11.6)	2(4.7)	
Vendors	8(22.2)	1(2.8)	19(52.8)	2(5.6)	5(13.9)	1(2.8)	
Use of TEM							**<0.001**
Yes	1(1.3)	0(0)	38(48.1)	15(19.0)	17(21.5)	8(10.1)	
No	50(28.1)	13(7.3)	89(50)	6(3.4)	12(6.7)	8(4.5)	
HIV status							**0.019**
Negative	44(21.8)	13(6.4)	90(44.6)	15(7.4)	22(10.9)	12(5.9)	
Positive	10(18.5)	0(0)	35(64.8)	1(1.9)	7(13.0)	1(1.9)	
Unknown	0(0)	0(0)	0(0)	1(100)	0(0)	0(0)	
DM							**0.005**
Positive	1(6.3)	0(0)	8(50)	5(31.3)	1(6.3)	1(6.3)	
Negative	51(21.4)	13(5.5)	117(49.2)	11(4.6)	28(11.8)	12(5)	

***This represents any corneal ulcer that is due to ocular disease like infected corneal ulcers rather than trauma, corneal perforation due to trauma is included in badly ruptured globe**

The magnitude of the types of eye removal surgeries done by the indications was as shown in **Table 12** below. Statistically significant findings showed that most eviscerations done were due to badly ruptured globe injury while enucleations and exenterations were mostly done due to tumors (**Table 12**).

Table 12:Indications of eye removal surgery by types of eye removal surgery done

Indications	**Evisceration Freq (%)**	**Enucleation Freq (%)**	**Exenteration Freq (%)**	**Chi-square p-value** **P<0.001**
Badly ruptured globe	49(90.7)	4(7.4)	1(1.9)	
Painful blind eye	12(92.3)	1(7.7)	0(0)	
Unsightly eyes	2(100)	0(0)	0(0)	
Tumors	2(1.6)	83(66.4)	40(32)	
Intra-ocular infection	16(94.1)	1(5.9)	0(0)	
Anterior staphyloma	29(100)	0(0)	0(0)	
Corneal perforation	12(92.3)	1(7.7)	0(0)	
Others	3(75)	0(0)	1(25)	

4.3 Quality of life of patients that had eye removal surgeries at Mulago National Referral Hospital

The QOL assessment with the SF-36 tool was assessed in 88 participants. The mean age of the participants was 36.5 years (SD= 14.4). The highest percentage of the patients were from the age group of 30-39 years old (**Table 13**). The group consisted mostly of males (61.4%, n=54) at a M:F ratio of 1.6:1 as shown in Table 13. Most of the participants in **Table 13** were from the urban areas (82.9%, n=73).

Table 13:Baseline characteristics of study participants

	Frequency (N=88)	Percentage %
Age (years)	**Mean 36.5 (SD=14.4)**	
< 20	12	13.64
20 - 29	19	21.59
30 - 39	25	28.41
40 - 49	15	17.05
50 - 59	12	13.64
60 and above	5	5.68
Sex		
Male	54	61.4
Female	34	38.6
Nationality		
Ugandan	81	92.0
Non-Ugandan	7	8.0
Tribe		
Bantu	74	84.1
Nilotic	9	10.2
Hamites	5	5.7
Residence		
Rural	15	17.1
Urban	73	82.9
Level of education of the patient		
None	8	9.1
Primary	31	35.2
Secondary	39	44.3
Tertiary	10	11.4

The largest percentage of the patients reported that they had stopped working because of the eye removal surgery (43.2%, n=38), and 25 %(n=32) were divorced or separated due to the loss of an eye as shown in **Table 14**.

Table 14:Socioeconomic characteristics of patients after eye removal surgery

Variable	**Frequency**	**Percentage**
Have you ever needed to change your working hours to part-time, quit a job or change your job or work tasks due to disease, disorder, illness, or injury?	**n=88**	
Yes, worked part-time	9	10.2
Yes, changed job or work tasks	17	19.3
Yes, stopped working	38	43.2
No	24	27.3
Are there leisure activities that you no longer take part in due to the loss of an eye?	**n=87**	
Yes	58	66.7
No	29	33.3
What is your marital status?	**n=88**	
Married	48	54.5
Single	18	20.5
Divorced	16	18.2
Separated	6	6.8

The lowest scores were in the role limitations due to emotional problems with a mean of 47.7(SD=45.4) and role limitations due to the physical problems 51.1(SD=41.7) (**Table 15**). Table 15 also shows the PSS score as 20.8 which signifies moderate stress.

Table 15:SF-36 dimensions and PSS scores of the patients

Variable	Mean (SD)	Cronbach alpha
SF-36 tool dimensions.		
Bodily Pain (BP)	79.2(17.3)	0.642
Physical functioning (PF)	68.8(28.2)	0.926
Role Physical (RP)	51.1(41.7)	0.851
Role Emotional (RE)	47.7(45.4)	0.889
Vitality (VT)	56.2(16.5)	0.619
Mental Health (MH)	55.4(21.6)	0.716
Social Functioning (SF)	58.8(21.8)	0.324
General Health (GH)	53.2(23.8)	0.718
PSS	20.8(6.5)	0.677

The QOL scores were also generally lower in the ages of above 50 years compared to the younger patients however the p-values were statistically insignificant as in **Table 16**. The PSS scores although statistically insignificant were highest in the 3rd and 5th decade of life (**Table 16**).

Table 16:SF-36 and PSS scores by age

	<20yrs	20-29yrs	30-39yrs	40-49yrs	50-59yrs	≥60yrs	p-value
Bodily Pain (BP)	75.4(15.8)	82.2(16.7)	80.3(14.6)	78.2(18.3)	80.8(22.4)	70(22.9)	0.7375
Physical functioning (PF)	71.3(23.6)	67.6(22.3)	76.2(26.4)	71.7(32.4)	63.8(29.9)	34(34.4)	0.0692
Role Physical (RP)	58.3(44.4)	53.9(37.5)	45(45.1)	56.7(45.8)	58.3(37.4)	20(27.4)	0.5028
Role Emotional (RE)	63.9(46)	45.6(43.3)	42.7(48.6)	51.1(48.6)	52.8(43.7)	20(29.8)	0.5649
Vitality (VT)	56.3(20.2)	55.3(19.3)	58(20.2)	58.7(26.6)	53.8(20.6)	49(33.6)	0.9559
Mental Health (MH)	58.3(23.8)	58.1(18.7)	55.7(24.3)	54.9(23.4)	49.7(18.7)	51.2(24.6)	0.9148
Social Functioning (SF)	63.5(15.5)	62.5(13.2)	58.5(19.7)	57.5(18.8)	57.3(9.9)	42.5(14.3)	0.2209
General Health (GH)	55.8(22.2)	52.9(20.6)	57.2(26.6)	54.3(29.6)	50.8(17.7)	30(9.4)	0.3356
PSS	19.4(6.5)	22.6(6.1)	19.8(7.7)	22.9(5.5)	19.8(5.4)	19(6.5)	0.4392

The SF-36 tool and PSS scores were similar with no significant variations in the findings for the male and female sex as shown in **Table 17**.

Table 17:SF-36 and PSS scores by sex

	Male Mean (SD)	**Female Mean (SD)**	**p-value**
Bodily Pain (BP)	78.9(17.9)	79.6(16.6)	0.8459
Physical functioning (PF)	69.4(27.4)	67.9(29.7)	0.8205
Role Physical (RP)	55.1(41.9)	44.9(41.2)	0.2642
Role Emotional (RE)	49.4(47)	45.1(43.3)	0.6692
Vitality (VT)	57.3(22.2)	54.4(20.7)	0.5419
Mental Health (MH)	57.9(22.4)	51.4(20.6)	0.1790
Social Functioning (SF)	58.1(18.2)	59.9(13.7)	0.6171
General Health (GH)	55.2(24.3)	50(23)	0.3229
PSS	21.9(5.5)	19.2(7.7)	0.0578

The QOL scores of the single, divorced, and separated patients were lower in all dimensions compared to the married however the p-values were insignificant ($p>0.05$) (**Table 18**). Patients who were divorced at the time of the study had especially low scores in the dimension of limitations of roles due to physical problems (28.1, SD=35.2).

