

**WILLINGNESS TO DONATE EYES AND ITS ASSOCIATED
FACTORS AMONG ADULTS IN A COMMUNITY IN KENYA**

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DECLARATION

I declare that this dissertation is my original work and has not been presented for the award of a degree in any other university.

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LIST OF ABBREVIATIONS

FGD	Focus Group Discussion
KBEB	Kanubhai Babla Eye Bank
KNH	Kenyatta National Hospital
LVPEI	L V Prasad Eye Institute
MSVI	Moderate/Severe Visual Impairment
PK	Penetrating Keratoplasty
SAFE	Surgery for trichiasis, Antibiotics, Facial cleanliness and Environmental improvement

ABSTRACT

Introduction: Corneal diseases are a significant cause of blindness and visual impairment in less developed countries. Advanced disease is managed by corneal transplantation. In Kenya, despite having an eye-bank, donation is very low.

Objective: To assess the knowledge, willingness and barriers to corneal donation.

Design: Cross-sectional study with qualitative and quantitative components.

Study site: Kiambiu slum in Nairobi and Kenyatta National Hospital (KNH).

Methods:

Adult residents were interviewed using semi structured questionnaires. Focus group discussions and key informant interviews were conducted using interview guides with the help of a trained research assistant. Quantitative data was analysed using Statistical Program for Social Sciences (SPSS) version 22 and summarised using descriptive statistics. Qualitative data was analysed by thematic analysis using Atlas.ti software and reported as per-verbatim quotes. Triangulation was used to ensure trustworthiness of data collected.

Results: In this study, 106 adults of median age 32.7 ± 11.7 years participated. They consisted of 61(59.4%) females and 45(42.5%) males; the dominant ethnic groups were Luo, 40(37.7%) and Luhya, 34(32.1%). Only 23.6% were aware of eye donation and 37.7% were willing to donate corneas. The main reasons for unwillingness to donate own corneas were the need to be buried with an intact body (51.6%) and refusal by family members (16.1%). The main reason for unwillingness to donate next of kin's cornea was objection by family members, 12(38.7%). Village elders play a crucial role when it comes to decision-making in the family concerning harvesting of corneas.

Conclusion: The level of knowledge and willingness to donate corneas was low. Awareness-creation programs should involve family members and village elders when pledging and harvesting corneas.

1.0 INTRODUCTION

1.1 Epidemiology

Globally, corneal disease is considered to be one of the most important causes of visual impairment and blindness and most of those affected live in the less developed world (1,2). In 2010, global estimation from WHO revealed that 39 million people were blind ($<3/60$) and 285 million had moderate to severe vision loss/impairment (MSVI) $<6/18$ to $\geq 3/60$ (3). Out of these, there are about 4.9 million people globally who are blind from corneal diseases (1).

Even though Africa represents 12% of the global population, it is estimated that 15% of those visually impaired worldwide are in Africa (2,4). Corneal blindness is the second leading cause of vision loss after cataract and in some areas accounts for 25% to 90% of all causes of blindness (5,7).

In Kenya, ocular morbidity due to corneal diseases is estimated to be 7.2% (8). The prevalence of blindness is 0.7%, with an estimate of 250,000 blind and 750,000 people with low vision (8). A report from the Ophthalmic Services Unit, department of Curative and Rehabilitative Services of the Ministry of Health in Kenya estimated that 3.75% of the patients had corneal disease with 0.48% of patients blind and 0.56% of patients suffering from low vision (defined as visual acuity in the better eye $>6/18-3/60$) (9). The exact burden of disease is yet to be determined as there is need for a comprehensive national survey to help identify this (8). The epidemiology of corneal diseases is sophisticated and includes a wide variety of infectious and inflammatory diseases (6). It is highly determined by the ocular diseases endemic in a region and the general standards of care therein.

2.0 LITERATURE REVIEW

2.1 Aetiology of Corneal Diseases

Historically, the major diseases responsible for corneal blindness include trachoma, leprosy, onchocerciasis, ophthalmia neonatorum and xerophthalmia. Majority occur in developing world countries. In Central Tanzania, Rapoza et al noted that corneal opacification is due to trachoma, keratoconjunctivitis, vitamin A deficiency, measles and trauma (10).

In Ethiopia, corneal blindness are responsible for 19.3% of blindness, which is largely attributed to trachoma, xerophthalmia, onchocerciasis and ocular trauma (11). Studies in India suggest similar aetiology including trauma, infectious keratitis and vitamin A deficiency (1,12).

Trachoma is the number one cause of infectious blindness and is associated with lack of water supply and poor facial cleanliness, with females and children being affected the most. It has been found in several countries including Nepal, Ethiopia, Tanzania and Kenya where it is endemic in 17 of 73 districts (8).

Childhood blindness is mainly contributed by xerophthalmia and ophthalmia neonatorum. Xerophthalmia is caused by vitamin A deficiency and populations affected are the poorest of the poor. It is often associated with measles. Ophthalmia neonatorum causes bilateral corneal opacification, especially in association with *Neisseria gonorrhoea*. *Chlamydia trachomatis* has also been implicated in causation of ophthalmia neonatorum, with an increase of incidence of chlamydial infections occurring in both developing and industrialized countries (6).

2.2 Management of Corneal Diseases

Fortunately, 80% of visual impairment is avoidable (13). There are several public health measures that have been successful in controlling these diseases. They include the SAFE strategy (Surgery for trichiasis, Antibiotics, Facial cleanliness and Environmental improvement) in trachoma, immunization against measles, vitamin A supplementation and prophylactic application of tetracycline eye ointment to all newborns at birth (6,8).

These successes have spawned a shift in focus towards other causes that were previously neglected. They are amenable to surgery as approximately 40% of corneal blindness can be

successfully managed through surgical intervention (14). They include ocular trauma, microbial keratitis, keratoconus and pseudophakic bullous keratopathy.

Ocular trauma has a global distribution with majority of cases noted in developing countries (15). In South India, 26% of corneal blindness was due to trauma and 71.5 % of those affected were children below 15 years of age (1).

Microbial keratitis has been described as a “silent epidemic” (16). It affects mainly those in the developing world. Burton et al noted that these patients typically have late presentation, severe lesions, filamentous fungal infections and poor visual acuity despite comprehensive antibiotic treatment. Majority of patients with fungal keratitis are farmers (17). A third of the cases developed perforation, with 8% undergoing evisceration. These are candidates who would potentially benefit from a PK.

Pseudophakic bullous keratopathy is one of the major indications for PK. Risk factors include use of phacoemulsification during cataract surgery (18). A review done by Kang et al noted that up to 26.0% of patients developed pseudophakic bullous keratopathy despite use of viscoelastic and new phacoemulsification techniques (19). Chen et al noted that 13.0% of patients who underwent PK had pseudophakic bullous keratopathy in Kenya, where the cataract surgical rate has increased (20). This could potentially increase the need for PK in the country.

Keratoconus has been noted to affect the older age group in the USA and UK, however it affects younger patients in the Middle East, Indian and African population, including Kenya (21-24) . Although previous studies done in Kenya suggest that keratoconus (KC) is a major etiological contributor to corneal diseases, its prevalence is yet to be determined. In a Kikuyu Eye Unit study by Yorston et al 50.0% of the grafts done were for keratoconus (7). Chen et al noted that a majority of corneal transplants performed in Kenya (66.1 %) were carried out for KC (20) with similar findings noted in previous studies (7,25). In a study done by Rashid et al in Kenya, it was noted that KC presents at a very early age (75.0% of patients were within 6 years and 25 years) (21). All patients were African (99.0%) mainly from a low socioeconomic background. Risk factors include vernal keratoconjunctivitis (26), which occurs more commonly in children in other African countries (27,28).

Records from 254 patients were analyzed, out of whom optical correction was given in 98.0% of patients. Early occurrence of the disease suggests a more severe form of the disease, which progresses more rapidly to surgery (29-31). 16.5% of patients were referred for corneal transplantation because optical correction was inadequate (21). A systematic review noted

that patients with keratoconus have a remarkably impaired vision related quality of life that progressively worsens (32). This may be addressed by performing PK for these patients.

2.3 Disability Adjusted Life Years

The gravity of corneal blindness in a society is affected by several factors besides its prevalence (1). In terms of Disability Adjusted Life Years (DALY), childhood blindness is second only to cataract (8). Corneal blindness tends to be more prevalent among the younger age groups as compared to cataracts; hence the total number of blind years is greater. Children have a longer life span and hence the many blind years (number of the blind children x length of life). This has been found to appreciably reduce their overall psychological, social and economic development (8). Penetrating Keratoplasty has been shown to correct the visual impairment in the majority of patients, therefore the child will be attend a regular school and improve their educational status (7,20).

2.4 Corneal Donation

2.4.1 History of Corneal Donation

Alexandra et al reviewed the history of corneal transplantation and identified a Greek physician named Galen who initiated corneal surgery in 130-200 AD. After several years of research into immunology, antiseptic principles and surgical techniques, the first prosperous corneal transplant was carried out in 1905 by Eduard Zirm (33). The tissue was harvested from a patient aged 11 years. Transplants were hardly undertaken mainly due to lack of donor programs and tissue was sparsely available. A prominent surgeon in New York City, Dr. R. Townley Paton was an early pioneer in sourcing and harvesting of donor cornea, which is currently referred to as eye banking.

In order to attain corneal tissue, Dr. Paton drove sixty-five kilometres to Sing Sing every time a prisoner was executed. Harvesting from prisoners was the only available source of donor eye tissue. To overcome this complex process, Dr. Paton and a few partners founded an eye bank in 1944. It was the first of its kind. New regulations governing eye donation had to be approved and the public urgently needed to be educated on the same. As corneal transplant surgery became more successful, the need for eye tissue for transplant multiplied. Eye banks began to increase in number in order to meet the need. Corneal tissue was primarily obtained

through enucleation; however, excision of a corneo scleral button is now practiced. After harvesting donor tissues, they are stored in an eye bank.

2.4.2 Eye Bank

Eye banks are the institutions that collect and process donor corneas, and redistribute them to trained corneal surgeons for transplantation (34).

Cornea harvesting is the surgical removal of the entire globe (enucleation) or the cornea (corneal button) from a deceased person. This is performed by adequately skilled eye care staff (eye bank personnel, doctors training in ophthalmology programmes, ophthalmologists, or medical practitioners) in homes, hospitals, and funeral grounds (34).

Before harvesting, information regarding donor risk assessment is acquired. This includes donor's biodata; cause and time of death and medical history. History is obtained from donor medical files, healthcare staff, family members and autopsy report if available. Blood samples should be collected just before death or soon after (not beyond 24 hours after death). The minimal tests required include HIV 1 and 2 antibodies, HBsAg; HBc antibody; HCV antibody; Syphilis and HTLV-I antibodies are required (35). In Kenya, the Kenyatta National hospital is fully equipped to perform these tests and would be a suitable location to establish eye banking services.

2.4.3 Donor Age and Post Mortem Time

Cornea should be harvested within 6 hours of death and preserved immediately. Upon examination with a specular microscope, if the endothelium is found inadequate the tissue will be excluded. Age limits are set depending on surgical corneal demand. Time between death and corneal harvesting must be documented (35).

2.5 Criteria on Contraindications to use of Corneal Tissue

Tissue would not be taken from donors with malignant diseases such as retinoblastoma, haematological neoplasm (such as leukaemia, lymphoma, myeloma) and malignant tumours of the anterior segment of the eye (i.e. primary tumours such as conjunctival intraepithelial neoplasia, squamous cell carcinoma or malignant melanoma) as well as metastasis in the anterior ocular segment from other primary malignant tumours.

History, clinical or laboratory evidence of HIV or AIDS, acute or chronic hepatitis B (except in the case of persons with a proven immune status), hepatitis C and HTLV I/II, transmission risk or evidence of risk factors for these infections.

Eye diseases and ocular surgery: congenital or acquired disorders of the eye (e.g. herpetic keratitis), or previous ocular surgery, that would prejudice graft outcome (e.g. corneas with previous refractive surgery, or stromal scars, may be acceptable for posterior lamellar keratoplasty).

There is only one eye bank in Kenya, the Kanubhai Babla Lions Eye bank (KBEB). It is situated at the Lions SightFirst Eye Hospital and is a charitable and comprehensive eye care institution located approximately 14 kilometres from Nairobi city centre. KBEB has trained some technicians to harvest corneas. Donor tissue is harvested from homes and hospitals from donors who are already committed to donate their corneas through signed pledge forms/cards. Pledge cards are handed out, with well known public figures signing their pledge cards during hugely advertised appearances. In Kenya, KBEB advertises on billboards along streets near major hospitals.

Donors are mainly approached through one on one interaction with Lions personnel in various social gatherings. Majority of the donors in Kenya are mainly Hindus. Anecdotal evidence suggests this could be due to their religious beliefs that promote charity such as organ donation or other activities that will be of help to humanity. However, a study done in India concluded that some participants were not willing to donate their eyes due to religious disbeliefs (36). Majority of participants in this study were from the Hindu religion. There is yet to be a cornea harvested from any black African in Kenya with anecdotal evidence suggesting it could be due to various cultural taboos, religious factors or lack of awareness.

In Ethiopia, there are public awareness programmes that include celebrities and public figures including the President of Ethiopia and sportsman Haile Gabreselassi who encourage corneal donation. They have managed to register approximately 6,000 Ethiopians as voluntary eye donors (34).

