OCULAR FINDINGS IN PERSONS WITH ALBINISM IN BUJUMBURA, BURUNDI

DR. JEAN JUNIOR NKUYUBWATSI

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DECLARATION

I declare that this research thesis is my original work and has never been published or presented for a degree in any other University.

Signed: _____ Date: 25/02/2022.

Dr. Jean Junior Nkuyubwatsi

APPROVAL BY SUPERVISORS

This thesis has been submitted with our approval as supervisors:

Dr. Nyenze Emmanuel Muindi
MBChB M.Med. Ophthal (UoN), FEACO, Oculoplastic (LV Prasad, India)
Lecturer, Department of Ophthalmology
University of Nairobi

Signed _____ Date 25/02/2022

Dr. Mukuria Mukiri
MBChB, M.Med Ophthal (UoN), FEACO, FAES-Cornea (Aravind, India)
Lecturer, Department of Ophthalmology,
University of Nairobi

Signed _____ Date 25.02.2022

Pr. Levi Kandeke
MBChB (University of Burundi), M.Med Ophthal (University of Geneva)
Senior Lecturer, Department of Ophthalmology
University of Burundi

Signed _____ Date 24/02/2022.

This work is dedicated to my parents and siblings for their moral support and understanding during the entire study period.

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LIST OF ABBREVIATIONS

AHPs	-	Anomalous Head Postures
BCVA	-	Best Corrected Visual Acuity
INS	-	Infantile Nystagmus Syndrome
KNH	-	Kenyatta National Hospital
OA	-	Ocular Albinism
OCA	-	Oculocutaneous Albinism
SPSS	-	Statistical Package of Social Science
UON	-	University of Nairobi
VA	-	Visual Acuity
VEP	-	Visual Evoked Potential
VI	-	Visual Impairment
WHO	-	World Health Organization

OPERATIONAL DEFINITION

Strabismus: misalignment of the eye, which may be manifest (tropia) or latent (phoria).

Iris transillumination: defects in iris pigment which may be scattered or completely absent, with visualization of the edge of the lens.

Foveal hypoplasia: condition in which the fovea is underdeveloped and characterized by the absence of foveal pigmentation and/or the foveal avascular zone.

Nystagmus: repetitive involuntary back and forth oscillation of the eyes.

Visual impairment: visual acuity of worse than 0.30(6/12) and up to 1.30(3/60) in the better eye

Myopia: form of refractive error, also called near-sightedness, in which an image forms in front of the retina.

Hypermetropia: form of refractive error, also called far-sightedness, in which an image forms behind the retina.

Astigmatism: form of refractive error, in which the curvatures of the cornea becomes irregular.

Myopic astigmatism: astigmatism in which all meridians are myopic but to different degrees or one meridian is myopic while the one opposite to it is without refractive error.

Hyperopic astigmatism: astigmatism in which all meridians are hyperopic but to different degrees or one meridian is hyperopic while the one opposite to it is without refractive error.

Mixed astigmatism: astigmatism in which one meridian is hyperopic and the other is myopic.

Significant hyperopia : hyperopia of more than +2.00 D.

Significant myopia : myopia of more than -0.50 D.

Significant astigmatism : astigmatism of more than ± 1.50D.

ABSTRACT

Background: Persons with albinism have varied ocular problems which can cause visual impairment or blindness. Moreover, there is a paucity of data on ocular findings in persons living with albinism in Africa particularly in Burundi.

Objective: To determine the patterns of ocular findings in persons with albinism in Bujumbura, Burundi.

Study design: Community based descriptive cross-sectional study.

Study population: All persons with albinism living in Bujumbura (age ≥ 5 years).

Methods: Approval of the Burundi "Albinos without borders" association was obtained and presented to the participants. Participants who met the inclusion criteria and consented to the study were recruited. Each participant underwent Visual acuity, stereoacuity, orthoptic assessment, amsler grid test, anterior segment, posterior segment examination and refraction.