Table 18:SF-36 and PSS scores by marital status

	Married Mean (SD)	Single Mean (SD)	Divorced Mean (SD)	Separated Mean (SD)	p-value
Bodily Pain (BP)	81.9(17.6)	73.2(17.8)	81.1(16.4)	70(10.7)	0.1549
Physical functioning (PF)	71.7(29.5)	71.9(30)	56.9(21.1)	68.3(25.2)	0.3127
Role Physical (RP)	57.3(40.6)	58.3(42.9)	28.1(35.2)	41.7(49.2)	**0.0770**
Role Emotional (RE)	53.5(45.5)	55.6(48.5)	29.2(40.1)	27.8(39)	0.1622
Vitality (VT)	58(21.8)	61.9(23.2)	45.9(17)	51.7(20.7)	0.1374
Mental Health (MH)	56.8(22.2)	58.9(25.4)	50.5(14.4)	46.7(25.1)	0.4980
Social Functioning (SF)	59.6(15.3)	61.1(16.5)	55.5(19.3)	54.2(20.4)	0.6680
General Health (GH)	55.2(26)	58.1(21.6)	45.9(15.1)	41.7(27.9)	0.2658
PSS	22.3(6.5)	18.8(7.2)	19.9(4.6)	17.5(6.9)	0.1094

The SF-36 tool showed that patients who had evisceration had significantly better scores than those that had enucleation and exenteration for dimensions of vitality (p=0.0002), role limitations due to physical problem (p=0.0088), mental health (p=0.0023), and general health (p=0.0109) as shown in **Table 19.**

Table 19:SF-36 and PSS scores by types of surgeries done.

	Evisceration Mean (SD)	Enucleation Mean (SD)	Exenteration Mean (SD)	p-value
Bodily Pain (BP)	81.3(17.5)	76.8(15.1)	74.6(19.9)	0.3567
Physical functioning (PF)	71.7(28.1)	71.6(28)	52.3(24.8)	0.0715
Role Physical (RP)	61.8(39.7)	38.6(42.8)	28.8(35.1)	**0.0088**
Role Emotional (RE)	55.3(45.3)	42.4(46.2)	25.638.9)	0.0868
Vitality (VT)	60.9(20.8)	57.5(21.1)	34.6(11.1)	**0.0002**
Mental Health (MH)	61.3(20.7)	50.2(21.7)	40(17.9)	**0.0023**
Social Functioning (SF)	58(15.9)	60.8(20.2)	58.7(12.9)	0.8064
General Health (GH)	58.7(25)	48.9(19.5)	38.1(18.2)	**0.0109**
PSS	21.8(6.4)	19.3(6.3)	19.5(7.1)	0.2195

The SF-36 dimensions of role limitations due to physical problems were low for people who had indications for surgery as tumors, intra-ocular infection, and painful blind eye as shown in **Table 20** with a significant p-value of 0.0340. Patients who had tumors as the indication for their eye removal surgery also scored significantly lowest in the dimensions of vitality (44.4), mental health (42.4), and general health (41.7) (**Table 20**). Patients that had an indication of painful blind eye had the worst PSS tool score (p=0.9058) as shown in Table 20.

Table 20:SF-36 and PSS scores by indications of eye removal surgery

	Traumatic eye injury Mean(SD)	Painful Blind eye Mean(SD)	Unsightly Eyes Mean(SD)	Tumors Mean(SD)	Intraocular infection Mean(SD)	Anterior staphyloma Mean(SD)	Corneal perforation Mean(SD)	P-value
Bodily Pain(BP)	82.5(13.4)	80.7(13.8)	100	77.2(18.0)	72.8(23.2)	80.3(22.5)	72.9(20.5)	0.5757
Physical functioning(PF)	73.5(26.4)	57.9(26.6)	100	64.4(29.1)	67.5(33.7)	76.7(25.2)	62.5(33.6)	0.5836
Role Physical(RP)	57.5(41.6)	46.4(33.6)	100	32.4(37.2)	43.8(49.6)	69.4(34.9)	83.3(40.8)	**0.0340**
Role Emotional(RE)	54.4(47.5)	57.1(41.8)	100	29.6(41.7)	50(43.6)	63(42.3)	50(17.8)	0.2691
Vitality(VT)	64.5(20.6)	67.9(14.1)	90	44.4(21.2)	56.9(20.5)	50.6(15.9)	55.8(20.6)	**0.0047**
Mental Health(MH)	63.5(20.4)	65.7(19.2)	88	42.4(119)	63(28.6)	48.9(9.3)	55.3(20.9)	**0.0020**
Social Functioning(SF)	56.3(14.6)	57.1(12.2)	62.5	62.5(18.7)	59.4(25.7)	54.2(8.8)	62.5(17.7)	0.7949
General Health(GH)	61.5(22.1)	54.3(15.4)	100	41.7(19.2)	52.5(34.7)	47.8(11.5)	63.3(34.3)	**0.0129**
PSS	21(7)	23(7.6)	21	19.7(6.8)	20.8(5.9)	20.1(6)	20.7(4)	0.9058

The SF-36 scores were significantly lower in patients who had not received a prosthesis compared to those who had a prosthesis (**Table 21**). The most significant difference was in the dimensions of role limitations due to physical problem (**p<0.001**), role limitations due to emotional problems (**p=0.0002**), general health (**p=0.0021**), vitality (**p=0.0075**) and physical functioning (**p=0.0041**) (**Table 21**). The PSS scores of those with/without prosthesis were similar as shown below.

Table 21: SF-36 dimension scores and PSS scores by presence of prosthesis

	Prosthesis Yes Mean (SD)	**Prosthesis No Mean (SD)**	**p-value**
Bodily Pain (BP)	80.8(18.3)	80(16.7)	0.4496
Physical functioning (PF)	78.6(23.8)	61.4(29.2)	**0.0041**
Role Physical (RP)	72.4(34.3)	35(39.8)	**<0.0001**
Role Emotional (RE)	67.5(43.5)	32.7(41.2)	**0.0002**
Vitality (VT)	63.2(20.3)	50.9(21.2)	**0.0075**
Mental Health (MH)	62.3(21.7)	50.1(20.6)	**0.0084**
Social Functioning (SF)	57.6(14.1)	59.8(18.3)	0.5425
General Health (GH)	62(23.5)	46.5(22)	**0.0021**
PSS	21.8(5.7)	20.1(7)	0.2290

CHAPTER 5: DISCUSSION

5.1 Patterns of eye removal surgeries at MNRH

This study was carried out in Mulago National Referral Hospital and found that 257 patients had had eye removal surgeries done over five years from 1st January 2018 to 31st December 2022.

The mean age of 30.2 years (SD = 22.5) which is slightly lower than the mean range of 36.4 to 37 years found in other studies in African countries like Ghana, Nigeria, and Ethiopia. (Gyasi et al., 2009). The most affected age group was that of below 20 years (37.4%, n=96) which concurred with studies done previously in Uganda, Kenya, Nigeria, and China. (Adima, 1993; Cheng et al., 2008; Etebu & Adio, 2013; Said, 2014). The high magnitude of the loss of an eye below 20 years is unfortunate due to the cumulative "blind years" ahead of these children. The QOL of these children may also be affected due to poor self-image secondary to facial asymmetry and the social outcast effect that could occur if the prosthesis is poorly fitted or not fitted at all as suggested by Musa et al(Musa et al., 2016).