Corneas harvested in Kenya are sourced from voluntary donation. A voluntary eye donor is any person who donates their eyes as an act of charity after his/her death, purely for the benefit of society and done from one's own free will without valuable consideration or legal obligation (37). Once a potential donor is identified and willing to donate, they fill in a pledge form. This is a form that states a person has willingly donated their corneas to be harvested upon death. It is filled in the presence of family members who also sign the form and give consent. Upon demise, the family members contact the eye banks who then go out to collect the tissue. Tissue harvested for corneal transplantation has a variety of other uses. These

include sclera patch grafting for patients with necrotizing scleritis, scleral staphyloma, scleral perforation (38) and for repair of extruded glaucoma drainage devices (39).

Notably, the demand for corneal tissue greatly outweighs the annual harvesting rate. Globally, it is estimated that approximately 12.7 million people require corneal transplantation, whereby one cornea is attainable for every 70 people (40). This situation is also reflected in Kenya. The total number of corneas harvested from KBEB were 138 in the year 2015, 208 in 2016 and 186 in 2017 out of which 74, 119 and 76 corneas were used in 2015, 2016 and 2017 respectively (41). In Ethiopia, the total number of corneal tissue harvested per year is 130-150 and out of these, 90-120 tissues are used in transplants per year(34). In an institute in India, a world record of 7166 corneas were harvested in 2017 with 2000 transplants performed in the same year (42). This suggests that there is potential for increase in corneal transplantation being performed in Kenya only if we are able to get more corneal donors.

Therefore, due to this shortage most of the corneal tissue is imported mainly from developed countries (7). The cost of importing corneal tissue is approximately 300-1000 U.S dollars, a price that a majority of those suffering from corneal diseases cannot afford. This highlights the need of harvesting local corneal tissue as it will be an affordable option for these patients. Some studies have revealed that cooperation from close relatives of potential donors is key to increasing the number of harvested corneas and therefore increasing willingness to donation among the population (11,34). This affects the quantity of tissues collected by eye banks. It is therefore useful for us to understand the knowledge, perceptions and the potential practice of Kenyan adults to corneal donation.

2.6 Eye Health Systems in Kenya

The current Kenyan population was estimated to be 38 million as per the national census carried out in 2009 (9). The human resource cadre includes ophthalmologists, ophthalmic clinical officers, optometrists, opticians and ophthalmic clinical nurses (8). There are approximately 110 ophthalmologists and 150 ophthalmic clinical officers with the majority of ophthalmologists practicing in and around Nairobi city.

Eye care services are currently provided by a combination of government, NGO's, private institutions and faith-based organizations (8). Among these treatment facilities, private institutions/mission hospitals are responsible for more than 90.0% of all corneal transplants performed in Kenya. There are approximately 12 surgeons who have been performing

corneal transplants; most of the tissue they use is imported. Of these, 4 are newly trained cornea surgeons: 3 trained in Aravind group of hospitals and 1 trained at LV Prasad Institute, as illustrated by Table 1.

Table 1: Institutions where corneal transplants are performed in Kenya

<i>National Referral Hospitals</i>	
Institutions	Number of surgeons who perform corneal transplants
KNH situated in the city of Nairobi	2 *
Moi Teaching and Referral Hospital	1
<i>Mission Hospitals /Faith Based Institutions</i>	
Institutions	Number of surgeons who perform corneal transplants
PCEA Kikuyu Eye Unit	3
Light House For Christ Eye Centre Located In Mombasa	1
Tenwek Mission Hospital Located In Rift Valley	1
<i>Private institutions **</i>	
Institutions	Number of surgeons who perform corneal transplants
Upper Hill Eye And Laser Centre Situated In The City Of Nairobi	2
Aga Khan University Hospital Situated In Suburban Nairobi	1
Lions Sightfirst Eye Hospital Situated In Loresho, Nairobi	2

* One of the specialists is a visiting surgeon from USA

** There are other private institutions in Kenya performing corneal transplant services

Corneal processing and transplantation services require to be set up in a highly specialized centre that has access to cornea transplant surgeons. In the public healthcare system, this would require a national referral health facility. It is the top most institution among the

hierarchy of health systems in Kenya that caters to distinctly specialized health care requirements.

Kenyatta National Hospital (KNH) would thus be the ideal centre to set up an eye bank that is accessible to all health care stakeholders in both the public and private health care sector. It is well equipped with laboratory services that can perform the necessary tests required on corneal tissue that are required.

2.7 Health Promotion and Behaviour Towards Corneal Donation

The health seeking behaviour of an individual is influenced by multiple factors, one of which is the individual's culture. This is especially so in regards to corneal donation. It may influence their perception towards eye donation, which is affected by religion, practices and traditional beliefs. These are also shaped by an individual's perspective which is majorly influenced by interactions with other people in society. There are several theories that seek to explain an individual's health seeking behaviour. In regards to corneal donation, the socio-ecological model elaborates this well. The Theory at a Glance: A Guide for Health Promotion and Practice frames the socio ecological model as the interaction between, and interdependence of, factors within and across all levels of a health problem. It focuses on the interplay between people and their physical and socio-cultural environments (43).

The socio ecological model identifies several levels of impact, which include individual factors, interpersonal factors, organizational factors, community factors and public policy factors.

Individual factors include knowledge, perceptions, beliefs and personality. Interpersonal factors consist of interactions with other people, which can either create barriers to health behaviour or create social support towards it. Organizational factors include rules and regulations that promote or restrain healthy behaviour. Community factors encompass formal or informal norms that prevail amidst people, groups or institutions that promote or limit healthy behaviour. Public policy factors include local or state policies or laws that support or limit healthy actions.

Little is known about corneal donation in Kenya. Anecdotal evidence suggests that corneal donation is limited by several factors. We would like to identify these factors, starting from the individual's knowledge, perception and beliefs. Interactions with family members have been shown in several studies to hinder corneal donation (11,44). Organizational factors in Kenya would include the lack of a national eye bank that is accessible to all patients and

other stakeholders countrywide. Community factors include cultural and religious beliefs, that in the African setting, have been shown to limit corneal donation (11,20). At the level of state/ government, the Human Tissue Act promotes corneal harvesting.

In Sub-Saharan Africa, a study done in Ethiopia by Gessesse et al concluded that a good proportion of participants were willing to donate their corneas although their level of awareness was low (45). An Australian study done by Lawlor et al documented that a favourable number of families agreed to solid organ donation but categorically refused cornea donation (44). According to this study, the decision not to donate was due to concerns surrounding disfigurement. This has now been addressed by the change in corneal harvesting technique, from whole globe enucleation to corneo scleral button. It also identified that the decision about corneal donation is more complex than the decision made by the deceased alone. It was concluded that several participants saw the value of involving their family members involved while determining whether or not they will donate.

A study done by Ting Chu et al showed refusal to donate is the most important limiting factor (46), while according to Bhandary et al in Malaysia found that even though a large proportion of patient attendants had knowledge on eye donation, willingness to donate corneas was poor (47).

2.8 Problem Statement

In Kenya, there is no published study outlining the willingness or barriers to corneal donation. According to the human tissue act, a person may donate his or her body part or any specified tissue for the purpose of corneal transplantation (48). In spite of this provision in our constitution, the level of corneal donation is still very low.

2.9 Justification

Corneal diseases are a significant cause of blindness and visual impairment especially in less developed countries. Advanced disease is managed by corneal transplantation. In Kenya, despite having the presence of an eye bank, the rate of corneal donation is very low and the current supply is unable to match demand. This is likely due to lack of awareness on corneal donation and cultural barriers/taboo. It could also be due to the fact that no study has been done in Kenya prior to establishing an eye bank that will seek to assess willingness to corneal donation and therefore help inform the success of an eye banking system in our setting. The

purpose of this study is to assess the awareness and willingness to donate corneas and at the same time spread awareness for eye donation.

2.10 Objectives

2.10.1 Broad Objective

The broad objective was to assess the level of knowledge about corneal donation, perceptions on willingness to eye donation and its associated factors among adults in a community in Kenya.

2.10.2 Specific Objectives

The specific objectives are;

- a) To assess the level of knowledge on corneal donation among adults in a community in Kenya.
- b) To determine the willingness on corneal donation among adults in a community in Kenya.
- c) To determine the barriers to corneal donation among adults in a community in Kenya.

3.0 MATERIALS AND METHODS

3.1 Study Design

The study was cross sectional using both qualitative and quantitative components. The quantitative aspect provided answers to the research objective while the qualitative aspect supplemented answers in quantitative part of the study by providing explanation to the data collected. The study adopted sequential mixed method design, starting with the quantitative component and followed by the qualitative component. This allowed the researcher to use the data collected from the semi structured questionnaire to inform the collection of data from the focus group participants and key informant interviews.

3.2 Study Area

Study sites were Kiambiu slum and KNH. The slum is located in Kamukunji constituency, approximately 4 kilometres east of the centre of Nairobi with a population of approximately 50, 000 residents. In the eventuality that a resident falls ill, they will likely seek for medical assistance from the nearby health centre. For those with complicated diagnosis, they will be referred to a centre that will offer specialized care. Kiambiu and its environs are under the catchment area served by KNH and it is the public hospital of choice. There is a high likelihood that these residents will be referred to KNH, creating a potential donor base for the voluntary eye banking services. The study site was chosen due to ease of availability of participants for home to home visits, presence of a community gate keeper whom I have established rapport with and a population that is considered highly likely to come to KNH for specialized treatment.

KNH is located approximately 3.5 kilometres from Nairobi City Centre in Kibra constituency, Nairobi, Kenya. It is a multi-specialty hospital that attends to an annual average of 70,000 in patients and 500,000 outpatients. It serves as a catchment area for Eastern, Central and Nairobi region, thus for this population. Furthermore, KNH is a potential centre to set up a national eye bank with availability of credible medical records and trained corneal specialists. Figure 1 below is a map showing the location of Kiambiu slum and KNH (49).

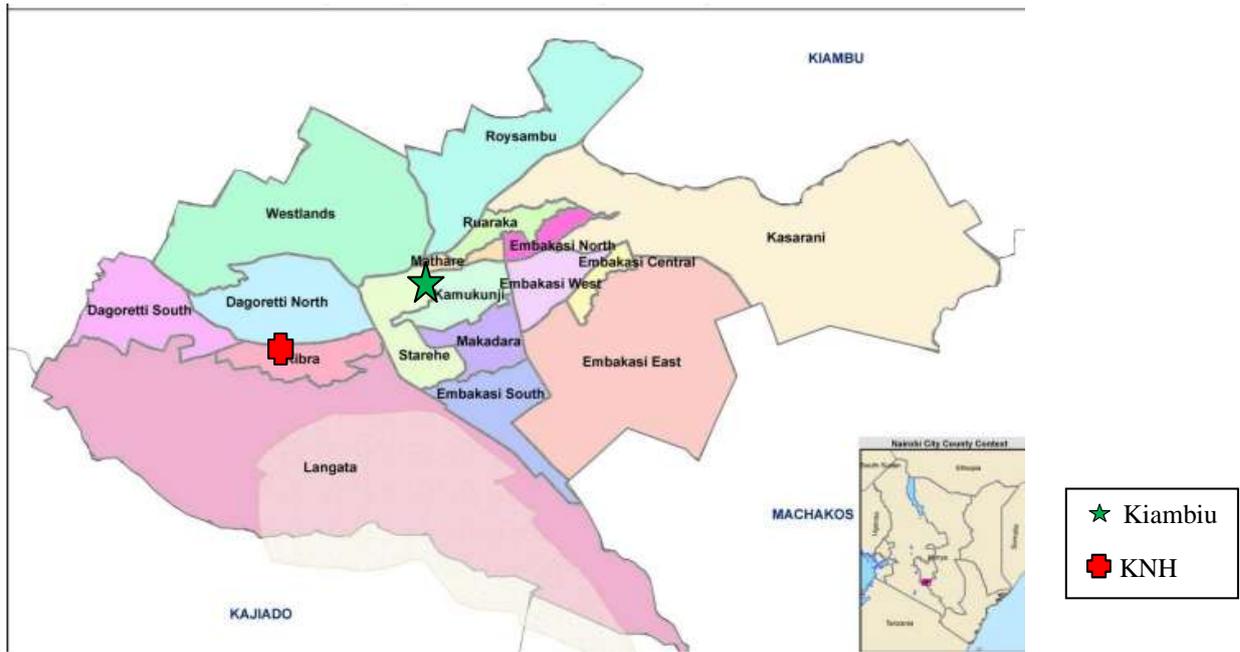


Figure 1: Map of Nairobi showing location of Kiambiu slum and KNH

3.3 Study Period

The study was carried out from August 2018 to June 2019.

3.4 Study Population

This included adults aged 18 years and older who reside in Kiambiu slum. They each had an equally likely chance to participate in the study. Key informant interviews were conducted in KNH. Informants included Head of Nursing Services KNH, Head of Department-Ophthalmology KNH, Deputy Director of Clinical Services KNH and Head of Ophthalmology services in Kenya.

3.5 Sample Size Determination

We administered semi structured questionnaires to 106 participants. This number was derived at based on studies done by Creswell et al on strategies for qualitative research (50). This also coincides using the Kish and Leslie computed sample size calculation formula shown below.

$$n1 = \frac{z^2 p(1-p)}{e^2}$$

In this formula,

p= proportion of persons expected to accept to donate cornea (50%)

e = sampling error of 0.1 and

Z = 95% confidence level (Z score 1.96).

$$\frac{1.96^2 \times 0.5(1-0.5)}{0.1^2}$$

Therefore n1= 96 participants.