Results: A total of 110 participants were enrolled in the study, 56 males (50.9%) and 54 females (49.1%). The median age was 18.0 (IQR 10.0-27.0) years. The common ocular complaints were photophobia (96%) and reduced vision (89%). Majority had moderate visual impairment 71.3%. The most common types of refractive errors identified were hyperopic astigmatism (39.1%) and myopic astigmatism (26.0%). Nystagmus and strabismus were present in 96.4% and 63.6% respectively. Stereopsis was absent in 98%. Iris transillumination defect was the most common anterior segment finding with 88.2%.The most common posterior segment findings was fovea hypoplasia with 97.3%.

Conclusion: Our study found high prevalence of visual impairment. Majority of the participants had not been seen by an eye care professional and very few used spectacles or sunglasses. Uncorrected refractive error was the main avoidable cause of reduced vision. Possible anatomical causes of visual impairment were fovea hypoplasia, optic disc hypoplasia and iris transillumination defect.

1.0.INTRODUCTION

Albinism is a genetic disorder of hypopigmentation due to abnormal melanin synthesis. There can either be an absence or reduction of melanin, which may interfere with the growth of the eye and the visual system.(1) In albinism, there is misrouting of the visual pathway from the eye to the brain; this is thought to be the main factor differentiating it from other visual conditions ensuing in foveal hypoplasia and other hypopigmentation ailments.(2)(3) In clinical practice, this characteristic finding alongside with phenotypic evaluation and ophthalmic examination is used to diagnose albinism .(4)

Different degrees of hypopigmentation occur as a result of distinct types of mutations. The phenotypic classification of albinism centers on a dichotomous foundation - ocular albinism (OA) and oculocutaneous albinism (OCA). Oculocutaneous albinism concisely indicates a reduced (incomplete OCA) or lack (complete OCA) of the skin, eyes, and hair melanin. On the other hand, ocular albinism involves the reduction or deficiency of melanin in the eyes only, with the melanocytic system presenting usual pigmentation to other body parts.(5) Visual acuity in people with oculocutaneous and ocular albinism ranges from 20/20 to 20/400 but is mostly below 20/ 80.(6)

According to the literature, there a strong correlation of greater amounts of refractive error, particularly corneal astigmatism, intraocular light scatter, light-induced retinal damage, and an undifferentiated fovea, all these features can cause blindness although the disorder is rare.(5)

A similar study done in Kenya in 2010, reported photophobia and reduced vision as the most common ocular complaints in persons with albinism. Other common ocular findings were iris transillumination defects, nystagmus, strabismus, refractive errors, absence of stereoacuity, foveal hypoplasia, retinal hypopigmentation and optic nerve hypoplasia.(7)

According to the UN Human Rights Office report of 2013, 900 people with albinism live in Burundi. Most of them live in Bujumbura, Gitega, and Ruyigi cities. Persons with albinism face several challenges, for example, crimes against persons with albinism include murder.(8)

To the best of our knowledge there is no study that has been conducted in Burundi on ocular findings in persons with albinism. As first of its kind the study purpose is to determine the visual deficits faced by persons with albinism. With this information measures can be taken to improve the situation especially in planning for eye care program in the country.

2.0.LITTERATURE REVIEW

2.1. Epidemiology of Albinism

Albinism can affect people from all ethnic background. Approximately one in 17,000 people have one of the types of albinism. There are various forms of albinism globally and their prevalence differs significantly.

Gronskov et al reported in the orphanet journal of rare disease that In most populations, OCA1 has a frequency of 1 per 40,000 individuals, but is not common among African-Americans. In the same journal it was reported that OCA2 is a popular type of albinism among patients of African origin. It is estimated that the total frequency of OCA2 in the USA is 1:36,000; among African Americans it goes up to 1:10,000. In some places of the Southern part of Africa, it affects 1 in 3,900 of the population. It has been established in Africa that, another type of albinism called OCA3 or Rufous oculocutaneous albinism affects 1:8,500 people, but is uncommon among Caucasians and Asians.(3)(9)

2.2. Clinical Description

According to a report published in the Middle East African Journal of Ophthalmology (2013), Similar ocular findings are observed in each type of OCA and OA, like different levels of early onset nystagmus, foveal hypoplasia, ametropia, iris and retinal pigment epithelium hypopigmentation, strabismus, and decreased best- corrected visual acuity. Photophobia and light scattering can be severe. Monocular visual evoked potentials can be used to demonstrate the irregular crossing of chiasmatic , post-chiasmatic fibers.(10) Albinism is frequently related to nystagmus, reduced vision, and refractive errors; therefore recognition visual acuity can change depending on abnormally stimulated head posture, the precision of glasses prescription, and the understanding of the visual acuity tester. To assess vision for patients younger than 2 years, fixation preference testing like Teller acuity cards is needed. Another new technique called sweep visual evoked potential (VEP) testing is used to examine visual acuity in persons with albinism who are not yet able to talk.(6) In patients with ocular and oculocutaneous albinism, a correlation has been reported among binocular grating acuity and future letter recognition acuity.