More males were affected than females (M: F ratio of 1.3:1) which is similar to previous studies done in Uganda, Ethiopia, Nigeria, and Israel. This is attributed to the trauma-prone behavior of the males as they are more likely to get involved in activities like fights, road traffic accidents, and poor adherence to protection from occupational dangers. (Adeoye & Onakpoya, 2007; Batten, 1971; Davanger, 1970; Moshfeghi et al., 2000). However, in Harare, Zimbabwe, Mukona et al found that females had more eye removals than males and they attributed their findings to the increased incidence of conjunctival SCC in HIV-positive females. (Mukona, 2019).

The highest percentage of the patients resided in urban (72.8%, n=187) areas and this is thought to be due to the tendency of patients in these areas to self-medicate with easily accessible unprescribed 'over counter drugs' which leads to the progression of illness as well as late presentation. A study done in a similar setting in a major hospital in Cameroon also had similar findings which he attributed to increased self-medication as well as persistent TEM use by patients in the urban areas(Eballé et al., 2011). It should also be noted that MNRH is in the central urban area of the country and therefore mostly serves the population from these areas thus patients from further rural areas may have present to more peripheral hospitals.

Children (33.1%, n=85) were found to have the most eye removal surgeries and similar to previous studies done in Niger and Nigeria, West Africa. (Eze et al., 2007; Musa et al., 2016). This is thought to be due to the increased incidence of childhood malignancies like retinoblastoma. In addition to the latter statement, increased activity of children especially in risky behaviours such as playing with dangerous objects or risky sports activities also makes children more prone to injury(Al-Dahmash et al., 2017; Bekibele et al., 2009; Said, 2014). These findings differ slightly from Adima et al's study in 1993 at MNRH, which found that peasants were most affected by eye removal surgeries and he attributed this to poorly treated corneal injuries sustained during farming activities (Adima, 1993). The highest percentage of motorists (74.2%, n=23) who underwent eye removal surgery due to badly ruptured globe were probably secondary to poor road usage and lack of protective gear like helmets which correlated with findings at a tertiary hospital in Northern Nigeria(Fomete et al., 2021).

Most of the patients (32%,n=82) reported to the hospital late, between 1 to 3 months of the duration of symptoms, similar to studies done previously in Uganda and South-Eastern Nigeria(Davanger, 1970; Eze et al., 2007). The late presentation is attributed not only to the initial self-medication but also to incidences of patients that were domiciled in remote areas and encountered transportation and referral problems worsened by financial constraints which was also shown in similar studies in Cameroon, Ethiopia, and Nigeria.(Eballé et al., 2011; Eze et al., 2007; Haile & Alemayehu, 1995).

Most of the traumatic injuries were sustained on the road (45.8%,n=33) and this concurs with findings by Vemuganti et al in India which is probably attributed to poor road usage, especially by motorists as well as lack of appropriate protective gear(Vemuganti et al., 2001).

Of the 257 patients, 21 %(n=54) were found to be HIV positive and the highest percentage (66.7%, n=36) was on HAART with 59.3% (n=32) patients having a history of being on HAART for longer than 2 weeks. Most of the HIV-positive patients (64.8%, n=35) had eye removal due to tumors with a statistically significant p-value of 0.019. These findings could be due to the 95% increased risk of developing ocular SCC when one is HIV positive and therefore increased risk of eye removal in HIV-positive patients as described in studies with similar findings that were done in Zimbabwe, Uganda, and Botswana. (Ateenyi-Agaba, 1995; Jackson et al., 2014; Mukona, 2019).

It was also noted that patients who were DM-positive had statistically significant eye removal surgeries due to tumors (50%, n=8) and intra-ocular infections (31.3%, n=5). DM patients are prone to the progression of ocular infections due to a more insidious disease progression and poor immunological response thus leading to eye removal.(Kyari et al., 2014; Sun et al., 2022).

Other ocular co-morbidities like chronic corneal ulcer (44.3%, n=27), glaucoma (19.7%, n=12), and uveitis (9.8%, n=6) were also found to be present in these patients. Mooren's ulcer was a significant contributor (40.7%, n=11) to the chronic corneal ulcer group of co-morbidities with 1 of the patients losing both their eyes. Mooren's ulcer is a chronic pain, peripheral corneal ulcer disease that is of unknown cause with no established effective treatment which increases the risk of loss of vision and complications like anterior staphyloma (Alhassan et al., 2014). A study done in Ruharo Eye Hospital in Southwestern Uganda showed that almost 2% of patients with Mooren's ulcer end up with evisceration and 17.3% into corneal perforation with no clinical trial basis for the treatment decisions of the disease which make it even harder to treat thus increased risk of poor outcomes(Kavuma & Arunga, 2016). Several other studies have also reported Mooren's ulcer as an emerging increased contributor to eye removal surgery in China and Nigeria(Fasina et al., 2013; Olatunji et al., 2011; Saati et al., 2007).

The contribution of glaucoma to cases of eye removal surgery had gone down to 0.86% in Adima's study in 1993 at MNRH from 5.8% in Davanger's study in 1968. Currently, the results showed that there was an increase in the history of patients that had glaucoma (4.7%, n=12) and this was similar to a study done by Setlur that showed an increase in the history of glaucoma probably due to post-trauma sequelae(Setlur et al., 2010). The increased incidence of glaucoma-related eye removal surgery may therefore also be due to the increased incidences of trauma-induced glaucoma in MNRH.

Self-medication was found in 24.9 %(n=64) of patients with the majority using steroid eyedrops (7.8%, n=20), and 30.7%(n=79) of the patients also used TEM. Several studies in Cameroon and Nigeria, West Africa showed similar findings however, the percentages of people who self-medicated (50-70%) and used TEM (60-80%) were much higher(Kagmeni et al., 2014; Nwosu, 2005). The use of TEM or unprescribed drug use before their presentation at the clinic is thought to be due to sociocultural beliefs, poverty, and difficulty accessing eye care services. Patients who use TEM for a longer period usually also delay presenting to the hospital. Arunga's study in

Mbarara, Uganda also reported a worsening in prognosis of ocular disease outcome among patients who used TEM in Uganda which may explain the higher risk of a more destructive eye removal surgery done in patients who use TEM for a longer time.(Arunga, Asiimwe, et al., 2019; Kagmeni et al., 2014) In agreement with the latter statement, our results showed that those who presented after 3 months of use of TEM, ended up having either enucleation or exenteration surgery done rather than evisceration.

The most common indication of eye removal surgery was tumors (48.6%, n=125) and this was similar to findings in studies by Kitzmann et al in the USA, Lavaju et al in Nepal, Mukona et al in Zimbabwe, and Said in Kenya(Kitzmann et al., 2003; Lavaju et al., 2015; Mukona, 2019; Said, 2014). This was dissimilar to previous studies done by Adima and Davanger who both found the most common indications to be traumatic eye injury followed by infective causes(Adima, 1993; Davanger, 1970). The magnitude of traumatic eye injuries in the previous studies was attributed to the political instability (civil wars) that led to numerous incidences of violence like raids, civil wars, and bombings in the country(Adima, 1993) while most of the traumatic injuries in this study were found to be due to road traffic accidents.

The most common types of tumors that led to eye removal surgery were retinoblastoma and SCC each accounting for 37.6 %(n=47). The preponderance of tumor-related eye removal due to retinoblastoma in ages below 10 years may relate to the fact that retinoblastoma is the most common childhood intraocular malignancy typically presenting in the first decade of life coupled with late presentation of the patients, leaving eye removal surgeries as the only therapeutic option like what Musa et al reported in Nigeria. The majority of the patients that had OSSN or SCC tended to report late to the hospital as in Zimbabwe (Mukona, 2019) and ended up needing eye removal surgery, yet regular and accessible screening processes that encourage early detection of OSSN amongst people especially those living with HIV may lead to better prognosis(Jackson et al., 2014). Adima reported that the 6 cases of SCC and their association with HIV, could well be argued as just the beginning of manifestation of HIV-associated SCC, and indeed there is almost a 7-fold increase in the number of cases found in our study(Adima, 1993).