It was approximated that we may have a 10% non-response rate

(10% * 96 participants = 9.6 participants = ~ 10 participants)

Therefore to compensate this we added these participants to the calculated number (ie 96+10)

Therefore n1= 106 participants.

We aimed to have eight FGDs with a minimum of 8 participants each and maximum of 12 participants each. However, the number of FGDs was determined by reaching the saturation point. This is because if the responses yield the same recurring themes then no new insights will be given by addition sources of data. When this point was reached, we analysed the data collected using thematic analysis. Key informant interviews had a minimum of four participants.

3.6 Inclusion Criteria

A person living/working in Kiambiu slum aged ≥ 18 years of age who gave consent to participate in the study.

3.7 Exclusion Criteria

A person living/working in Kiambiu slum aged ≥ 18 years of age with impaired mental status since they are unable to consent to the study.

3.8 Data Collection Procedure

Two research assistants from the community were selected and trained to assist in data collection. The research assistants included two nurses from Living in Total Health Initiative (LITHI) clinic situated within the slum. They were willing to participate in the research and permission was obtained from LITHI administration.

The nurses were trained on administration of the questionnaires and also use of the eye model to further explain the anatomy of the eye as per the protocol of the questionnaire.

They were trained to explain what eye donation entails and to answer any questions at the end of the interview process in regards to donation. This was useful as it helped to spread awareness on eye donation among the community. The study was conducted via administration of questionnaires through home visits, focus group discussions (FGDs) and key informant interviews. Permission was sought from the local administrative authority before administering the questionnaires.

Stratified sampling was carried out for both the quantitative and qualitative aspects of the study. According to the national census carried out by the Kenya National Bureau of Statistics in 2009, the population of Kiambiu slum is estimated to be 50,000. Since we were only interested in those residents who fulfil the inclusion criteria, our sampling frame was less than 50,000.

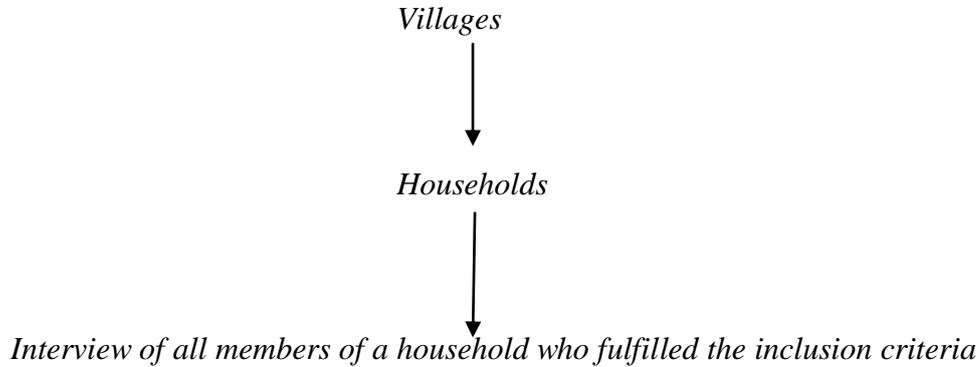
3.8.1 Administration of Questionnaires

Participants were selected via stratified sampling. In order to administer the questionnaires, I stratified the participants based on villages and households. There are six villages within Kiambiu slum. We used simple random sampling to choose which of these villages to select our participants from. The community gatekeeper had already mapped out the households and this aided in identifying which households to administer the questionnaire. The households were written down in form of a list. Simple random sampling was used to select which houses in the list will be selected for administration of the questionnaire. All members of each household who fulfil the inclusion criteria were interviewed via face to face interview. We aimed to interview 106 participants as per the sample size calculated.

Each participant gave informed written consent and then the questionnaire was administered. The research assistant administered the questionnaire in a language the participant was conversant with. The questionnaire consisted of several semi-structured questions that assessed socio-demographic characteristics, questions regarding knowledge on eye donation,

willingness to donate eyes and barriers to corneal donation. An eye model was used to demonstrate the location of the cornea for those who were not familiar with the terminology. The technique was as illustrated below;

Administration of questionnaires



3.8.2 Focus Group Discussions

After administration of questionnaires, we proceeded to select participants for the FGD. They were selected via stratified sampling. These participants were not part of those interviewed using the questionnaire. They were further stratified depending on presumed socioeconomic status, gender and age. We used the list of households mapped and excluded the ones that were part of the administration of questionnaires. Out of the households remaining, the research assistants and community gatekeeper identified which household is in a stone house or shanty, which member of each household is male or female and the age of each member of the household. The participants were then invited to a focus group discussion. Each focus group had 8-12 participants with homogenous characteristics e.g. 18-35 year old males who reside in shanties formed one group, females who are 36 years or older and reside in stone houses formed another group.

The research assistant was trained on data collection prior to conducting the FGD and also participated in note taking. An audio recorder was used to supplement written notes. The qualitative analyst assisted the principal investigator to conduct the interviews, transcribe and analyze the data collected.

The FGDs were conducted in a rented facility within the slum that was easily accessible to all invited participants. This was in order to reduce the likelihood of participants sharing information concerning the study. We recruited 8-12 participants per FGD who had not been interviewed during administration of questionnaires, were comfortable in each other's presence, communicated in the same language, and had homogenous characteristics e.g. age,

type of residence(in order to cater for socioeconomic segregation, we divided participants into those living in mud houses/shanty to be in different focus groups from those living in ‘mabati houses/stone houses’. Interview guides were used to collect data through audio recording of the interviews.

The technique of stratification for FGDs was as illustrated in Figure 2

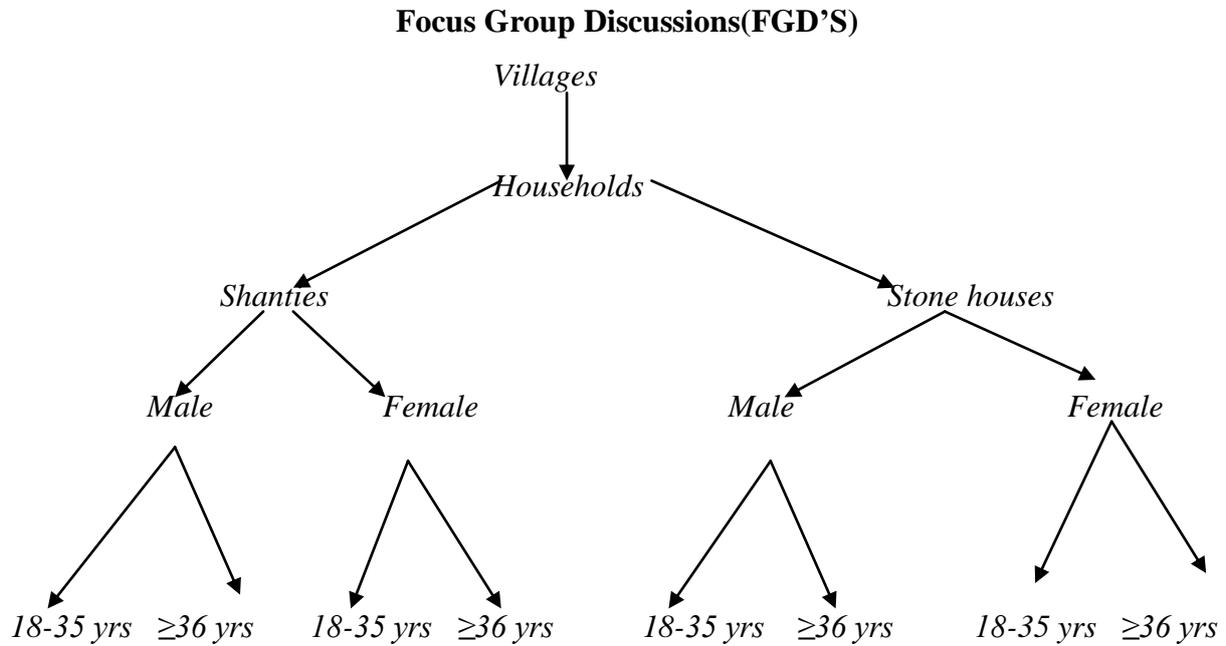


Figure 2: Stratification for FGDs

3.8.3 Key Informant Interviews

The principal investigator and qualitative analyst conducted the key informant interviews and notes were taken to supplement the audio recordings. Participants in the key informant interviews included a minimum of two religious leaders of influence within the slum, Head of Nursing Services in Kenya, Head of Ophthalmic Services in Kenya and Head of Department-Ophthalmology at KNH.

The nursing officer provided information on their perception towards counselling patients and relatives concerning eye donation. Nurses interact more frequently with patients/ relatives in comparison to other health cadres in most hospitals. The head of the Ophthalmology department at KNH provided information about factors that limit corneal transplantation at the institution. The head of the Division of Ophthalmic services at the ministry of health in Kenya provided information on whether the government was willing to improve public awareness to eye donation.

3.8.4 Data Storage

All data was handled with confidentiality and the principal investigator stored the questionnaires in a locked cabinet and kept the key at all times. Data was stored on a computer which was password protected.

3.9 Data Statistical Analysis

Qualitative data was analyzed via thematic analysis using Atlas.ti software. The first step involved reducing the data through phrases, words and concept in the data allowing the formation of codes. Further reduction of the data was conducted through classifying the codes into categories. This involved categorization of respondent's profile and codes emerging from the participants. The final stage involved searching common threads among the participant's categories to form themes. The study used sequential mixed method design in the discussion of findings in presentation of study results. Statistical Package for Social Scientists (SPSS) Version 22.0 was used to statistically analyze the coded data. The descriptive parts of the data were summarized using measures of central tendency and dispersion. The analyzed data were organized and presented in tabular and graphical forms.

3.10 Ethical Consideration

Ethical approval was obtained from the Kenyatta National Hospital/University of Nairobi Ethics and Research Committee. The objective of the study was clearly explained to each participant. Written informed voluntary consent was sought from each study participant. Confidentiality was assured through keeping records safely locked away and all soft copy records were password protected. Participant identifiers were omitted by assigning anonymised codes.

4.0 RESULTS

The total number of participants recruited for the quantitative section in this study was 106. It was carried out between the months of March and April 2019. The following sub-sections profile results of the survey.

4.1 Socio-Demographic Characteristics

A total of 106 respondents participated in the study with a mean age of 32.7 years (standard deviation(SD) \pm 11.7). The minimum age was 20.8 years and the oldest respondent was 61.5 years. This is illustrated below.

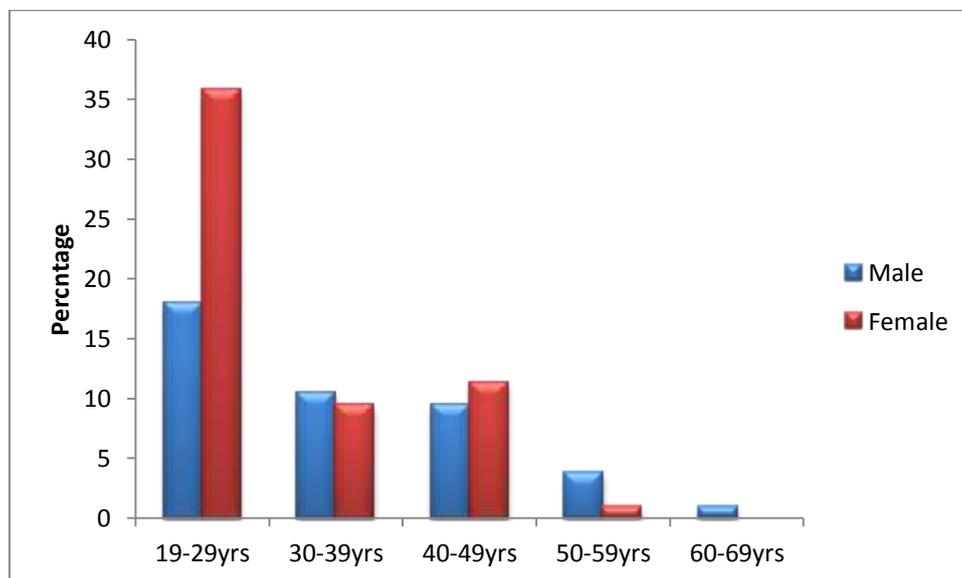


Figure 3: Age and gender distribution of participants

Out of these respondents, 61(57.5%) were female and 45(42.5%) were male. Majority of participants were Christians and out of these, 63(59.4%) attended mainstream churches. The dominant ethnic groups were Luo, 40(37.7%) followed by Luhya, 34(32.1%).

With regard to marital status, the married participants were 83(78.3%) while 20(18.9%) were single. More than half the group, which is 60(56.6%) respondents, had completed post primary education. Table 2 profiles the socio-demographic characteristics of the respondents.

Table 2; Sociodemographic characteristics of the study respondents

Variable	Category	Frequency(%) (N=106)
Gender	Male	45(42.5)
	Female	61(57.5)
Religion	Mainstream churches	63(59.4)
	Evangelical	38(35.8)
	No church	3(2.8)
	Did not disclose	2(1.9)
Ethnicity	Luo	40(37.7)
	Luhya	34(32.1)
	Kikuyu	13(12.3)
	Kamba	10(9.4)
	Others	8(7.55)
	Did not disclose	1(0.9)
Marital status	Married	83(78.3)
	Single	20(18.9)
	Others	3(2.8)
Completed educational level	Secondary school	47(44.3)
	Primary school	42(39.6)
	College/ University	13(12.3)
	No formal education	4(3.8)
Occupation	Business	44(41.5)
	Craft	20(1.9)
	Formal employment	12(11.3)
	Housewife	10(9.4)
	Unemployed	8(7.5)
	Did not disclose	6(5.7)
	Others	5(4.7)
	Trader	1(0.9)

4.2 Level of Knowledge on Corneal Donation

Out of 106 respondents, majority 81(76.4%) had not heard about eye donation and only 25(23.6%) had heard about it (figure 4).