Bradfield et al conducted a retrospective review in 2007 in USA, it was found that sweep VEP testing can be used as a prognostic tool for recognition acuity in children with albinism. It has been noted that in children with albinism, teller acuity over-estimates recognition acuity. Unfortunately, the available studies that compare grating with recognition acuity in albinism used an insignificant number of patients since the disorder is a rare diagnosis.(3)(6)(9)

Some genetic conditions with nystagmus demonstrate a mixture of immunological and pigmentation deficiencies.(11) Some examples of autosomal diseases with these features are Hermansky-Pudlak, Chediak-Higashi, Griscelli, and paroxysmal autonomic instability with dystonia syndromes. At the molecular level, the relationship between immunodeficiency and albinism indicates that both melanosomes and secretory lysosomes are secreted abnormally. In Chediak-Higashi syndrome, marked by recurrent infections and albinism, the existence of unusually large lysosomes and melanosomes has been shown, which suggests that melanosomes are not secreted normally, therefore reinforcing the theory of a functional linkage with the secretory lysosomes of hematopoietic cells.(10)

2.3. Studies on Ocular findings in Albinism

2.3.1. Global Perspective

A cross-sectional hospital-based descriptive study conducted by Khanal et al. (2016) among all diagnosed oculocutaneous albinotic cases, found maximally reduced visual acuity in all participants and the most common refractive error was myopic astigmatism. It was reported that a wide spectrum of visual defects impairing the visual functions was present in patients with OCA. Optical correction significantly improved visual acuity which highly contributed to the decreased visual disabilities in patients with albinism.(5)

Dorey et al. (2003) investigated the link between the clinical and electrophysiological anomalies of individuals undergoing visual evoked potential examination for albinism. A contralateral dominance in the VEPs was reported in the study in many patients with clinical signs of albinism. The strongest link for pattern appearance interhemispheric latency disparity was with foveal hypoplasia followed by nystagmus and iris transillumination.(2)

Wildsoet et al. (2000) concentrated on the refractive implications of albinism in the context of emmetropization. Reduced visual acuity was found among all participants and in general, there was a tendency toward hyperopia in their refractive errors. It was also reported that the operational restrictions of emmetropization are reflected by the diverging refractive profiles of myopic subjects.(4)

2.3.2. Africa and Regional View

Mokaya et al. (2010) conducted a school-based cross-sectional study among students with albinism to establish the ocular findings in Kenya. Their study found that photophobia (91%) and reduced vision (78%) were the common ocular complaints with most of the pupils having moderate visual impairment (86.5%). Other common ocular findings were nystagmus (98%) and strabismus (91%). In most pupils stereopsis was absent (93%). Iris trans-illumination defects (87%) were also found to be the commonest anterior segment finding and foveal hypoplasia, hypopigmentation of the retina and optic nerve hypoplasia were the commonest posterior segment findings.(18)

A study by Jhetam and Mashige (2019) conducted in South Africa looked at the ocular findings and vision status of learners with OCA. It found that optical correction improved the level of visual acuity, contrast sensitivity, and reading rate. There were 81 participants with OCA in the study. It was as well found in that study that 72.8% of binocular vision anomalies were esophoria and esotropia. 41.4% of the learners had myopic astigmatism while with the rule astigmatism was predominant (64%). In this study, it was concluded that learners with OCA showed various ocular and vision defects which impaired visual functions with Optical correction significantly improving VA and contrast sensitivity.(19)

A study by Geraud et al (2018) conducted in Congo-Brazaville evaluated refractive disorders in albino children of Brazzaville and assessed their impact on the visual acuity. It found that all children had nystagmus, including 2 cases with strabismus (6.25%). All children had astigmatism, 56.25% of whom were hypermetropic. The mean uncorrected visual acuity in the better eye was 0.18+/-0.14. The mean corrected visual acuity in the better eye was 0.33+/-0.15. The improvement in corrected visual acuity was statistically significant P=0.002 .(20)