There has been a marked reduction in the number of eye removal surgeries done due to intra-ocular infection (6.6 %, n=17), compared to the previous study in 1993(17.14%,n=52)(Adima, 1993). This may be due to a combination of improvement of the primary and community eye health care

services, general improved water and sanitation practices, improved health-seeking behaviors of individuals as well as the availability of medical interventions in the periphery which minimizes the progression of ocular infections.

The commonest type of eye removal surgery that was done was evisceration (48.6%, n=125) followed by enucleation(35%,n=90) then exenteration (16.4%,n=42). Studies done in Nigeria(Enugu state), Ethiopia, Korea, Israel, and Turkey also showed similar findings(Batten, 1971; Eze et al., 2007; Günalp et al., 1996; Kim et al., 2007; Moshfeghi et al., 2000). However, Vemuganti et al in Nepal found enucleation to be more commonly done than evisceration which matched their findings of tumors being the single most common indication(Vemuganti et al., 2001). There was no incidence in the records during the study where enucleation was chosen over evisceration because of the prevention of sympathetic ophthalmia. Contrary to earlier studies done by Batten and Davanger, evisceration were performed more than enucleations(Batten, 1971; Davanger, 1970) which was similar to findings by Yousof et al who reported that it was due to evisceration being a safe and quicker alternative to enucleation, especially with dissolution of the fear of sympathetic ophthalmia(Yousuf et al., 2012).

The percentage of exenteration surgeries done increased from 3.2% (Adima, 1993) to 16.4% in this study and this may be attributed to the increased incidence of OSSN associated with late presentation(Ateenyi-Agaba, 1995).

5.2 Quality of life of patients that have undergone eye removal surgeries.

The results for the SF-36 tool dimensions of our study participants showed similar mean values to similar studies that have been done in Denmark and Korea except for the role limitations due to physical problems (51.5) and role limitation due to emotional problems (47.7) that were markedly less than those seen in the latter studies mentioned above(Ahn et al., 2010; M. L. Rasmussen et al., 2012).

The lower scores in the role limitation due to emotional problems may be due to the feelings of being and looking different (altered body images) that result in poor self-confidence and self-image

(M. L. R. Rasmussen et al., 2012). The role limitations due to physical problems and role limitations due to emotional problems may be especially low due to social stigma post-surgery that has been noticed to be worse in Africa compared to other continents, leading to some people abandoning treatments in case of need of eye removal surgery and eventually having fatal outcomes(Hilkert et al., 2017).

The mean PSS score of 20.8(SD=6.5) found in our study was higher than the PSS score of 12.3 (SD=6.9) in a study in a tertiary hospital in Denmark(M. L. Rasmussen et al., 2012). This may be due to the emphasized intergration of post-surgical counselling/ mental support to the patients in Denmark and therefore leading to early diagnosis and intervention of stress, anxiety and depression.

The QOL scores were not significantly different between the different ages except for physical functioning which showed an almost significant (p=0.06) decrease with increasing age. However, it is expected for the physical functioning to decrease with age.

There were also no significant differences in the findings of the QOL and PSS scores between the different sexes which was similar to findings by Juan et al, who noted that the level of anxiety and depression were not related to gender(Ye et al., 2015). These findings were different from those in Korea, where it was found that females especially those who were married tended to have more perceived stress and it was attributed to the increased concern about self-image(Ahn et al., 2010).

Similar to the findings in Denmark, the highest percentage (54.5%, n=48) of the eye removal patients were married at the time of the study which was twice more than those in Korea. (Ahn et al., 2010; M. L. R. Rasmussen et al., 2012). Notably, married patients had generally higher QOL scores compared to the rest of the group and this is similar to findings in several studies that have assessed the QOL of eye removal patients(Awadalla et al., 2007; Luttik et al., 2006). In this study, the divorced (29.2%) and separated (27.8%) patients had the lowest scores in the role limitations due to the physical problems and this may be because divorced and separated patients are less likely to have a good support system to lighten the burden or limitations in some activities that are otherwise provided by a partner to married patients(Coday et al., 2002).

The highest percentage of participants (43.2%, n=38) in MNRH reported that they stopped working or lost their job due to eye removal surgery. This calls for concern because of the

socioeconomic implication especially since most of these patients are meant to be economically active and productive. 66.7%(n=58) of the participants also reported that there were leisure activities in which they opted not to participate due to the eye removal surgery which could have further affected the mental health of these patients as leisure activities are meant to be a way of social improvement and relaxation. The job separation and social alienation of these patients puts them at a high risk of anxiety and depression(Ye et al., 2015).

In all the SF-36 dimensions, the patients that had evisceration had better scores than enucleation and exenteration. Exenteration significantly (p=0.0088) had the lowest scores in the role limitations due to the problem (28.8) and this could have been because patients that have exenteration usually have much more disfigurement and rarely receive prosthesis, especially in low resource centers like MNRH. Patients also had significantly (p=0.0023) decreasing mental health scores with evisceration having the highest (61.3) and exenteration the lowest (40). These findings were similar to the study done in Turkey, and Erogul et al thought it was related to the increased incidences of chronic illnesses in patients that had exenteration or enucleation thus these patients have pre-existing mental strain(Erogul, 2017). The latter statement also explains why there were statistically significant deteriorating scores from evisceration to enucleation and then to exenteration in the dimension of general health in MNRH.

The comparison of the SF-36 scores showed that patients with chronic indications such as tumors, and anterior staphyloma were more likely to have worse QOL than those with acute indications like traumatic eye injury, and corneal perforation. The most affected dimensions were role limitations due to problem (p=0.0340), vitality (p=0.0047), mental health (p=0.0020), and general health (p=0.0129). The longer duration of illness tends to affect someone mentally and physically even before the eye removal surgery and therefore these patients are prone to having lower scores. This was similar to studies done in Denmark, Korea, and Nigeria(Olatunji et al., 2011; M. L. R. Rasmussen et al., 2012; Song et al., 2006). The indication of unsightly eyes had the best scores in all dimensions of the SF-36 tool. This may be attributed to the idea that these participants sought out the eye removal surgery in order to improve cosmesis rather than other indications that were imposed on the participants for therapeutic reasons.

The most significant differences in the QOL scores were noted in patients that had a prosthesis versus those who did not have a prosthesis. The patients who had not received a prosthesis had

lower scores in all dimensions than those that did, with the most significant ($p<0.05$) in physical functioning, role limitations due to the physical problem, and role limitations due to emotions, vitality, mental health, and general health. These findings have been consistent in most studies done and Goiato et al found that ocular prostheses may cause a positive influence on the patients' relations and that this fact can be associated with psychological improvement (Goiato et al., 2013). Therefore, prosthetic restoration has a fundamental role in the patient's personal identity recovery and reintegration into society(Fernandes et al., 2009). In this study, only 38.1% (n=98) of patients received a prosthesis which means that 61.9% of the patients may have poor QOL due to the effect of lack of a prosthesis.

5.3 Study Limitations

This was a cross-sectional study done over a short period which may not have been representative of the patterns of eye removal surgery over a long period; maybe a longer period of study would have described the patterns better.

The record-keeping was not very efficient and therefore some files could not be retrieved while others had missing information. It would have been better and easier to do the study if all the data was retrievable.

Generalisability is an issue since the study only involved patients who presented to MNRH which is in an urban setting and therefore the quality of life of most of these patients may not apply to those in rural settings. MNRH is also the biggest national referral hospital in Uganda and so, it receives more patients that have worse prognoses which may not be representative of the pattern of eye removal surgeries in the country.