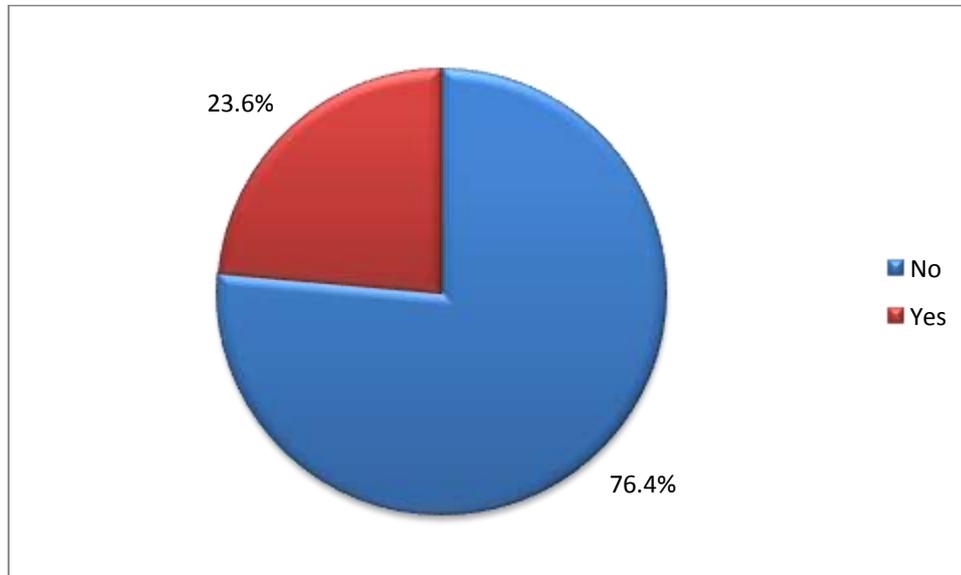


Figure 4: Participants who have heard about eye donation

The main source of information included family/friends 12(48.0%) followed by a radio and television 4(16.0%). The graph below (figure 5) shows the source of information.

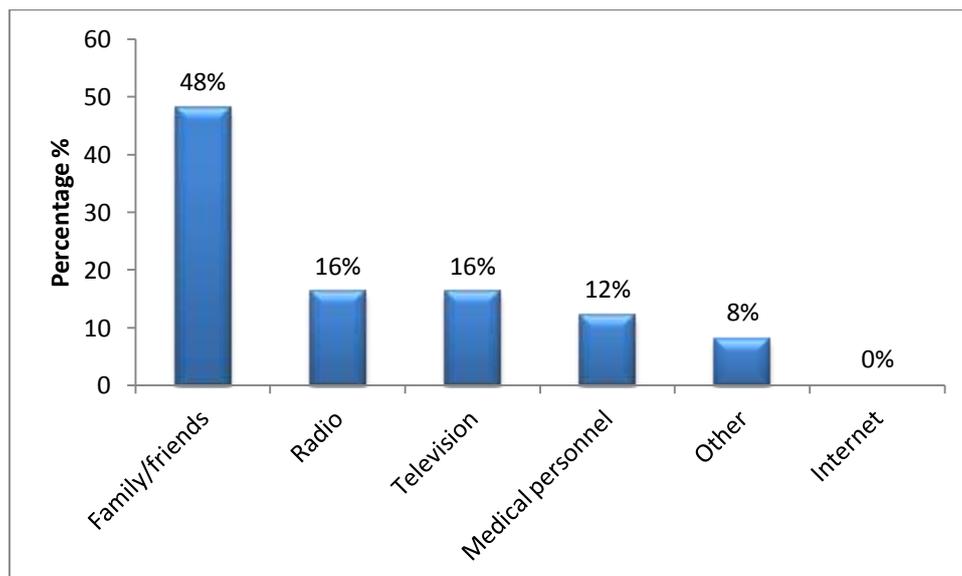


Figure 5: Source of information on eye donation

Majority of those aware (n=25), that is 11(44.0%) did not know which part of the eye is donated with only 8(32%) of them having correct knowledge that the cornea is the part of the eye donated.

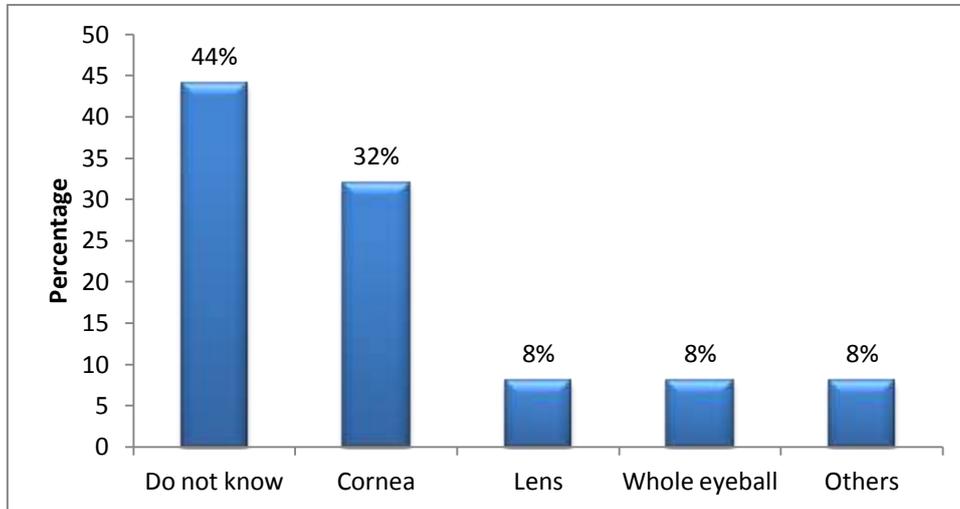


Figure 6: Knowledge on part of the eye donated

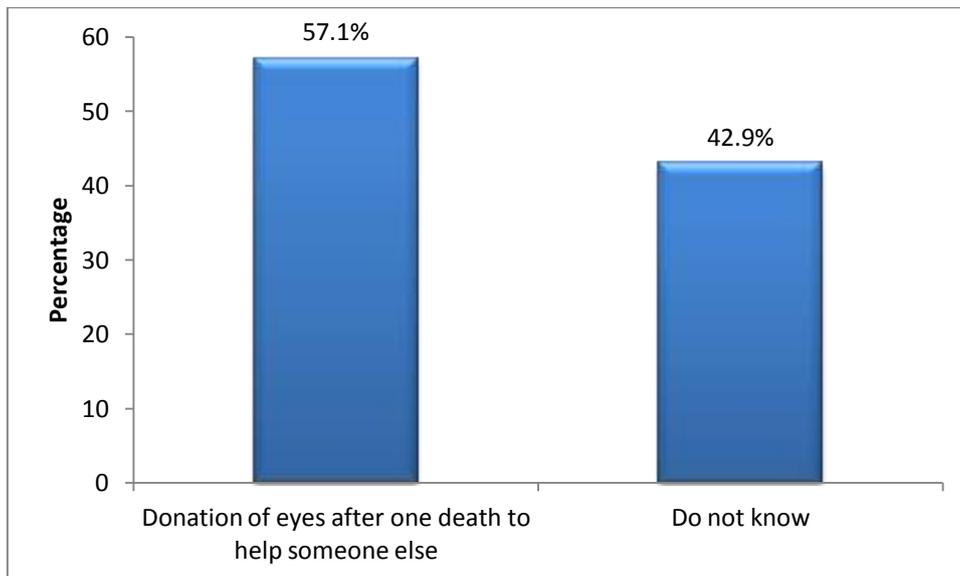


Figure 7: Participants understanding on corneal donation

From those who knew that the cornea is the part of the eye donated, 4(57.1%) of them acknowledged that corneal donation is after one's death to help someone else see. Most, 5(62.5%) of the participants did not know that the Kenyan constitution allows corneal donation and 4(50.0%) of them acknowledged that the cornea cannot be removed from a living person for donation. More than half, that is 15(60%) respondents agreed that a living

person can pledge to donate their eyes. With regard to eye banking, 9(8.5%) participants have heard of an eye bank and only 1(11.1%) respondent knew that there's an eye bank in Kenya. Approximately 36(34.0%) participants were of the opinion that an eye can be sold or bought.

Table 3: Knowledge on corneal donation:

Variable	Yes	No	I don't know
	Frequency(%)	Frequency(%)	Frequency(%)
Does the Kenyan constitution allow corneal donation? (N=8)	2(25)	1(12.5)	5(62.5)
Can the cornea be removed from a living person for donation? (N=8)	2(25)	4(50)	2(25)
Can a living person pledge to donate his or her eyes? (N=25 ;*7 (28.0%) did not disclose)	15(60%)	2(8.0%)	1(4.0%)
Is it necessary to get the opinion of a close relative when pledging for eye donation? (N=106)	85(80.2)	18(17)	3(2.8)
Have you ever heard of an eye bank? (N=106)	9(8.5)	97(91.5)	0(0.0)
Is there an eye bank in Kenya? (N=9)	1(11.1)	2(22.2)	6(66.7)
Can a human eye be bought or sold? (N=106)	36(34.0)	47(44.3)	23(21.7)

Some questions had fewer participants answering them hence N<106

4.3 Willingness on Corneal Donation

In this study, majority 60(56.6%) participants were unwilling to donate their cornea while 40(37.7%) were willing. The figure below is a pie chart illustrating the willingness to corneal donation.

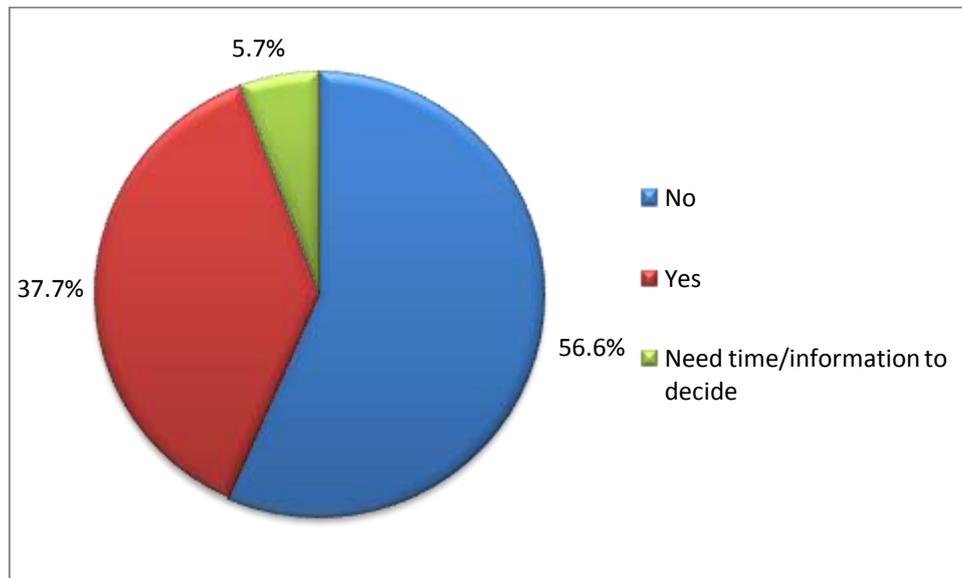


Figure 8: Proportion of participants willing to donate their own cornea

The reasons for unwillingness were mainly the need for an intact body after death 32(51.6%) and refusal by family members 10(16.1%). The figure below illustrates the reasons for perceived lack of willingness to donate.

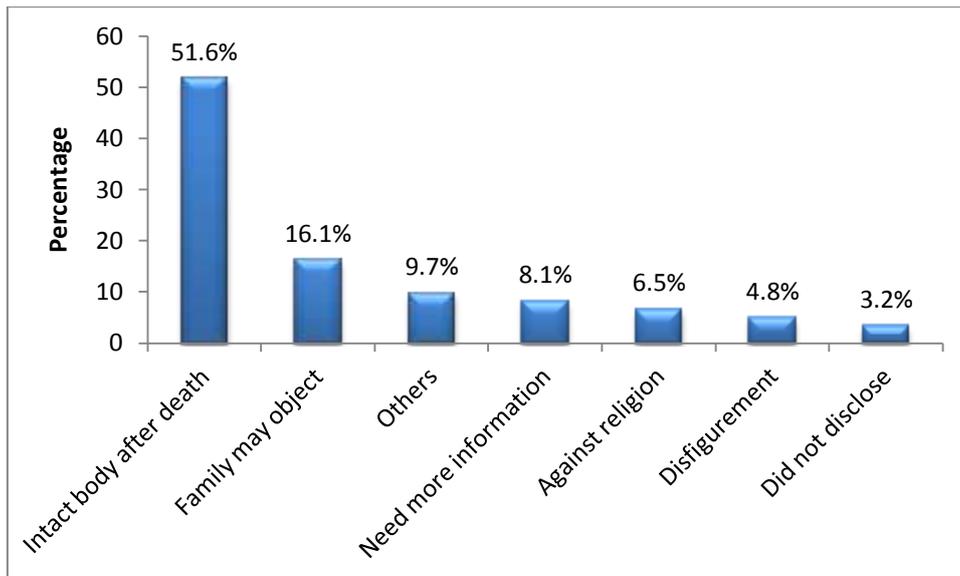


Figure 9: Perceived reasons for lack of willingness to donate own cornea

On the other hand, 40(37.7%) respondents were willing to donate their own cornea. Their perceived reasons were because it is a pleasure to help a blind person, 30(75.0%) and the eyes are not useful after death, 6(15.0%). This is as illustrated in the figure 10 below.