3.0. JUSTIFICATION

Due to the existence of a strong correlation with greater amounts of refractive error, particularly corneal astigmatism, intraocular light scatter, light-induced retinal damage, and an undifferentiated fovea, albinism can cause visual impairment and blindness even if the disorder is rare.(5) For this reason, it is crucial to identify from an early age; refractive errors, poor visual acuity, and treat them as required. There are not enough published literature and data in Africa about the patterns of ocular findings in persons with albinism. Visual performance can be improved in persons with albinism by enhancing their retinal image or training them on how to use their residual vision. To do so, adequate optometric care is needed. As a disease that can lead to severe visual impairment or even blindness, it is necessary that eye care providers understand its impact on vision and adopt appropriate policies about it.

Albinism is a disease associated with social discrimination and stigmatization. Most Albinos are ignored in our societies; this leads to inadequate healthcare delivery towards them. Furthermore, ocular associations are poorly understood by healthcare providers.(21) Once the magnitude of treatable or correctable ocular morbidity in this population is addressed, measures can be taken to improve the situation especially in planning for eye care programs in Burundi. As the first study to be done in Burundi on this topic, the study reports the deficits in vision found among persons living with albinism in Bujumbura.

4.0. OBJECTIVES

4.1.Broad Objective

To determine the patterns of ocular findings in persons with albinism in Bujumbura, Burundi

4.2.Specific Objectives

1. To establish the magnitude of ocular morbidity among persons with albinism in Bujumbura.
2. To identify the possible anatomical causes of visual impairment.
3. To determine the avoidable causes of reduced vision in the study population.

5.0. MATERIAL AND METHODS

5.1. Study Design

A community-based cross-sectional descriptive study was adopted.

5.2. Study Setting

The study was done in Bujumbura which is the main city and economic capital of Burundi. With a population of roughly 1,092,859, the city serves as Burundi's largest port and is located on the western shore of the country. Bujumbura is on the north-eastern shores of lake Tanganyika which is the second deepest lake in the world.

Map of Burundi showing Bujumbura

The study was done only in Bujumbura. According to the Burundi "Albinos without borders" association, most of the persons with albinism who live upcountry are afraid to come out because they fear being persecuted. Persecution of persons with albinism is based on the belief that certain parts of their bodies can transmit supernatural powers. Such superstition is still present more especially in rural areas of Burundi. This belief has been exploited by various traditional witch doctors and other people who mostly use them as ingredients in rituals, concoctions, and potions claiming that their magic comes with prosperity.

5.3. Study Population

All persons with albinism living in Bujumbura (age ≥ 5years). This age cut off was chosen because children younger than 5 years are less likely to cooperate for tests like amsler grid test and stereoacuity test. Similarly, a study done in Kenya in 2010, the youngest participant was 4 years.

5.4. Inclusion Criteria

All persons with albinism (age ≥ 5years) living in Bujumbura.

5.5. Exclusion Criteria

Persons with albinism on whom an eye examination couldn't be performed (example: persons with mental health diseases).

5.6. Study Period

The study period was one month (1^{st} – 31^{st} of December 2020)

5.7. Sample Size

Using the sample size calculation formula for a proportion (22):

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

Where n is the minimum sample size and Z is the statistic corresponding to the level of confidence at 95% (CI is at 1.96), P* is expected frequency (here we used 11%, which is the prevalence of severe visual impairment in a similar study done in Kenya in 2010), and d is precision (corresponding to effect size) (0.06).

$$n = \frac{(1.96)^2\ 0.11\ (1-0.11)}{(0.06)^2}$$

$$= 104$$

When the formula is substituted we get **104 persons with albinism**.

5.8. Sampling Procedure

The study employed a consecutive sampling technique. The researcher identified persons with albinism living in Bujumbura with the help of the Burundi "Albinos without borders" association. The association brought together all persons with albinism in Bujumbura. About 120 persons with albinism (age ranging from 3 to 50 years) are registered in the association as residents of Bujumbura, but the exact number of albinos in the city is not known. Thus, all the 120 persons with albinism were contacted and recruited consecutively until the sample size was achieved. The turnout daily included 7 to 8 participants.