A study design with a comparison group of patients with eye surgeries that didn't involve removal would have best answered the QOL of patients that have had eye removal surgery.

The study had issues of information bias since the information was collected as secondary data which may have been poorly recorded or misclassified. There is also information bias during the administration of the SF-36 and PSS tools as they are dependent on the information provided by the patients which may not be well reported.

5.4 Strengths of the study

There was a good sample size attained to answer both objectives in comparison to most other studies that have been done in the world. The Cronbach's alpha of the SF-36 tool and PSS tool in our study was 0.619-0.926 and 0.677 respectively which demonstrated satisfactory reliability in the measurement of the QOL of these patients.

Through the study, some of the patients who had not yet received prostheses were encouraged to acquire them.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

Of the 257 patients that had eye removal surgery, the highest percentage (37.4%, n= 96) were below the age of 20 years and mostly children (33.1%, n=85). The M: F ratio was 1.3:1. The leading type of surgery done was evisceration (48.6%, n=125), followed by enucleation (35%, n=90), and lastly exenteration (16.4%, n=42).

Most patients (32%, n=82) presented late to hospital by 1-3months and 24.9% (n=64) self-medicated with over the counter while 30.7% (n=79) used traditional eye medicine. The common indications of eye removal surgery were tumors and badly ruptured globe due to trauma. The highest occurring tumors were Retinoblastoma (37.6%, n=47) and Squamous cell carcinoma (37.6%, n=47).

The QOL of life of the study participants was low and especially due to limitations caused by emotional and physical problems secondary to the eye removal surgery. Patients in this study were experiencing moderate stress.

Eye removal surgery also harmed the socioeconomic position of these patients as 43.2% of the study participants lost their jobs after surgery. Patients who lacked a prosthesis had a poor QOL and significantly ($p<0.05$) lower scores in the SF-36 tool dimensions compared to those who had a prosthesis. Married patients had a better QOL than single, divorced, and separated patients due to better social support.

6.2 Recommendations

1. Health policymakers and other stakeholders need to increase eye health promotion to create awareness that may in turn improve the early eye health-seeking behavior and reduce the number of eye removal surgeries.

2. Health policymakers and other stakeholders need to initiate intensive screening for ocular tumors like SCC among people with HIV and retinoblastoma among children through genetic screening to facilitate early detection of the disease and early intervention like topical 5 fluorouracil for early-stage ocular SCC.

3. Health policymakers and other stakeholders can support policies to improve the QOL of patients that have had eye removal surgery by providing integrated pre- and post-surgical rehabilitation services that include continuous mental health support through scheduled counseling sessions, improved cosmesis through the provision of free or subsidized implants, and/or prostheses and provision of supplementary income generating avenues for patients who lose their jobs.

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8.0 APPENDICES

Appendix I: IRB(SOMREC) Approval letter

MAKERERE UNIVERSITY
P.O. Box 7072 Kampala, Uganda
E-mail: rresearch9@gmail.com
Phone: 256 414 533541
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COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE
RESEARCH ETHICS COMMITTEE

01/06/2023

To: Hawa Naiga

Makerere University
0773577817

Type: Initial Review

Re: Mak-SOMREC-2023-612: EYE REMOVAL SURGERIES AT MULAGO NATIONAL REFERRAL HOSPITAL- PATTERNS AND QUALITY OF LIFE OF AFFECTED PATIENTS

I am pleased to inform you that at the **179** convened meeting on **16/05/2023**, the MAK School of Medicine REC (Mak-SOMREC), committee meeting voted to approve the above referenced application.
Approval of the research is for the period of **01/06/2023** to **01/06/2024.**

As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **01/06/2024** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by MAK School of Medicine REC (Mak-SOMREC):

No.	Document Title	Language	Version Number	Version Date
1	Protocol	English	Reasearch Proposal after SOMREC review and changes	2023-05-29
2	Informed Consent forms	LUGANDA	Approved for submission by supervisors	2023-05-18
3	Informed Consent forms	ENGLISH	Approved for submission by supervisors	2023-05-18
4	Work plan changes	ENGLISH	Approved for submission by supervisors	2023-05-18
5	Application for waiver of informed consent if applicable to your study	ENGLISH	Approved for submission by supervisors	2023-03-31
6	COVID-19 & EBOLA risk management plan for the study	ENGLISH	Approved for submission by supervisors	2023-03-30
7	Data collection tools	ENGLISH	Approved for submission by supervisors	2023-03-30

Yours Sincerely

Prof. Ponsiano Ocama
For: MAK School of Medicine REC (Mak-SOMREC)

Appendix II: Waiver of consent letter

MAKERERE UNIVERSITY
P.O. Box 7072 Kampala, Uganda
E-mail: rresearch9@gmail.com
Phone: 256 414 533541
Fax: 256 414 541036/0414 532204

COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICINE

RESEARCH ETHICS COMMITTEE

June 1, 2023

Dr. Hawa Naiga
Department of Ophthalmology

Dear Dr. Naiga,

RE: APPROVAL OF CONSENT WAIVER

In your letter dated 2nd April 2023, you requested the committee to waive off consent for the study entitled **"Eye removal surgeries at Mulago National Referral Hospital- patterns and quality of life of affected patients" Mak-SOMREC-2023-612.** The study involves review of case files of patients that had eye removal surgery at the Eye Department in Mulago National Referral Hospital from 1st January 2018 to 31st December 2022.

On behalf of the committee, I am glad to inform you that the committee has granted waiver of the informed consent process for the retrospective part of the study.

Yours sincerely,

Dr. Aloysius Gonzaga Mubuuke
Vice Chairperson School of Medicine Research and Ethics Committee

Appendix III: Letter of clearance from Mulago National Referral Hospital

TELEPHONE: +256-41554008/1
FAX: +256-414-5325591
E-mail: admin@mulago.or.ug
Website: www.mulago.or.ug

IN ANY CORRESPONDENCE ON THIS SUBJECT PLEASE QUOTES NO.....

MULAGO NATIONAL REFERRAL HOSPITAL
P. O. Box 7051
KAMPALA, UGANDA

5 June 2023.

Dr. Naiga Magembe Hawa
Principal Investigator
Department of Ophthalmology
Makerere University.

Dear Dr. Naiga,

RE: RECOMMENDATION FOR ADMINISTRATIVE CLEARANCE TO CONDUCT A STUDY AT MULAGO NATIONAL REFERRAL HOSPITAL.

The Administration and Management of Mulago National Referral Hospital is pleased to inform you that you have been offered clearance to conduct the study titled **MHREC 2520: "Eye Removal Surgeries at Mulago National Referral Hospital – Patterns and Quality of Life of Affected Patients".**

The above clearance is granted to you on the following conditions;

- That you will follow the research ethical processes
- Agreed to comply with all institutional policies and regulations of Mulago National Referral Hospital
- Agreed to provide end of study report and acknowledge Mulago hospital in all publications

Administrative clearance is valid for one (1) year effective from 5 June 2023 to 4 June 2024

By copy of this letter, we reiterate our commitment to support this study.

DR. BYANYIMA ROSEMARY
AG. EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL

EXECUTIVE DIRECTOR
MULAGO NATIONAL REFERRAL HOSPITAL
P.O. BOX 7051, KAMPALA
MULAGONATIONALREFERRALHOSPITAL

Copied to;

1. **Dr. Naiga Magembe Hawa – Study Principal Investigator**

Appendix IV: Data collection tool for objective 1

Data extraction tool to collect information from the case files in Mulago National Referral Hospital

Code number……..

Part A: Socio-demographic data

1. Age……..
2. Sex Male. ……. Female……
3. Nationality
    - Ugandan
    - Non-Ugandan
    - Refugee
4. Tribe
    - Bantu
    - Nilotic
    - Hamites
5. Residence ……..