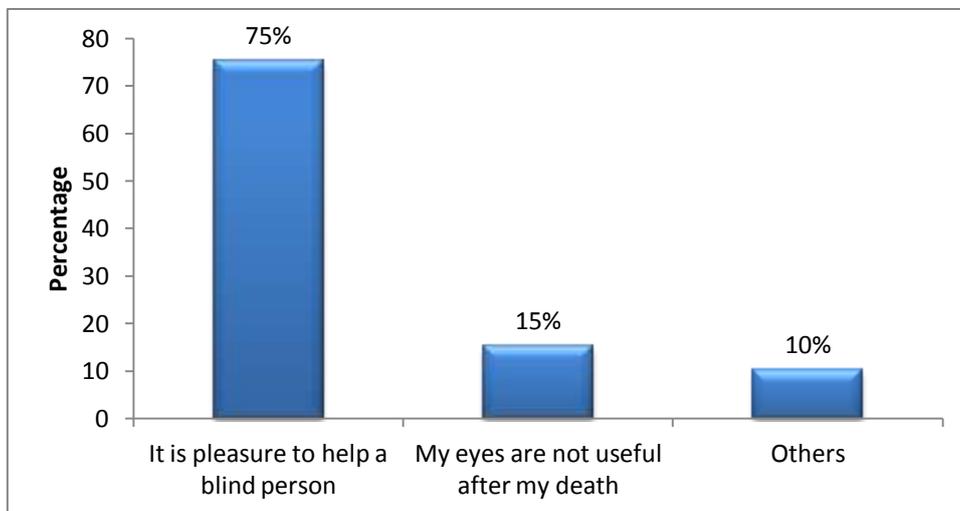


Figure 10: Perceived reasons for willingness to donate own cornea

However, more than half, that is 72(67.9%), of the participants would agree to their next of kin's cornea being harvested if they had pledged to corneal donation. The pie chart below demonstrates the number of participants willing to do so.

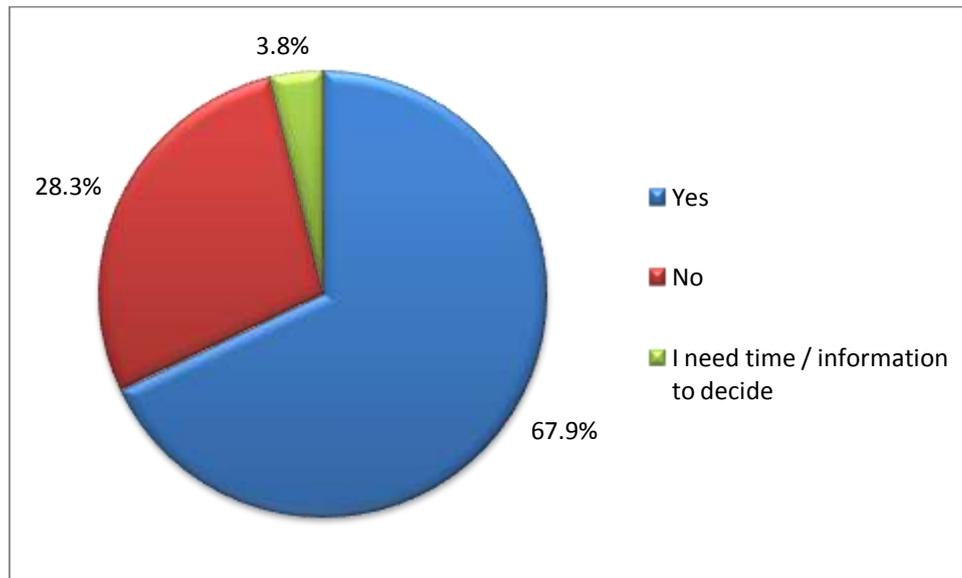


Figure 11: Number of participants willing to agree for their next of kin's pledged cornea to be harvested

The main reasons were to respect the wishes of the deceased, 40(55.6%) and deriving pleasure from helping a blind person, 26(36.1%). The table below lists the reason for accepting the next of kin's cornea to be harvested if pledged.

Table 4: Perceived reasons for agreeing to next of kin's pledged cornea to be harvested

Perceived reason for agreeing to next of kin's pledged cornea to be harvested.	Frequency	Percentage(%)
I would like to respect his/her wishes	40	55.6
It is pleasure to help a blind person	26	36.1
His/her eyes are not useful after death	5	6.9
Others (Only if paid)	1	1.4
Total	72	100.0%

30(28.3%) participants were not willing to donate the pledged cornea of their next of kin. The figure below lists perceived reasons for refusal to donate pledged cornea of next of kin.

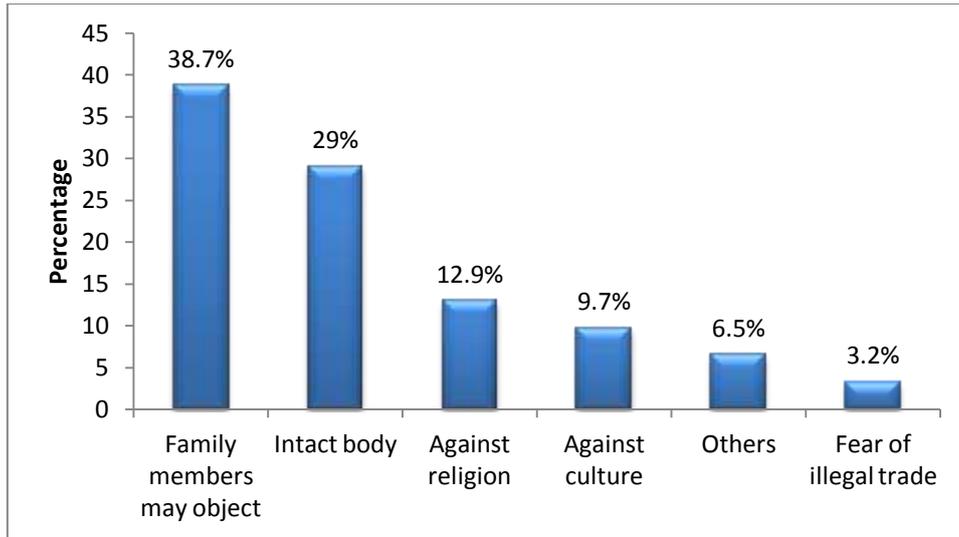


Figure 12: Perceived reasons to refuse the harvesting of next of kin's pledged cornea

The majority of participants, 12(38.7%) acknowledged that other family members may object to donation. Some participants, 4(12.9%) stated that it is against their religion.

Only 3(9.7%) of respondents noted that it is against their culture/tradition to donate.

4.4 Barriers to Corneal Donation

In this study, majority of participants,73(68.9%) did not have any cultural practices or traditions that would affect their decision to donate their own cornea. The pie chart below demonstrates the proportions of participant's responses to cultural practices in regards to eye donation.

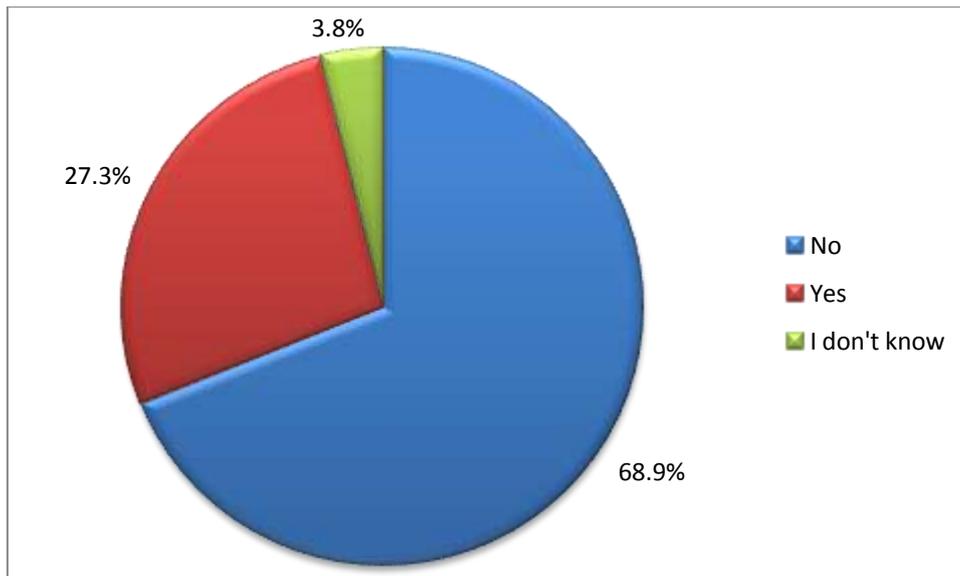


Figure 13: Proportion of participants affected by culture when deciding to donate cornea

Of those who had cultural beliefs that would affect decision to donate their own cornea, majority 22(68.8%) stated that it was because their culture requires the deceased to have an intact body. This is associated with beliefs that the dead will haunt the living and fear of use of body parts in witchcraft. This is as illustrated in the table below.

Table 5: Cultural practices that affect decision to donate cornea

Cultural practices that affected the decision to donate cornea	Frequency(%)
Body has to be intact before burial (dead haunt the living/ fear of use in w/craft)	22(68.8)
Other reasons (not sure of tradition/ confidential information)	5(15.6)
Did not disclose	3(9.4)
Eye donation is against the culture/ grandmother condemned act of donation	2(6.2)
Total	32(100.0)

Approximately 46(43.4%) had reservations towards corneal donation with majority 21(47.7%) responding that it is a shocking and new concept to them as they have never heard of eye donation before. The tables below illustrate this.

Table 6: Fears/Reservations towards corneal donation

Do you have any fears/reservations towards corneal donation?	Frequency (%)
Yes	46(43.4)
No	60(56.6)
Total	106(100.0)

Table 7: Reasons for fear towards corneal donation

Fears/reservations towards corneal donation	Frequency(%)
Shocking news, something new and foreign/ idea of harvesting from the dead is strange	19(43.2)
The information is scary; people who steal eyes may target me; if I agree I may be killed before my time	7(15.9)
Not an African concept/ taboo/unacceptable/ not happy to talk about death	4(9.1)
Did not disclose	4(9.1)
Human body should not be destroyed/ don't think the dead should be interfered with/ fear of disfigurement	3(6.8)
Against my religious belief	3(6.8)
Freemasonry/ fear of being sacrificed to illuminati	3(6.8)
Don't have adequate information/ don't understand how it can be achieved/ need more info	1(2.3)
Total	44(100.0)

4.5 Qualitative Findings

A total of eight FGD's were conducted with each group having 8-12 respondents. They were stratified based on gender, age and presumed socioeconomic status. Data was analyzed using thematic analysis and when saturation point was reached, further analysis was not done. In addition, a total of 3 key informant interviews were conducted. The following section describes the participant's views in relation to corneal donation.

4.5.1 Level of Knowledge on Corneal Donation

All the community members who participated in the FGD (females ≥ 35 years living in stone houses and those < 35 years living in mud houses; males ≥ 35 years living in stone houses and < 35 years living in mud houses) were not aware of eye donation.

All participants (females' ≥ 35 years living in stone houses and those < 35 years living in mud houses; males' ≥ 35 years living in stone houses and < 35 years living in mud houses) had never heard of human eye donation before but have heard of animal/plastic eye as expressed by the following participants.

"I have never heard of it. I've only heard of goat's eyes being put"(FGD, middle aged female, stone house zone)

"I have never heard of a human eye being donated, maybe a goat/sheep's eye"(FGD, young female, mud zone house)

"I once saw an old man being put an animal eye not a human eye."(FGD, young male, mud zone house)

All women and men aged ≥ 35 years and six men aged < 35 years reported the cornea cannot be removed from a living person for donation. Two men aged < 35 years believed that someone can give one eye to help. This is as expressed in the statements below;

"It is not possible"(FGD, middle aged female, stone house zone)

"As a sacrifice to help someone else but just to give one eye."(FGD, young female, mud zone house)

"It cannot. I need my eyes."(FGD young men, mud)

All participants (females' ≥ 35 years living in stone houses and those < 35 years living in mud houses; males' ≥ 35 years living in stone houses and < 35 years living in mud houses) agreed that the next of kin has to be informed if someone would like to pledge their cornea, as stated below.

"It has been said that once my cornea is removed they will replace it with something plastic. My people will definitely find out. So they have to be told because maybe they may have a heart like mine and may want to donate as well"(FGD, middle aged female, stone house zone)

"My opinion is that it is best to only tell the person who is closest to you, it is not a must to go advertising to everyone about my intention to donate. It has no value". (FGD, middle aged female, stone house zone)

"It is a must"(FGD, young female, mud house zone)

All women aged ≥ 35 years; ten women aged < 35 years; eight men aged ≥ 35 years and seven out of eight men < 35 years reported that it is mandatory to get the consent for eye donation from the next of kin after the death. Upon death of a voluntary eye donor, majority of participants stated that the next of kin has to be informed and only three participants said that it is not necessary. The next of kin were reported to be parents (six participants), husband (four participants), son (three), brother/sister (three); friend (two) and mother (one participant).