5.9. Data Collection Procedure

Approval of Burundi “Albinos without borders” Association was obtained and presented to the participants. With the help of the administration of the group, the participants were contacted in advance to arrange for the examination. All the tests were conducted at a selected health facility within Bujumbura “Clinique de l’oeil”. Informed consent was issued with a brief explanation of the procedure which was given to the participants before the examination. A demonstration of key tests like taking of visual acuity was done. All participants present on the day of examination with the consent given were recruited into the study. The researcher provided to the participants transportation means to come to the study settings.

A research assistant was recruited to help in collecting the data. Registration of each participant and findings was recorded in individual questionnaires. Any known history and complaints related to an ocular problem were also noted.

5.9.1. Materials Required

1. LogMAR chart / Snellen chart
2. Amsler Grid Chart
3. Titmus Fly test kit
4. Slit Lamp
5. Indirect Ophthalmoscope
6. 20D Lens
7. Direct Ophthalmoscope
8. Retinoscope
9. Refraction set and box
10. Lensometer
11. Dilating eye drops
12. Questionnaire forms
13. Consent forms

5.10. Measurements

5.10.1. Visual Acuity

This was done in a well-lit area using LogMAR chart, held at a distance of 4 meters. Visual acuity for each eye was taken separately after occluding the other eye. The last correctly read line was recorded as the visual acuity. This assessment was repeated after the best subjective correction and the findings were recorded as best-corrected visual acuity. Lea Chart was used for pre-school children.

5.10.2. Stereoacuity

The Titmus Fly Test was used to assess stereoacuity for those who could understand instructions. When held at a distance of 40 cm. the fly has a discrepancy of 3,600 sec of arc. In the stereoscopic assessment, participants were requested to show the subjective plane of the fly's wings physically using their finger. The test card was turned 90° to rule out the use of monocular cues. Participants who were able to see the wings of the fly at 0° and 180° were subjected to the stereo animals and stereo circle test.

5.10.3. Orthoptic Assessment

Any abnormal head posture was noted followed by corneal light reflexes (Hirschberg) using a torch and finally cover tests at far and near. Extraocular muscle motility was assessed and the presence of nystagmus noted.

5.10.4. Amsler Grid Test

The Amsler Grid chart was used to describe any defects in macular function for those who are cooperative and can follow instructions. The chart used consisted of a grid of black lines on white paper. The chart was held at a distance of 25 cm and each participant was asked several questions as follows: 'Can you see the central black dot? If you can see the central black dot . Keep looking directly at it, do you see all four corners and sides of the chart? Do you see any missing or distorted areas of the chart in any way and are any of the lines not straight or not equal in size? If not, describe what you see and then draw it.

5.10.5. Anterior Segment Examination

This was done using a slit lamp biomicroscope where anterior segment structures were examined in details. Following is a description of the minimal characteristics that were identified per structure:

- Lids: masses, scars
- Conjunctiva: discharge, injection, masses
- Cornea: clarity, opacity
- Anterior chamber: depth, hyphema, hypopyon
- Iris: presence, color, shape, transillumination defects
- Pupil: assessment using a source of light in dim lighting to determine anisocoria, reaction to light, abnormal pupillary reflex
- Lens: presence, clarity, position, opacity

5.10.6. Posterior Segment Examination

All participants had their pupils dilated with tropicamide dilating drops for fundus examination. An indirect ophthalmoscope was used to look for the optic nerve, macula, and retinal pathology. Special attention was paid to the macular area, looking out for the absence of a foveal reflex; reduction in the usual hyperpigmentation of the fovea; lack of the macular pigment, and retinal vessels which cross the fovea.