    Rural ☐ Semi-urban ☐ Urban ☐
6. Occupation of patient…….
    - Motorist
    - Industrial / construction workers
    - Agricultural workers
    - Office work
    - Unemployed
    - Children(0-4 years)
    - Student
7. Level of education of the patient

    None ☐ Primary ☐ Secondary ☐ Tertiary ☐

    ☐ Referral ☐ Self Referral

Date of admission ……

Date of surgery……

Date of discharge …….

Duration of stay in Hospital

- Less than 2 weeks
- 2 weeks to 1 month
- 1 month to 3 month
- Above 3 months

Part B: History

Presenting complaint……..

Affected eye

- RE
- LE
- BE

Duration of presenting complaint

- Less than 2 weeks
- 2 weeks to 1 month
- 1 month to 3 month
- Above 3 months

History of presenting complaint/ associated symptoms

- Pain
- Swelling of eye
- Mass on the eye
- Tearing
- Reduced vision
- Fever
- Use of TEM

- Period of use ……..

- Use of any other medication
  - Less than 2 weeks
  - 2 weeks to 1 month
  - 1 month to 3 month
  - Above 3 months
    - Prescribed
      - Antibiotic eye drops
      - Anti-glaucoma eye drops
      - NSAID eye drops
      - Analgesic eye drops
      - Anti-viral eye drops
      - Topical corticosteroids
    - Self-treatment
      - Antibiotic eye drops
      - Anti-glaucoma eye drops
      - NSAID eye drops
      - Analgesic eye drops
      - Anti-viral eye drops
      - Topical corticosteroids
- Reddening of eye
- Trauma to eye
  - Location of the patient at the time of injury
    - Work
    - Home
    - School
    - Road
  - Mechanism of injury
    - Blunt force injury
    - Penetrating injury
- Comment about other eye

- Normal
- Abnormal(please specify)…….

Review of other systems

- CVS
  - Easy fatiguability
  - Difficulty in breathing
  - Chest pain
  - Cough worsening in the supine position
  - Palpitations
- RESP
  - Difficulty in breathing
  - Chest pain
  - Cough
  - Wheezing
- GIT
  - Abdominal pain
  - Vomiting
  - Nausea
  - Diarrhoea

Past Ocular History

- History of eye surgery
- History of eye medication
- History of glasses/contact lens prescription
- History of ocular disease
  - Chronic corneal ulcer
  - Glaucoma
  - Uveitis
  - Allergic conjunctivitis
  - Bacterial conjunctivitis

Past Medical History

- HIV status
    - Negative
    - Positive
        - On HAART
        - Less than 2 weeks
        - 2 weeks to 1 month
        - 1 month to 3 months
        - Above 3 months
            - HAART naïve
            - Unknown
    - Unknown

- Type 2 DM
    - Positive
        - On medication
        - Less than 2 weeks
        - 2 weeks to 1 month
        - 1 month to 3 months
        - Above 3 months
        - Defaults on medication
        - Not on medication
    - Negative
- Other chronic illnesses ……
- Other chronic drug use…….
- Drug allergies
    - Positive
    - Negative
- Food allergies

- Positive
- Negative

Past Surgical History

- Surgery……..
- Blood transfusion …….

Family Social History

- History of blindness in family
- Smoking
- Alcohol use
- Familial illness
    - Type 2 DM
    - HTN
    - Malignancy
    - Genetic illnesses

Part B: Clinical data

Examination

1. General examination
    - Anemia
    - Jaundice
    - Lymphadenopathy
    - Nutritional status
    - Temperature……..
2. Systemic examination
    - CVS
        - BP ……..
        - PR……..
        - Heart sounds
            - Normal

- Abnormal
- RESP
  - SPO2……
  - RR……

3. Other remarkable findings, please specify …….
4. Ocular examination (Mark the circles that apply)

Examination	RE	LE
Visual acuity	PH With eyeglasses	PH With eyeglasses
Refraction	○ Known …… ○ Unknown	○ Known ……. ○ Unknown
Intraocular pressure	○ Normal(8-20mmHg) ○ Low (Less than 8mmHg) ○ High(Above 20mmHg)	○ Normal(8-20mmHg) ○ Low (Less than 8mmHg) ○ High(Above 20mmHg)
Eyelids	○ Normal ○ Abnormal(please specify) …….	○ Normal ○ Abnormal(please specify) …….
Eyelashes	○ Normal ○ Abnormal(please specify) …….	○ Normal ○ Abnormal(please specify) …….
Conjunctiva	○ Normal ○ Abnormal(please specify) …….	○ Normal ○ Abnormal(please specify) …….
Sclera	○ Normal	○ Normal

	○ Abnormal(please specify) …….	○ Abnormal(please specify) …….
Cornea	○ Clear ○ Corneal ulcer ○ Corneal tear/ perforation ○ Corneal infiltrates ○ Corneal edema ○ Corneal scar ○ Anterior staphyloma	○ Clear ○ Corneal ulcer ○ Corneal tear/ perforation ○ Corneal infiltrates ○ Corneal edema ○ Corneal scar ○ Anterior staphyloma
Anterior chamber	○ Deep ○ Quiet ○ Shallow ○ Flare	○ Deep ○ Quiet ○ Shallow ○ Flare
Pupil	○ Round ○ Occluded ○ Regular ○ Irregular ○ Reactive ○ Non-reactive ○ RAPD ○ Anterior synechia ○ Posterior synechia	○ Round ○ Occluded ○ Regular ○ Irregular ○ Reactive ○ Non-reactive ○ RAPD ○ Anterior synechia ○ Posterior synechia
Lens	○ Clear ○ Opaque ○ Aphakic ○ Pseudophakic	○ Clear ○ Opaque ○ Aphakic ○ Pseudophakic
Vitreous	○ Clear ○ Not clear	○ Clear ○ Not clear
Fundus	○ Normal	○ Normal

	○ Abnormal (please specify) …….	○ Abnormal (please specify) …….
Eye movement	H(Tick appropriately)	H(Tick appropriately)

5. Investigations done
    - Complete Blood Count
        - Normal
        - Abnormal
            - Abnormal Hb
            - Abnormal PLT count
            - Abnormal WBC
        - Not done
    - RBS
        - Normal
        - High
        - Low
        - Not done
    - ESR
        - Normal
        - High
        - Not done
    - CRP
        - Normal
        - High
        - Not done
    - HIV
        - Positive
        - Negative
        - Not done
    - COVID-19 pneumonia
        - Done (please add the findings)…….

- Not done
- B scan
  - Done (please add the findings)…….
  - Not done
- CT-scan
  - Done (please add the findings)…….
  - Not done
- MRI
  - Done (please add the findings)…….
  - Not done

6. Diagnosis ……..
7. Indication of surgery……..
   - Traumatic eye injury
   - Painful Blind eye
   - Unpleasant cosmesis
     - Phthisis bulbi
     - Others …….
   - Tumors
     - Squamous Cell Carcinoma
     - Retinoblastoma
     - Melanoma
     - Rhabdomyosarcoma
     - Others, please specify…….
   - Intraocular infection
     - Panophthalmitis
     - Endophthalmitis
   - Anterior staphyloma
   - Corneal perforation
   - Others, please specify…….

PART C: SURGERY

1. Which surgery was done?
    - Eye removal surgery
    - Others, please specify ……..
2. Which eye removal surgery was done?
    - Evisceration
    - Enucleation
        - Extended enucleation
        - Modified enucleation
    - Exenteration
        - Lid-sparing exenteration
        - Non-lid sparing exenteration
3. Was an implant used?
    - Yes
    - No
4. Was tissue biopsy done
    - Yes
    - No
5. If yes to question 2 above, what was the histopathological diagnosis?