The main reason was that failure to do so will raise issues with family members as they will want to know where the eyes went to. For those who did not find it necessary, it was stated to be because the family already knew of his/her intention to donate, it was their personal secret or they did not approve of it. This is as stated below.

"It is a must that they are told because it will raise problems with the family. They will want to know where the eyes went to because when I was alive I had both eyes."(FGD, young female, mud zone house)

"They have to inform me. They have to tell me where the eyes went to, I must be shown the pledge form and it must be signed by the deceased. I must be called because if they don't do so it will become a case. How can my wife be buried without her eyes? It's impossible. They must inform me."(FGD, middle aged male, stone house zone)

"For the sake of peace and to avoid any quarrels I think it is important to inform them," (FGD, middle aged man, stone house zone)

" I don't think they will complain because I had already informed them of my intention to donate before I died. So they will not raise any problems, they will just acknowledge that I had informed them."(FGD, young female, mud zone house)

"No, it is not necessary. That is a personal secret." (FGD, middle aged man, stone house zone)

"It is difficult for me to answer that question because I cannot pledge to eye donation. If my wife pledged then she should go back to her people. If it was my mother then I will tell her to do it without my approval and to carry her own burden." (FGD, young male, mud zone house).

Two women aged ≥ 35 years; one woman aged < 35 years; seven men (≥ 35 years) reported that they would agree to eye donation of a relative who passes on while in a hospital in the event that they had earlier signed as next of kin; and when the community and family was well versed with 'what eye donation is'; to help those left alive;

Most respondents (five women aged ≥ 35 years) stated that it will depend whether the relative is a spouse or a child and also if the relatives will be present during that time of decision making. One participant (male aged < 35 years) stated that he will accept, however another participant (male aged ≥ 35 years) expressed that he will agree as he cannot stop the process. These findings are as expressed below.

"If it my husband's eyes it will be difficult. My relatives are those who believe that once someone dies they will come back. They may say I have probably joined the illuminati, I have removed their son's eyes and I planned his death. I cannot stay in that home; I will be chased away immediately. They will say I have killed their child. If it is my child I have a right to say that the eyes can be removed to help someone else. But if it is my husband they will have to investigate and ask where the eyes went to and conclude that I made money from their son's eyes." (FGD, middle aged female, stone house zone)

"I will agree because maybe someone out there needs to be helped," (FGD, young male, mud house zone)

"I will just agree because even if I don't they will still harvest them and put something else. When you get the body you'll just realize they have removed the eyes. Even if there are CCTV cameras recording everything, it is difficult to access those files. They will never accept that they sold those eyes. As long as the deceased had pledged to do so, they will just harvest. Nowadays these people do not obey the law." (FGD, middle aged male, stone house zone)

Some participants (two women aged < 35 years) were of the opinion that it would only be right if the deceased had consented or other family members are present to help make the

decision. Two participants (men aged <35 years) expressed they would want financial compensation. The findings are as expressed below.

"It would only be right if the doctors had talked to the deceased about it before he died and the next of kin was aware." (FGD, young female, mud zone house)

"I will incite my family members to demand to be paid if they want our relative's eyes. The amount will depend on the accumulated expenses that the deceased has remaining in view of funeral costs." (FGD, young male, mud house zone)

"That will bring very many issues. The eyes cannot be removed just like that. The family must be involved." (FGD, middle aged man, stone house zone)

In order to improve process of harvesting cornea from the hospital, nearly all respondents across the FGDs stated that it can be done through public education campaigns for example use mass media, health education forums and use of doctors to educate the public. This is as expressed below.

"You can educate people for them to know that only those who have volunteered can have their eyes removed. To know that even if they are buried with their eyes it will not help anyone." (FGD, middle aged female, stone house zone.)

"Africans are very difficult people. It is important for the person closest to the relative pledging to donate to be present when the doctor is giving information on eye donation." (FGD, young female, mud house zone)

"Use of road shows, so that people can understand this, just the way we understood about blood donation. So that when you want to harvest it is known to be a regular thing." (FGD, young male, mud house zone)

"Advertise using radio, TV, newspaper, in Kiswahili and English". (FGD, middle aged female, stone house zone)

Two participants (men aged <35 years and ≥35 years) however were of the opinion that it is not necessary to have eye education campaigns as it is not necessary. This is as expressed below.

"I think awareness will not work. I think people should just steal those eyes and then it should remain as a secret." (FGD, young male, mud zone house)

"No need to educate. Let them continue harvesting as they do because they are already doing it. If you now start educating people they will wisen up. Some people may want their relative to die so that they sell his/her eyes in order to cater for funeral expenses. Let them continue doing it as a secret."(FGD, middle aged male, stone house zone)

Two participants (male aged <35 years, female aged ≥ 35 years) were of the opinion that acceptance of eye donation will take time. This is as expressed below.

" It will take time for people to accept that information. For example in the 80's and 90's we didn't know much concerning HIV. People back in the village used to say it is chira/ taboo. People were not aware, but now they know and they have accepted it. Similarly it will take a while for people to accept eye donation."(FGD, young male, mud house zone)

"I think time will be far spent waiting for the relatives to come and we make a decision to harvest the cornea. It will be hard. It should be such that if we had a will and we had both agreed, I will call the relatives and tell them I proceeded with the donation because of the will and it is done."(FGD, middle aged female, stone house zone)

4.5.2 Cultural Views Regarding Eye Donation

Majority of participants (seven women aged ≥ 35 years; three women aged < 35 years, eight men aged <35 years and eight men aged ≥ 35 years) stated that eye donation according to their culture is unheard of however most agree that it is not acceptable. Most of them believe that the dead have to be buried with an intact body. This is as expressed below.

" I am a Luo. According to our culture, when someone dies they have to be inspected. If they find that the eyes are missing they will ask where the eyes went to. If it was an accident they will understand that maybe his head was hit by a car so they won't ask. But if they were removed they won't accept it. They will refuse to collect the body and it will remain in the mortuary. It will be a problem because they have never heard of it before."(FGD, middle aged female, stone house zone)

"It is hard because tradition must be followed. If the man is dead, the men will wash him and dress him. If they find him with any parts missing they will call the elders first to talk before discussing it with the other family members. The elders will have to follow traditional methods of finding out who took the

corneas from the dead person. I am a tiriki, we have many different customs.”(FGD, middle aged female, stone house zone)

“According to the Luo custom, no one is as respected as a dead person. He /she is given all due respect, even removing a finger is a problem as you may be blamed for killing him so that you can use the finger to repair yours. Now if you remove the eyes it will be a bigger problem, something they will never forget for the rest of their lives, it will become a statement in the whole of Kenya. They will say that eye donation is a hoax and a lie. That is where the problem is.”(FGD, young male, mud house zone)

Two respondents (female <35 years) also believe that the dead will haunt the living demanding that their eyes be returned to them, as expressed below.

“It is said that someone can rise again from the dead, so if this person rises without his eyes what will he/she see with? The person will definitely raise problems. That is our culture(Luo), I will not sleep, and his/her spirit will disturb me in my dreams asking for the eyes. It will force us to go exhume the body and return the eyes. If the eyes are not found there will be no peace. There will be no option but to commit suicide because he/she will keep haunting me, I will not be at peace. That is what we Luo people believe.”(FGD, young female, mud house zone)

“If the person had agreed to give his/her eyes while alive then he/she will not disturb the living. But if there was no agreement then he will haunt the living. I am a Luo.”(FGD, young female, mud house zone)

Four participants (one male ≥ 35 years and three males <35 years) expressed that the family members may resort to physical violence in order to protect their loved one's eyes. This violence is also seen when they are communicating with the corpse, for they believe that the corpse can still hear them. These are as expressed below.

“The people harvesting will be beaten and chased away from the homestead if they want to come harvest from the dead corpse. They resort to physical violence because they are not educated. It is important for people to understand about eye donation. They should know that it is not a problem. But currently they don't know and they have not been informed.”(FGD, middle aged male, stone house zone)

“Our country Kenya has very many cultures. If I agree to pledge my cornea, there will be war in order for you to harvest them. Our people will never agree. They will say this deceased person has joined a cult, is a devil worshipper, how is it that it is only the eyes that these people are after? You will be chased away because they will say you are the people who killed me. It is important to know how these issues can be addressed because I may agree to pledge to donate but once you come to harvest them you will be only two doctors and will be outnumbered by my people. I am a Luo.”(FGD, young male, mud house zone)

“Sometimes if a dead person refuses to go and be buried he will receive a thorough beating. If this doesn’t work then the corpse is transported with his legs facing upcountry and his head facing Nairobi so that he goes thinking that he is going towards Nairobi.”(FGD young male, mud house zone)

“In the Luo culture, they do not believe that someone will die and go away completely, that they have never believed. The Luo person believes that someone will still communicate after they are dead. Even when the corpse is being transported upcountry he refuses to have the car move while on the road. Someone then has to come and plead with the corpse in order for the car to move. The car usually has no technical failure but it will not move. The corpse will have to be spoken to and pleaded with so that the car can start moving again.”(FGD, young male, mud house zone)

Four participants (two females aged <35 years; two females aged ≥35 years) do not believe that culture plays a role when it comes to eye donation. Other cultures do not have any restrictions when it comes to eye donation. This is as expressed below.

“I am a Luhya/Luo. As long as someone believes in some things that is when they happen. If you do not believe then nothing will happen. I do not believe.”(FGD, young female, mud house zone)

“Our culture does not have such beliefs of disturbing the living through dreams/spirits. I am a Kikuyu.”(FGD, young female, mud house zone)

“I don’t believe in our customs/ traditions so much. As long as someone has died, I don’t think it’s a problem. I am a Luo.”(FGD, middle aged female, stone house zone)

“I am a Luo married into a family that comes from Nyakach; they worship God. They don’t follow traditional cultural practices”.(FGD, middle aged female, stone house zone)

All participants (females’ ≥ 35 years living in stone houses and those < 35 years living in mud houses; males’ ≥ 35 years living in stone houses and < 35 years living in mud houses) agree that the role that village elders in decision making concerning eye donation is very important. These elders are regarded in high esteem by members of the community and it is difficult to oppose them once a decision has been made. This is as illustrated below.

“The village elders are the decision makers. They are the ones who are the problem because once they decide on something it must be done.”(FGD, young female, mud house zone)

“If a body is found without the eyes then he/she will be considered an outcast. For example if someone died in a fire the body will be buried at night and not during the day. Now if they find a body without eyes the elders will believe there is a spirit linked to it and all people belonging to that family for generations to come will have their eyes removed by the elders upon their death. It is because those elders believe that the eyes are cursed in that homestead, so everyone in that family must have their eyes removed upon their death. They will not understand that I had my eyes removed willingly. Or for example if my eyes popped out during an accident they will tell the rest of the community to stay away from our family because we seem to have eyes that like popping out on their own.”(FGD, young female, mud zone house)

“Those village elders will never understand. In fact they can twist the eye donation programme to be that of being involved in idol worship/sacrifice. If I try to go speak to them about matters of eye donation they will become stressed. They will start asking why their child is suddenly talking about matters of death and removal of eyes. They will think I am possessed and will start rebuking me. They will not listen to me. They will not agree. I will be rebuked.”(FGD, young female, mud zone house)

All participants (females’ ≥ 35 years living in stone houses and those < 35 years living in mud houses; males’ ≥ 35 years living in stone houses and < 35 years living in mud houses) suggested that eye donation may become acceptable once the elders agree on it. It was found

to be important to engage the elders via dialogue via use of the local administrative units (chiefs), doctors, use of media and practical examples. This is as expressed below.

"The doctor must look for time to talk to these elders for them to understand."(FGD, young female, mud zone house)

"Those who have undergone eye transplants should come as living testimonies to the village elders. Those elders already have very many eye problems and are not happy with people getting these animal or plastic eyes. If they see these people who have received eyes and are working, especially in the presence of the chief or assistant chief they will accept. They cannot go against what the chief says. If they had accepted that people can get animal eyes or plastic eyes, will they refuse a human eye? If they see it is a human eye, nobody will refuse."(FGD, young male, mud zone house)

"Best way to reach people is through radio using vernacular languages."(FGD, young female, mud zone house)

4.5.3 Religious Views Regarding Eye Donation

Most participants (five males aged ≥ 35 years) stated that they have never heard of eye donation in their religion. They said that they have never heard it being taught. This is as expressed below.

"I have never heard of it. I attend PAG" (FGD, middle aged male, stone house zone)

" I don't know. I have never heard of it. Religion came to help both the good and the bad people. It's open. I am catholic."(FGD, middle aged male, stone house zone)

"I have never heard of it. I attend Baptist church." (FGD, middle aged male, stone house zone)

Two participants (both male aged ≥ 35 years) stated that the issue of eye donation is neither here nor there. This is as expressed below.

"They have not refused nor have they talked about it. I am a Protestant."(FGD, middle aged male, stone house zone)

"I am SDA. I have never heard whether they have accepted or refused such a thing."(FGD, middle aged male, stone house zone)

Two participants (one male aged ≥ 35 years; one male aged < 35 years) however stated that their religion will not allow it. Some of their religions believe that it will result in loss of dignity, as expressed below.