5.10.7. Refraction

Objective refraction was done for all participants with clear media. Cycloplegic refraction was only performed for patients who were ≤ 15 years and were accommodating. One drop of 1% cyclopentolate was instilled into each eye three times at 10-minute intervals. The participant was required to close his/her eyes and put pressure over the lacrimal puncta for 5 minutes to reduce the systemic absorption of the drug. Objective refraction was done 45 minutes after installation of the first drop using a Retinoscope (Keller). Subjective refraction was done one day after for those who underwent cycloplegic refraction. Participants were informed about the possible side effects of cyclopentolate which could be blurry vision, drowsiness or fever (for up to 24 hours)

and were given a prescription of paracetamol in case they developed fever after leaving the examination center and advised to visit the nearest hospital in case of any persistent adverse reaction. For participants over 15 years, dry objective refraction was done. The participants were given a fixation target at six meters. Besides, fogging of the eye with a plus 6 diopter lenses was done to relax accommodation. This was done followed by subjective refraction.

5.11. Quality Assurance Protocol

To ensure reproducibility and validation of this study a number of techniques was carried out, this include:

- Calibration of equipment
- Clear documentation on any changes within the data collection protocol
- Clear documentation and handling of collected data
- Data was entered and stored in spreadsheets

5.12. Ethical Considerations

The research was conducted following the Declaration of Helsinki. Consent was obtained in writing from the participants/guardians. The ethical authorization was obtained from KNH/ UON Ethics and Research Committee. Consent to conduct the study was obtained from "Albinos without borders" Association.

Participant's details and identification were kept anonymous at all times through the use of coded questionnaires with matching codes on their files. The information on the questionnaire were only accessible to the primary investigator and statisticians who upheld confidentiality and adhere to data protection standards. Participants with conditions requiring management were given appropriate treatment and referrals.

5.13. Data Management and Analysis

5.13.1. Data entry and storage

Data collection was done using a structured questionnaire which was developed based on the study objectives. Data entry was done using Microsoft Excel. After data entry, the coded data was exported into SPSS version 25 for analysis. The available data in soft copy form was stored in a password protected laptop only accessed by the researcher or with approval from the researcher.

5.13.2. Data analysis

The data analysis included descriptive analysis. Categorical data was analyzed using frequencies and percentages and represented in graphs and charts. Continuous data was analyzed using mean (SD) and median (IQR). This was represented in tables. Statistical analyses using commercial software (SPSS version 25) was used. Magnitude of ocular morbidity, anatomical causes of visual impairment and avoidable causes of reduced vision were analyzed descriptively using frequencies (n) and percentages (%) and presented in Tables and Charts. A paired t test was conducted to investigate the difference in visual acuity before and after correction. The level of significance was 0.05.

6.0. RESULTS

A total of 120 participants were contacted, out of which 110 responded and were enrolled in the study, giving a response rate of 91.6%.

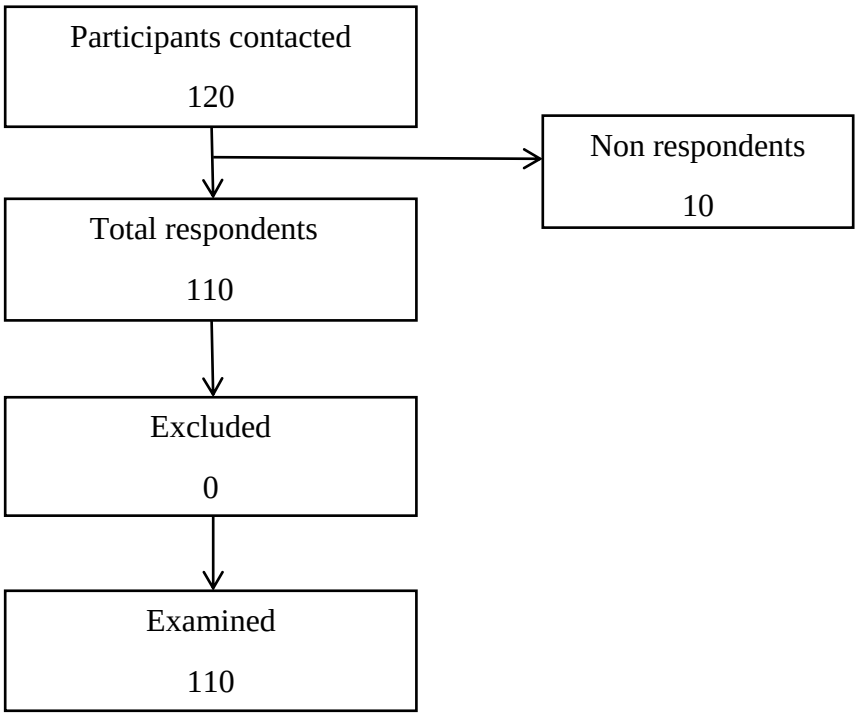

Figure 1: The Participation flow chart

A total of 110 participants were enrolled in the study. More than half (50.9%) of the respondents were male and the median age was 18.