……

Appendix V: Informed Consent Form (English Version)

TITLE OF THE STUDY: EYE REMOVAL SURGERIES AT MULAGO NATIONAL REFERRAL HOSPITAL – PATTERN AND QUALITY OF LIFE OF AFFECTED PATIENTS

PRINCIPAL INVESTIGATOR: **DR NAIGA MAGEMBE HAWA**, Department of Ophthalmology, Makerere University College of Health sciences

INTRODUCTION: This form explains to you the important details about the study to decide whether you agree to participate or not. You need to understand the purpose, how it may help you, any risks, and what is expected of you if you decide to participate. You are being asked to be in a research study that is assessing the quality of life of patients after eye removal surgery.

PURPOSE OF THE STUDY: This study aims to assess the pattern of eye removal surgeries done in Mulago National Referral Hospital and to assess the quality of life of the patients after the surgical removal of one or both eyes.

STUDY PROCEDURE: If you decide to participate in the study, you will be required to come to Mulago National Referral Hospital to be interviewed. If you are not able to travel to the hospital, the questionnaire will be administered over the phone. The questionnaire may be read out to you or if you choose you may self-administer the questionnaire. You will be duly informed in case there is a need for further examination or referral. The interview will take a total of 20 minutes.

RISKS/DISCOMFORTS: Participation in the study may cause some emotional reactions in response to the pain and other physical limitations caused by the injury. Therefore during the interview, the P. I will monitor for any emotional aggravation while the questionnaire is being administered and if noted will ensure that the questionnaire is administered with caution to avoid any further mental or emotional instability. Counseling will be readily available in case more emotional support is needed.

POTENTIAL BENEFITS: You will have a complete quality-of-life assessment. If the findings from the quality of life questionnaire show a need for intervention, you will benefit from free diagnosis and consultation with a psychiatrist or necessary physician. Results from this study are expected to be used in complementing management protocols and improving your general care.

There will be a transport refund offered to patients who will come in to fill in the questionnaires physically at the eye clinic.

CONFIDENTIALITY: A study number only known to the principal investigator and yourself will be used. Your name will not appear on any of the study documents. The records of the study will be kept strictly confidential. Research records will be kept in a locked file, and all electronic information will be coded and secured using a password-protected file.

The principal investigator, research assistant, Supervisors, and the local Research Ethics Committee (REC) and Uganda National Council for Science and Technology (UNCST) are entities that may have access to private information that identifies the research participants by name.

You will not be identified in any publications or presentations about this study.

COST FOR PARTICIPATION: There will be no payment required for participation in this study.

COMPENSATION FOR PARTICIPATING IN THE STUDY: Refreshments will be provided to you upon completion of the interview. The participant's time will be compensated with a fee of 10,000 Uganda shillings only.

TRANSPORT REIMBURSEMENT: A transport refund of 10,000 Uganda shillings will be provided to compensate for patients that will travel to the hospital to participate in the quality of life study.

YOUR RIGHTS AS A RESEARCH VOLUNTEER: The form gives you information about the study. Once you understand the research and agree to be enrolled, you will be required to sign the form, a copy of which will be given to you. Participation in the study is entirely voluntary. You may decide to withdraw from the study at any time, and such a decision will not affect the kind of medical management you are entitled to.

QUESTIONS REGARDING THE STUDY: In case of questions or problems related to the study, you can ask or contact:

Dr. Naiga Magembe Hawa at the Department of Ophthalmology, Mulago Hospital, or on the mobile phone number +256 773577817 at any time during the study.

QUESTIONS REGARDING PARTICIPANTS' RIGHTS

If you have any questions concerning ethical issues or issues related to your right while participating in the study, you may contact the School of Medicine research and ethics committee chairman, Prof Ocama Ponsiano, by Telephone at +256 772 421190.

STATEMENT OF INFORMED CONSENT

..... has described to me what is going to be done, the risks, the benefits involved, and my rights regarding this study. I understand that my decision to participate in this study will not alter my usual medical care. In the use of this information, my identity will be concealed. I am aware that I may withdraw at any time. I understand that by signing this form, I do not waive any of my legal rights but merely indicate that I have been informed about the research study in which I voluntarily agree to participate. A copy of this form will be provided to me.

Participant Name _____

Signature/thumbprint of participant_____

Date _____

Name of witness_____

Signature of witness_____

Date_____

Name of Research Assistant_____

Signature _____

Date _____

Appendix VI: Informed Consent Form (Luganda Version)

EKIWANDIKO EKYOKWETABA MU KUNOONYEREZA

Omutwe gw'okunoonyereza : Okulongoosa okuggyawo amaaso mu ddwaliro lye Mulago eddwaliro ly'eggwanga eriweebwayo : Enkola n'omutindo gw'obulamu bw'abalwadde abakolwako.

OMUNONNYEREZI OMUKULU

MUSAWO NAIGA MAGEMBE HAWA, okuvva mu kitongole ky'ebyaamaaso mu ssettendekero y'abassawo ey'e Makerere.

ENNYANJULA: Foomu eno etangaaza ebifa kukunoonyereza byoteekedwa okumanya nga tonnaba kusalawo oba weenyigira mu kunoonyereza okukwata ku abalwadde abalongooseddwa okuggyamu amaaso. Fomu eno ekutegeza ebigenda okukolebwa ko n'eddembe lyo.Bwotegeera okunoonyereza era n'okkiriza okwetabamu, ojja kuteekako omukono ku kiwandiiko kino.

Omugaso g'wokunoonyereza: Omugaso gw'okunoonyereza kuno kwekuzuula ebikwatagana ku mutindo gw'obulamu bw'abalwadde abalongooseddwa okuggyamu amaaso mu ddwaliro mulago eddwaliro ly'eggwanga eriweebwayo.

Emitendera: Bwosalawo okwetaba mu kunoonyereza ojja kubuuzibwa ebibuuzo ebikwata kubulamu bwo. Ojja kukeberebwa,omubiri gwonnawamu n'amaaso. Bwewaba nga waliwo eby'okukebera ebirala, ojja kutegeezebwa.Okubuzibwa n'okwekebejebwa bijja kutwala eddakika abiri.

Obulabe: Okwetaba mu kuyinza okukuleteera ennyike kumutiima wammu nokukaaba nga ojukiziddwa embeeera eyaletebwa obukossefu bwokwokeebwa okwakoosa n'amaaso ggo oba agooyo gwojanjaaba. Eddaggala erimu liyinza okubalagala nga litekeddwa mu maaso okugekebejja.

Eby'okuganyulwa.: Ojjakukeberebwa amaaso gonna, singa wanaabaawo ekizibu ku bulamubwo, ojjakufuna okubudaabudibwa okwetaagisa. Singa wanaabaawo obulwadde obuzuulidwa, ojja kwongerwayo nga bwekinaaba kisaanidde.

Okusasula: Tewetaga kusasula sente zona okusobola okwetaba mu kunonnyereza kuno.

Okusasula n'okuddizibwa: Ojja kuwebwa yo ekyokunnywa oluvnnyuma lwokwekebejebwa.Ojja kuwebwa Omutwalo ggumu okusasuza ebbanga jetunakozesa mu kukebejjwa.

Okuddamu okusomesa entambuza: Ssente za siringi za Uganda 10,000 zakuweebwayo okuliyirira abalwadde abagenda okugenda mu ddwaaliro okwetaba mu kunoonyereza ku mutindo gw'obulamu

Okukuuma ebyama: Namba emanyiddwa oyo yekka akulira okunoonyereza wamu naawe yejja okukozesebwa. Erinyalyo terijja kulabikira kubiwandiiko byakunoonyereza byonna. Ebikwata kubulamu bwo n'enzijanjabayo tebijja kuweebwa muntu yenna nga towadde lukusa okujjako bano wammanga; abantu abaweebwa olukusa, setendekero y'e Makerere, minisitule y'ebyobulamu, akakiiko akakwasaganya ebyasayansi wamu n'etekinologiya akamanyidwa nga Uganda National Council for Science and Technology. Tojja kutegeerebwa mu biwandiiko byonna oba ebilagibwa ebikwata kukunoonyereza.