“According to the Islamic culture, if you bury a corpse without their body parts you will have denied him/her his dignity and the right to belong. That is the reality.” (FGD, young male, mud house zone)

“I don’t think they will agree. In the church they strictly follow bible teachings. It has not been written anywhere. I am SDA “(FGD, middle aged male, stone house zone)

4.5.4 Key Informant Interviews

Key informant interviews expounded more concerning the state of eye banking in Kenya as reported in the excerpts below.

“There is only one eye bank in Kenya. However, we (KNH) don’t have a physical structure in terms of eye banking. There is a commitment by the hospital to establish eye banking services within the next 5 years as part of the strategic plan. The financial resources will be identified and correctly channelled. KNH is willing to train staff on eye banking procedures. “(Key informant, department of Ophthalmology, KNH)

“I am aware of eye donation and I think it is a good idea because harvesting it may help somebody else who still needs it. I have heard of the human tissue act but I have not read it. I would encourage relatives to donate next of kin’s cornea only if there is evidence that the patient was willing to donate. Nurses trained in counselling can be selected for further training on eye donation and I would be willing to encourage the rest of the nursing team to counsel a patient’s relatives on eye donation. We would also need the help of the social workers. Majority of Kenyans do not know about eye donation, they only know of kidney and blood donation, and now breast milk donation which is coming up. In order to increase awareness on eye donation, we should incorporate outreaches by nurses, health education in clinics, project days at KNH and social media platforms ” .(Key Informant, department of nursing, KNH)

“There has been more uptake of services towards corneal diseases. We don’t have a functional eye bank; the KBEB has few donations that are sporadic and cannot sustain the market, thus most corneal tissue is imported. There is no reason why you should go to India for transplant when it can be done right here. We are in partnership with LVPEI, one of the leading institutes in India working out to develop the corneal bank in Kenya. The role of government is to facilitate eye donation and it is willing to support eye donation campaigns and all organ donations per say. In the last few months we’ve been attending some meetings that discuss required policies for eye donations. That is evidence that the government is supporting organ donation in Kenya. “(Key informant, MOH, department of Ophthalmic Services)

When it comes to religion, the two key informants interviewed stated that their religion may allow corneal donation. They were also willing to advocate for eye donation among their congregants. This is as exemplified below.

“When I look at eye donation, I don’t think that within religion it will harm the person. As long as the person has consented to it it’s okay. According to our religion I don’t think it is unacceptable. I would be willing to advocate for awareness. The bible says that if no one is sent as a messenger the information will not reach the people. I can teach others about it, but it will be up to the person and some organisations to help increase awareness. This can also be done through meetings and brochures with contact numbers to the eye donation unit. On the ground, for example in informal settlements, there are many groups e.g. community health volunteers to take the message to the villages. Then follow up is made, so that someone can make an informed decision. “(Key informant, Christian).

“I think it is okay because already God has called you. There is someone out there who will need a part of your body. Once you donate your eyes upon death and they are tested and found to be fit, it can be used by someone else. My view I feel that is very ok, as a catholic leader, I don’t think it is a bad thing. I can advocate for eye donation to members of our church, with the permission of our priest. In the Catholic Church, we have Jumuiya, which is a small Christian community. With permission from our priest, I can approach the leaders of the jumuiya who can then teach their group members on eye

donation during their meetings. That would be the best way to increase awareness.” (Key informant, Catholic)

5.0 DISCUSSION

This is the first published study to our knowledge to explore the knowledge, willingness and barriers to eye donation in Kenya using mixed method design. All participants targeted to answer the questionnaires were interviewed (100.0%). Triangulation was used in this study to ensure trustworthiness of data collected.

This study found that few participants 25(23.6%) were aware of corneal donation. Previous studies from other developing countries show that there is a higher level of awareness(56.7%) to corneal donation (11). This could be because the eye banking system is functional and there are eye donation campaigns supported by well-known personalities, including athletes and politicians (34). In Kenya however, the eye banking system is not fully functional, as most tissue is imported and whatever is harvested locally is sporadic and unreliable (7,20) . Other studies show that awareness to corneal donation ranges from 2.9% among residents of Saudi Arabia (51) to 54.7% among individuals attending outpatient clinics in Turkey (52) .

In our study, the main sources of knowledge on corneal donation was from family and friends 12(48.0%) as compared to other studies where this source contributed less at 19.0% (53) and 27.4% (36). In other studies (11,36,51,53-57) the most common source was television and other media (38.4%-95.0%). This difference is likely to be due to fact that there are no eye donation campaigns in Kenya and most participants in this study do not have access to a television set as compared to participants in other studies.

Majority of participants, 85(80.2%) found it necessary to get the opinion of family members when pledging for corneal donation. An Australian study by Lawlor et al identified that the decision about corneal donation is more complex than the decision made by the deceased alone. It was concluded that many individuals saw the benefit of having their family members involved in the decision-making process (44). This highlights the importance of involving the family unit when it comes to advocating for eye donation and creating awareness, as their opinion will highly influence an individual's decision to donate their cornea.

A large proportion of respondents had never heard of an eye bank, 97(91.5%) and over half of those aware, 6(66.7%) did not know that there is an eye bank in Kenya. Only 11.1% of participants were aware of an eye bank in Kenya. This is lower than a study done by Tilahun et al in Central Ethiopia where 16.7% responded that there is an eye bank in Ethiopia(45). This discrepancy is probably because eye donation campaigns are not present in Kenya as compared to Ethiopia, with the only eye bank in Kenya being located in a private hospital where most likely majority of participants have little access to as compared to it being set up

in a public hospital. From the experience of the already established kidney donation programme in Kenya, it was noted that the success of an organ donation programme depends on availability of dedicated resources, both physical and financial. The key informants at the ministry of health in Kenya and at KNH stated that the government is working hand in hand with an institution in India to develop an eye bank at KNH and there is space allocated to this project. It was also noted that the government is willing to support eye donation campaigns.

The proportion of those willing to donate own cornea was 40(37.7%), which is similar to a study done in North West Ethiopia (11) and India (53). However it is higher than the studies done in Malaysia (57) and Pakistan (58) and lower than the studies done in South India (56), Australia (44) and Singapore (59,60). The difference might be aroused from variation in literacy level, awareness level, availability of eye banks and study setting.

It was found that the main reasons for willingness to donate own corneas were deriving pleasure when helping a blind person, 30(75.0%) and the eyes not being of use after death, 6(15.0%). This is similar to other studies done in other African countries (11,61). This shows the great sympathy the people have towards the blind and their readiness for this noble purpose. This may indicate a person's selfless concern for others in order to achieve a desired goal in life. This may matter when a person decides to donate the eyes.

In this study, the main reason for unwillingness to donate own cornea was the need for an intact body upon death, 32(51.6%). This is consistent to another study where it was found necessary to have an intact body after passing away/dislike to separate the eye from the body, 59.4% (45). This could be for cultural reasons in our society where great respect is given for the dead body and taking a part of it may result in disfigurement of the body, considered doing against the norm.

Harvesting of cornea of the next of kin who had pledged to donate was found acceptable in 72(67.9%) of respondents. This is similar to another study (11) where the majority of the study participants, 73.3% were also willing to donate pledged close relatives' eyes upon the death of a person. This could probably be because the relatives may wish to respect the wishes of the deceased. Therefore there is need for those who have pledged their cornea to inform their family members of the decision made. This may probably increase the eye donation level within the country.

The main reason for unwillingness to donate their next of kin's eyes was because other family members may object to eye donation (38.7%). This finding is similar to a study done in Australia but different from studies done in other African countries where the main reason

for refusal was the need for an intact body (11,44,45). This difference is probably due to the fact that majority of participants expressed that it is the village elders who are the ultimate decision makers. It is highly likely that the participants may want to help someone else see but at the same time are aware that this decision may be too complicated for them to make alone and therefore were unwilling to donate. Some studies have revealed that cooperation from close relatives of potential donors is key to increasing the number of harvested corneas and therefore increasing willingness to donation among the population (11,34). As this is a complex process, it will also require the presence of trained counsellors and social workers, as stated by the head of nursing services at KNH.

The second most common reason for participants to refuse harvesting of kin's cornea was the need for the deceased to have an intact body, 9 (29%) similar to a study done in Northwest Ethiopia (27). This could be attributed to the interchangeable beliefs between an individual's culture and need to preserve the deceased as intact upon death. Religion and culture were also cited as reasons for refusal to donate next of kin's cornea at 4(12.9%) and 3(9.7%) respectively. This is similar to a study done in Northwest Ethiopia (27). This could partly be attributed to the religious teaching on handling and disposal of corpses. Addressing the religious leaders to educate people the basic teachings of their religions in relation to donations may help combat such misunderstandings. Key informant interviews carried out among the religious leaders revealed that their religion does not clearly state whether eye donation is acceptable or not but they deduced it to be allowable. Majority of these leaders were willing to advocate for eye donation campaigns.

However, in this study, there was no association between age, gender, level of education, ethnic community, level of awareness and willingness to donate. Similar findings were noted across various studies in relation to these variables (11,47).

Regarding fear concerning eye donation, 46(43.4%) had reservations towards eye donation. It was associated with lack of adequate information and fear of black market trade. This is probably due to lack of information concerning the concept as most participants have never heard of it. Addressing these issues during eye donation campaigns may help to alleviate these fears.

5.1 Limitations

- a) As the study was done in a slum setting, the results cannot be generalized to the entire population in Kenya.
- b) The study was carried out at approximately the same time that the government of Kenya was carrying out a mass registration of all Kenyans onto a mass registration programme known as 'huduma namba'. This programme involved registration of an individual's biodata and personal information. Some participants associated huduma namba to religious prophecies of end times and cultism. Therefore, some participants were very cautious to participate in this study as they erroneously thought I was part of the huduma namba campaign and they believed the information collected in this study may be used against them one day to initiate them into a cult.
- c) Religion is a key factor that contributes to willingness towards corneal donation. In this study, all the participants in the quantitative section were Christians as we were unable to get any Muslims willing to participate in the study.

5.2 Conclusions

- a)** Awareness on corneal donation was found to be low among study participants with high levels of unwillingness to donate their corneas. The main reasons for this were the need for an intact body and refusal from family members.
- b)** Barriers to corneal donation mainly include the need for an intact body upon death and cultural demands, especially from the village elders. Culture dictates that if the deceased is not buried with an intact body they will haunt the living. Some participants were fearful of black market trade of eyes if the eye donation programme was to start in Kenya.
- c)** The decision to donate pledged next of kin's cornea was found to be complex as the decision requires the presence of other family members.

5.3 Recommendations

- a)** Eye donation campaigns are required to increase the level of awareness towards corneal donation. This includes involvement of use of mass media (radio, TV), use of local administrative units to reach the village elders, use of community health volunteers, health education talks and involvement of family members of influence when a donor is considering to pledge for eye donation.
- b)** There is need for strict government policy measures to ensure safety of corneal donors.
- c)** Further studies can be carried out to assess the effect of various religions and religious beliefs on willingness to corneal donation

5.4 Acknowledgements

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APPENDICES

Appendix I - Informed Consent Form (English Version)

Title of Study: Willingness to donate eyes and its associated factors among adults in a community in Kenya

Sponsor: KNH Research Fund

Principal Investigator

Dr. Mary Ngarachu

Tel: +254 724283167

Email; mnjoki450@gmail.com

University of Nairobi

Supervisors

1. Dr. Millicent Bore
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University of Nairobi, Kenya.
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University of Nairobi, Kenya
3. Dr. P.T Nyaga
Tel: 0722901709
Email; ptnyaga@yahoo.com
Kenyatta National Hospital.

Introduction

My name is Dr. Mary Ngarachu. I am doing my postgraduate masters in Ophthalmology at the University of Nairobi. My postgraduate thesis is onwillingness to eye donation among adults in a community in Kenya.

It is a mixed method study that will be conducted in February 2019.

The purpose of this consent form is to give you information that might help you to decide whether to participate in the study or not. You are allowed to ask questions related to the study and implications on your part. The consenting process will take place in a private place that is comfortable to you.

Purpose of study

The results of this study will enable us to assess the knowledge and willingness to donate corneas and at the same time spread awareness for eye donation.

Study design and site

The study will be a mixed study carried out at Kiambiu slum and KNH

Procedures to be followed

The principal investigator together with the trained interviewers will administer questionnaires and conduct interviews and focus group discussions

Benefits

The results of the study may inform the development of a corneal eye bank in KNH by studying a community representing people who are likely to be admitted in KNH.

Risks of accessing records

There is no risk if we access the records in this study. We will maintain privacy and confidentiality of all information obtained.

Assurance of confidentiality

The information given and records will remain confidential and will not appear when we present this study or publish its results.

Storage of data

The data will be stored in secure cabinets and computers with password/s and will only be accessible to the investigators.

Range of information desired

Patient demographic data, level of knowledge concerning eye donation, perception to eye donation and willingness to eye donation will be assessed.

Right to refuse or withdraw

It is important that you understand the following general principles that will apply to all participants in the study:

1. Participation is entirely voluntary.
2. You may withdraw from this study at any time without penalty or loss of benefits.

Please feel free to ask any questions that you may have. Do you agree to participate?

I acknowledge that this consent form has been fully explained to me in a language that I understand and had the opportunity to ask questions which have been answered to my satisfaction. I agree voluntarily to participate in this study and understand that I have the right to withdraw at any time without penalty.