Table 1: Demographic characteristics (n=110)

		Frequency (n)	Percentage (%)
Sex of the respondent	Male	56	50.9
	Female	54	49.1
Age	Median (IQR)	18 (IQR 10 – 27)	
Age of the respondent	≤10 years	29	26.4
	11 -20 years	40	36.4
	21-30 years	27	24.5
	31-40 years	7	6.4
	>40 years	7	6.4

Photophobia and reduced vision were the most common ocular complaints. Other reported symptoms were itchy eyes, redness, foreign body sensation and tearing.

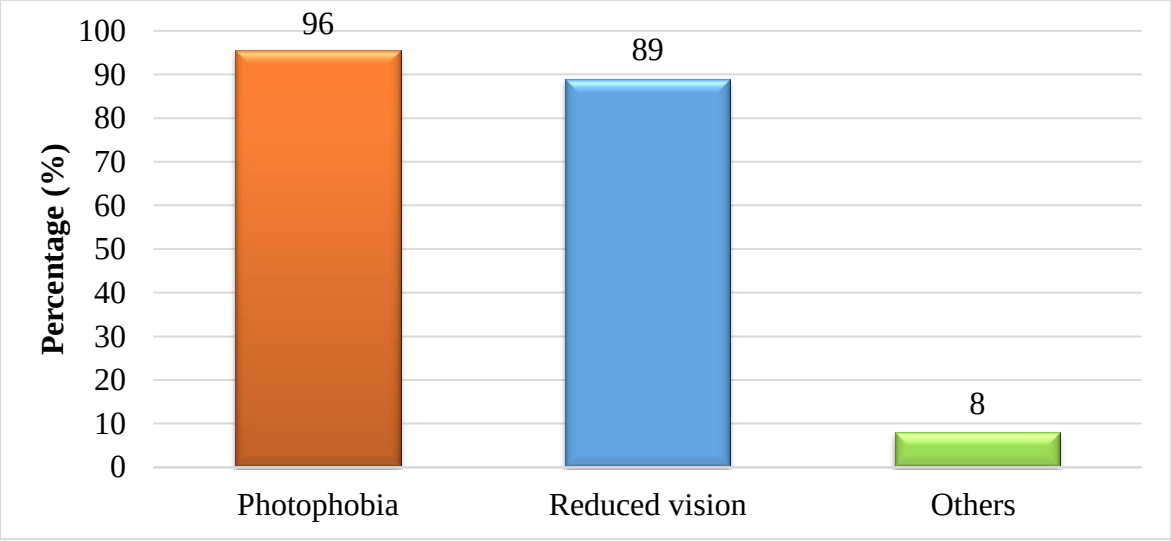

Figure 2: Ocular complaints (n=110)

On general examination 40 (36.4%) participants were found to have abnormal head posture and 20 (18.2%) participants were using spectacles.

Table 2: General examination (n=110)

		Frequency (n)	Percentages (%)
Head Posture (n =110)	Abnormal	40	36.4
	Normal	70	63.6
Use of spectacles/ low vision aid (n =110)	Yes	20	18.2
	No	90	81.8
Efficiency of spectacles/low vision aid (n =20)	Appropriate correction	6	30.00
	Inappropriate correction	14	70.00

For participants who did not use spectacles, the most common reason given was that their parent/guardian could not afford them (67%).