Ebibuuzo ebikwatakukunoonyereza: Bwoba olina ebibuuzo ebikwata kukunoonyereza tuukirira akulira okunoonyereza musawo Naiga Magembe Hawa enamba y'essimu 0773 577 817.

Ebibuuzo ebikwata ku ddembelyo mu kunoonyereza: Bwoba olina ebibuuzo ebikwata ku ddembe lyo mu kunoonyereza, tuukirira sentebe w'akakiiko akakwasisa empisa mu tendekero ly'abasawo ery'e Makerere sabakenkufu Ponsiano Ocama kunamba y'essimu 0772421190.

Nze atadde omukono wansi nsomye era ntegeezedwa kyekitegeza okwetaba mu kunoonyereza okwo waggulu/omulwadde gwendabirira. Ntegeera nti okuteeka omukono kukiwandiiko kino, kiraga nti ntegeezedwa ebikwata kukunoonyereza kweneeyagalidde okwetabamu. Kkopi y'ekiwandiiko kino egyakumpeebwa.

Erinnya ly'eyetabye mukunonyereza_____

Omukono oba ekinkumu_____

Ennaku z’omwezi_____

Erinnya l’yomujulizi_____

Omukono_____

Enaku z’omwezi_____

Abuziza ebibuzo_____

Omukono_____

Ennaku z’omwezi_____

Appendix VII: Questionnaire for Objective 2

QUESTIONNAIRE FOR OBJECTIVE 2

This questionnaire will be used to collect quality-of-life-related information from the patients.

Code number……

Demographic factors

1. Age……..
2. Sex Male. ……. Female……
3. Nationality
    - Ugandan
    - Non-Ugandan
    - Refugee
4. Tribe
    - Bantu
    - Nilotic
    - Hamites
5. Residence ……..

    Rural ☐ Semi-urban ☐ Urban ☐

6. Does the patient use a "prosthesis?
    - Yes
    - No

36-Item Short Form Survey Instrument (SF-36) RAND 36-Item Health Survey 1.0 Questionnaire Items

Choose one option for each questionnaire item.

1. In general, would you say your health is:

- ○ 1 - Excellent
- ○ 2 - Very good
- ○ 3 - Good
- ○ 4 - Fair
- ○ 5 - Poor

---

2. **Compared to one year ago**, how would you rate your health in general **now**?

- ○ 1 - Much better now than one year ago
- ○ 2 - Somewhat better now than one year ago
- ○ 3 - About the same
- ○ 4 - Somewhat worse now than one year ago
- ○ 5 - Much worse now than one year ago

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

	Yes, limited a lot	Yes, limited a little	No, not limited at all
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	○ 1	○ 2	○ 3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	○ 1	○ 2	○ 3
5. Lifting or carrying groceries	○ 1	○ 2	○ 3
6. Climbing **several** flights of stairs	○ 1	○ 2	○ 3
7. Climbing **one** flight of stairs	○ 1	○ 2	○ 3
8. Bending, kneeling, or stooping	○ 1	○ 2	○ 3
9. Walking **more than a mile**	○ 1	○ 2	○ 3
10. Walking **several blocks**	○ 1	○ 2	○ 3
11. Walking **one block**	○ 1	○ 2	○ 3
12. Bathing or dressing yourself	○ 1	○ 2	○ 3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

	Yes	No
13. Cut down the **amount of time** you spent on work or other activities	○ 1	○ 2
14. **Accomplished less** than you would like	○ 1	○ 2
15. Were limited in the **kind** of work or other activities	○ 1	○ 2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	○ 1	○ 2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	○ 1	○ 2
18. **Accomplished less** than you would like	○ 1	○ 2
19. Didn't do work or other activities as **carefully** as usual	○ 1	○ 2

---

20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

- ○ 1 - Not at all
- ○ 2 - Slightly
- ○ 3 - Moderately
- ○ 4 - Quite a bit
- ○ 5 - Extremely

---

21. How much **bodily** pain have you had during the **past 4 weeks**?

- ○ 1 - None
- ○ 2 - Very mild
- ○ 3 - Mild
- ○ 4 - Moderate
- ○ 5 - Severe
- ○ 6 - Very severe

---

22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both work outside the home and housework)?

- ○ 1 - Not at all
- ○ 2 - A little bit
- ○ 3 - Moderately
- ○ 4 - Quite a bit
- ○ 5 - Extremely

These questions are about how you feel and how things have been with you **during the past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
23. Did you feel full of pep?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
24. Have you been a very nervous person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
25. Have you felt so down in the dumps that nothing could cheer you up?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
26. Have you felt calm and peaceful?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
27. Did you have a lot of energy?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
28. Have you felt downhearted and blue?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
29. Did you feel worn out?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
30. Have you been a happy person?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6
31. Did you feel tired?	○ 1	○ 2	○ 3	○ 4	○ 5	○ 6

32. During the **past 4 weeks**, how much of the time has **your physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?

- 1 - All of the time
- 2 - Most of the time
- 3 - Some of the time
- 4 - A little of the time
- 5 - None of the time

How TRUE or FALSE is **each** of the following statements for you.

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
33. I seem to get sick a little easier than other people	1	2	3	4	5
34. I am as healthy as anybody I know	1	2	3	4	5
35. I expect my health to get worse	1	2	3	4	5
36. My health is excellent	1	2	3	4	5

PERCEIVED STRESS SCORE

Administration

The questions in the PSS ask about feelings and thoughts during the last month. In each case, respondents are asked how often they felt a certain way.

It consists of 10 questions, takes 5-10 minutes to complete, and is for individual or group administration.

The questions in this scale ask you about your feelings and thoughts during THE LAST MONTH. In each case, please indicate your response by placing an "X" over the circle representing HOW OFTEN you felt or thought a certain way.

	Never	Almost Never	Sometimes	Fairly Often	Very Often
	0	1	2	3	4
1. In the last month, how often have you been upset because of something that happened unexpectedly?	☐	☐	☐	☐	☐
2. In the last month, how often have you felt that you were unable to control the important things in your life?	☐	☐	☐	☐	☐
3. In the last month, how often have you felt nervous and "stressed"?	☐	☐	☐	☐	☐
4. In the last month, how often have you felt confident about your ability to handle your personal problems?	☐	☐	☐	☐	☐
5. In the last month, how often have you felt that things were going your way?	☐	☐	☐	☐	☐
6. In the last month, how often have you found that you could not cope with all the things that you had to do?	☐	☐	☐	☐	☐
7. In the last month, how often have you been able to control irritations in your life?	☐	☐	☐	☐	☐
8. In the last month, how often have you felt that you were on top of things?	☐	☐	☐	☐	☐
9. In the last month, how often have you been angered because of things that were outside your control?	☐	☐	☐	☐	☐
10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	☐	☐	☐	☐	☐

JOB SEPARATION DUE TO DISABILITY

1. Have you ever needed to change your working hours to part-time, quit a job or change your job or work tasks due to disease, disorder, illness, or injury?
    - Yes, worked part-time
    - Yes, changed job or work tasks
    - Yes, stopped working
    - No
2. 'If the answer is yes to the previous question; was this because of eye disease?

- Yes
- No

3. What is your marital status?
    - Married
    - Single
    - Divorced
    - Separated

SOCIOECONOMIC POSITION

1. What is your occupation? ----------
2. Are there leisure activities that you no longer take part in due to the loss of your eye?
    - Yes
    - No
3. If yes, please write down the types of activities. ----------