Participant's name(optional): _____

Participant's signature or thumb print: _____

Date: _____

Study No.: _____

Name of witness: _____

Signature of witness: _____ Date: _____

Investigator's signature: _____ Date: _____

Contact: If you have questions in future, please contact The Secretary, University of Nairobi, College of Health Sciences Ethical Review Committee, P. O. Box 19676-00202, Nairobi, and Telephone: 020-2726300-9 ext. 44355, email Uuonknherc@uonbi.ac.ke

Kiswahili

Jina la Utafiti: Uelewano na sababu zinazolenga mchango wa macho miongoni mwa watu wazima katika jamii nchini Kenya.

Mdhamini: KNH Research Fund

Mchunguzi

Dkt. Mary Ngarachu

Simu: +254 724283167

Barua pepe; mnjoki450@gmail.com

Chuo Kikuu cha Nairobi

Wasimamizi

1. Dr. Millicent Bore Tel: +254 721999125

Email; millicentbore@gmail.com

Chuo Kikuu cha Nairobi, Kenya

2. Dr. Stephen Gichuhi

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Chuo Kikuu cha Nairobi, Kenya

3. Dr. PT Nyaga

Simu: 0722901709

Email; ptnyaga@yahoo.com

Kenyatta National Hospital

Kianzilishi

Jina langu ni Dr Mary Ngarachu. Kwa sasa nafuatilia shahada ya bwana katika Ophthalmologia. Ninafanya utafiti kama utimizaji wa sehemu ya utafiti wangu. Ninafanya utafiti juu ya uelewano na sababu zinazolenga mchango wa macho miongoni mwa wenyeji wa Kiambiu. Utafiti huu utafanyika katika mwezi wa pili mwaka wa 2019.

Lengo la fomu hii ya idhini ni kukupa taarifa ambayo inaweza kukusaidia kuamua kushiriki katika utafiti huu au la. Unaruhusiwa kuuliza maswali kuhusiana na utafiti na matokeo kwa sehemu yako. Utaratibu wa kukubali utafanyika mahali pa faragha ambapo ni pazuri na wewe.

Kusudi la utafiti

Matokeo ya utafiti huu yatawezesha kuchunguza ujuzi na nia ya kuchangia macho na wakati huo huo kueneza ufahamu kwa mchango wa macho.

Eneo la utafiti huu

Utafiti huu utafanyika Kiambiu na kwenye hospitali kuu ya Kenyatta

Taratibu za kufuatiwa

Mpelelezi mkuu pamoja na wasaidizi wake watasimamia maswali na mahojiano na majadiliano ya kikundi

Faida

Matokeo ya utafiti inaweza kuwajulisha maendeleo ya benki ya macho katika hospitali kuu ya Kenyatta kwa kujifunza jumuiya inayowakilisha watu ambao wanaweza kuhudumiwa kwenye hospitali hii.

Hatari za kupata rekodi

Hakuna hatari ikiwa tunapata rekodi katika utafiti huu. Tutadumisha faragha na siri ya habari zote zitakazopatikana.

Uhakikisho wa siri

Taarifa iliyotolewa na rekodi itabaki siri na haitaonekana wakati tunapowasilisha utafiti huu au kuchapisha matokeo yake.

Uhifadhi wa data

Data itahifadhiwa katika makabati yenye usalama na tarakilishi na password/s na itapatikana tu kwa wachunguzi.

Aina za habari zinazotakikana

Takwimu za jina ya mwenye kuhusika, umri, kiwango cha ujuzi kuhusu mchango wa macho, mtazamo kwa mchango wa macho na nia ya mchango wa macho utabainishwa.

Haki ya kukataa au kujiondoa

Ni muhimu kuelewa kanuni zifuatazo ambazo zitatumika kwa washiriki wote katika utafiti:

1. Kushiriki ni kikamilifu kwa hiari.
2. Unaweza kujiondoa kwenye utafiti huu wakati wowote bila adhabu au kupoteza faida.

Tafadhali jisikie huru kuuliza maswali yoyote ambayo unaweza kuwa nayo. Unakubali kushiriki?

Nakubali kwamba fomu hii ya ridhaa imenipelezea kikamilifu katika lugha ambayo ninaelewa na nilikuwa na fursa ya kuuliza maswali ambayo yamejibiwa kwa kuridhika kwangu. Nakubali kukubali kushiriki katika utafiti huu na kuelewa kwamba nina haki ya kujiondoa wakati wowote bila adhabu.

Jina la mshiriki(hiari): _____

Sahihi ya mshiriki au kuchapisha kidole: _____

Tarehe: _____

Nambari ya utafiti: -----

Jina la shahidi: _____

Saini ya shahidi: _____ Tarehe: _____

Sahihi ya Mpelelezi: _____ Tarehe: _____

Mawasiliano: Ikiwa una maswali baadaye, tafadhali wasiliana na Katibu, Chuo Kikuu cha Nairobi, Kamati ya Ukaguzi wa Maadili ya Sayansi ya Sayansi ya Afya, PO Box 19676-00202, Nairobi, na Simu: 020-2726300-9 ext. 44355, barua pepe uonknherc@uonbi.ac.ke

Appendix II - Questionnaire

Date

Serial Number

SECTION 1 :PARTICIPANTS' SOCIO-DEMOGRAPHIC DATA		
S.no	Questions	Response options
1.	Date of Birth	_____
2.	Gender	1. Male 2. Female
3.	Religion	Specify _____
4.	Ethnicity	Specify _____
5.	Marital status	1. Single 2. Married 3. Other(specify) _____
6.	Completed educational level	1. No formal education 2. Primary school 3. Secondary school 4. College /University
7.	Your occupation	_____
SECTION 2: PARTICIPANTS' KNOWLEDGE ABOUT EYE DONATION		
1.	Have you ever heard about eye donation?	1. Yes 2. No
	If no, the data collector should state that eye donation is the act of donating the eyes after one's death for it to be given to a needy person in order for them to see again. Data collector should explain what a corneo scleral button is using the eye model then skip to question 8	
2.	What is your source of information?	1. Internet 2. Medical personnel 3. Newspapers/Magazine 4. Television 5. Radio 6. Family member/Friends

		7. Other _____
3.	Which part of the eye is donated? (all negative responses skip to question 7)	1. Whole eyeball 2. Cornea (corneo scleral button) 3. Lens 4. I don't know 5. Others
4.	What is your understanding on corneal donation?	1. Donation of eyes after one's death to help someone else see 2. Others..... 3. Do not know
5.	Does the Kenyan constitution allow corneal donation?	1. Yes 2. No 3. I don't know
6.	Can the cornea be removed from a living person for donation?	1. Yes 2. No 3. I don't know
7.	Can a living person pledge to donate his or her eyes?	1. Yes 2. No 3. I don't know
8.	Is it necessary to get the opinion of a close relative when pledging for eye donation? (If answered no to question 1)	1. Yes 2. No 3. I don't know
9.	Have you ever heard of an eye bank?	1. Yes 2. No (If No skip to question 11)

10	Is there an eye bank in Kenya?	1. Yes 2. No 3. I don't know
11	Can a human eye be bought or sold?	1. Yes(specify)..... 2. No 3. I don't know

SECTION 3: PARTICIPANTS' WILLINGNESS TO DONATE THEIR CORNEA

1.	Would you be willing to donate your cornea?	1. Yes 2. No 3. I need time/more information to decide
2.	If yes to question 1, what is your perceived reason on willingness to donate?	1. It is pleasure to help a blind person 2. My eyes are not useful after my death 3. Other_____
3.	If no to question 1, what is your perceived reason?	1. I need more information to decide 2. Family members object to eye donation 3. It is against my religion 4. I want my body to be intact after death 5. I don't want to be disfigured after the procedure 6. Other-----
4.	Would you agree to your next of kin's cornea being harvested if he/she had pledged to donate their eyes?	1. Yes 2. No(skip to question 6) 3. I need time/more information to decide
5.	If yes to question 4, what is your perceived reason on willingness to donate?	1. It is pleasure to help a blind person 2. I would like to respect his/her wishes 3. His/her eyes are not useful after death 4. Other_____
6.	If no to question 4, what is your perceived reason?	1. It is against our religion 2. It is against our culture/tradition 3. Other family members may object to eye donation 4. I want to be the body intact after death

		5. I don't want the body to be disfigured after the procedure 6. Fear of illegal trade of organs 7. Other-----
--	--	--

SECTION 4 BARRIERS TO CORNEAL DONATION

1.	Are there any cultural practices/traditions that will affect your decision to donate?	1. Yes(specify)..... 2. No
2.	Do you have any fears/reservations towards corneal donation?	1. Yes(specify)..... 2. No

Appendix III - Key Informant Interview Guide

Religious leader serial number

1. What are the views and teachings of your religion concerning eye donation?
2. Would you be willing to increase the level of awareness regarding eye donation amongst members of your religion? How can this be achieved?

Nursing officer in Charge serial number.....

1. What is your opinion regarding eye donation?
2. Do you know about the Human Tissue Act section 49 IX i, ii?
3. Would you be willing to counsel a patient/ patient's relatives regarding eye donation if the patient is a voluntary eye donor?

Head of department -Ophthalmology, KNH serial number.....

1. Does the department have adequate resources to facilitate eye banking?
2. Is KNH willing to train people on eye banking and techniques of corneal harvesting?

Head of Ophthalmic services in Kenya serial number.....

1. What is the significance of the increasing trend on incidence of corneal blindness and prolonged blind years on our population?
2. Is the government willing to support eye donation campaigns?
3. Is the government willing to advocate and increase awareness on eye donation?
4. How can this be achieved?

Appendix IV - Focus Group Discussion Questions

1. Have you ever heard about eye donation?
2. Can the cornea be removed from a living person for donation?
3. Is it mandatory to get the consent for eye donation from the next of kin after the death of a voluntary eye donor? Why?
4. What is your opinion about corneas being harvested from a relative who passes on while in a hospital? How can this process be improved?
5. Are there any views regarding accepts eye donation in your culture? Which ones are they? Which culture do you come from?

Appendix V - Work Plan

YEAR 2018/2019	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	Apr	May	Jun
Proposal development											
Ethics approval											
Data collection											
Data analysis											
Report writing											
Dissemination of the result											

Appendix VI: Budget

Components	Unit of Measure	Duration/ Number	Unit Cost (Kshs)	Total Cost (Kshs)
Personnel				
Research Assistant	1 pax	16	1,500.00	24,000.00
Statistician				30,000.00
Transcribing fee	13 scripts	1	2,000.00	26,000.00
Printing				
Consent Form	1 copy	8 pages	10.00	80.00
Questionnaires	1 copy	6 pages	10.00	60.00
Final Report- Coloured	6 copies	15 pages	20.00	1,800.00
Final Report-Black & White	1 copy	125 pages	10.00	1,250.00
Photocopying				
Consent Form	235 copies	4 pages	3.00	2,820.00
Questionnaires	130 copies	6 pages	3.00	2,340.00
Final report	5 copies	125 pages	3.00	1,875.00
Final report binding	6 books	1	500.00	3,000.00
Other costs				
ERC Fees	1		2,000	2,000.00

NACOSTI	1		1,000	1,000.00
Poster Printing	1	1	2,500	2,500.00
FGD meetings	100 pax		100	10,000.00
Batteries	2 pairs	1	240	480.00
Note Books	5 pieces	1	50	250.00
Pens	10 pieces	1	30	300.00
FGD venue	8 days		2,000	16,000.00
Box files	2 pieces	1	200	400
Total				126,155.00

Appendix VIII : Ethical Approval



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel: (254-020) 2726300 Ext 44355



KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: <http://www.erc.uonbi.ac.ke>
Facebook: <https://www.facebook.com/uonknh.erc>
Twitter: [@UONKNH_ERC](https://twitter.com/UONKNH_ERC) https://twitter.com/UONKNH_ERC



KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 725300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/69

27 February, 2019

Dr. Mary Njoki Ngarachu
Reg. No. H58/87509/2016
Dept. of Ophthalmology
School of Medicine
College of Health Sciences
University of Nairobi

Dear Dr. Ngarachu,

RESEARCH PROPOSAL – WILLINGNESS TO DONATE EYES AND ITS ASSOCIATED FACTORS AMONG ADULTS IN A COMMUNITY IN KENYA (P747/10/2018)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 27th February 2019 – 26th February 2020.

This approval is subject to compliance with the following requirements:

- Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
- All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
- Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
- Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
- Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
- Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
- Submission of an *executive summary* report within 90 days upon completion of the study. This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

Protect to discover

For more details consult the KNH- UoN ERC website <http://www.erc.uonbi.ac.ke>

Yours sincerely,



PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

- c.c. The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Dean, School of Medicine, UoN
The Chair, Dept. of Ophthalmology, UoN
Supervisors: Dr. Millicent Bore (UoN), Dr. Stephen Gichuhi (UoN), Dr. P.T. Nyaga (KNH),
Mr. James Kariuki Ngumo

Protect to discover

THIS IS TO CERTIFY THAT:
DR. MARY NJOKI NGARACHU
of UNIVERSITY OF NAIROBI, 67157-200
Nairobi, has been permitted to conduct
research in *Nairobi County*

Permit No : NACOSTI/P/19/97163/29011
Date Of Issue : 26th March, 2019
Fee Received :Ksh 1000

on the topic: **WILLINGNESS TO DONATE
EYES AND ITS ASSOCIATED FACTORS
AMONG ADULTS IN A COMMUNITY IN
KENYA.**

for the period ending:
25th March, 2020




.....
**Applicant's
Signature**


.....
**Director General
National Commission for Science,
Technology & Innovation**

**THE SCIENCE, TECHNOLOGY AND
INNOVATION ACT, 2013**

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Technology and Innovation (Research Licensing) Regulations, 2014.

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