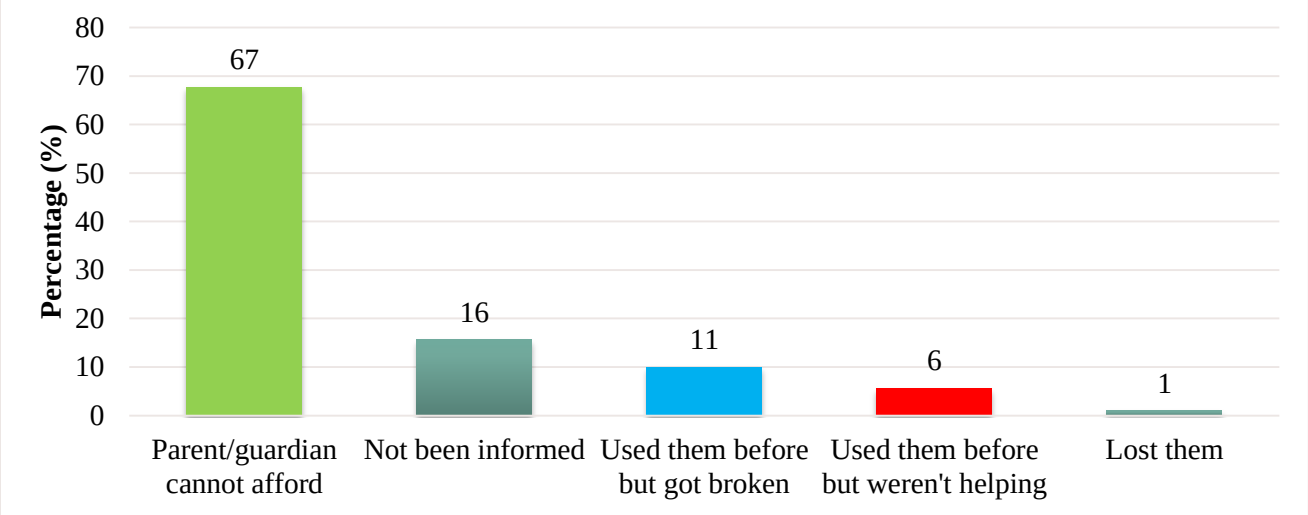

Figure 3: Reasons for not using spectacles/low vision aid (n=90)

Majority (71.3%) of the participants had moderate visual impairment. 2 participants couldn't respond to visual acuity assessment.

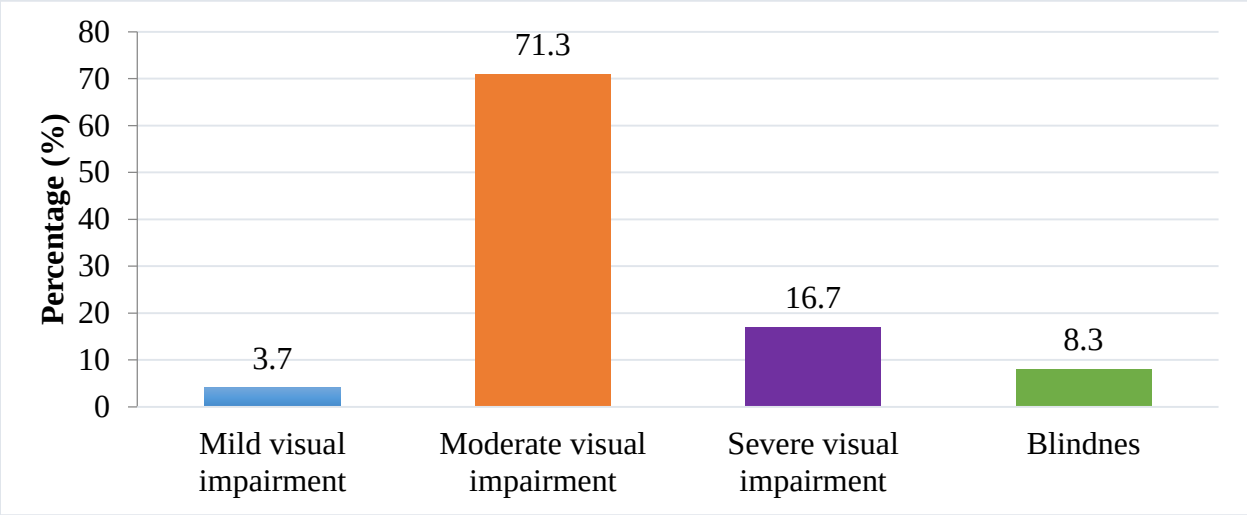

Figure 4: Presenting visual acuity in the better eye (n=108)

There was an improvement of visual acuity with spectacle correction but still the majority (80.6%) had moderate visual impairment.

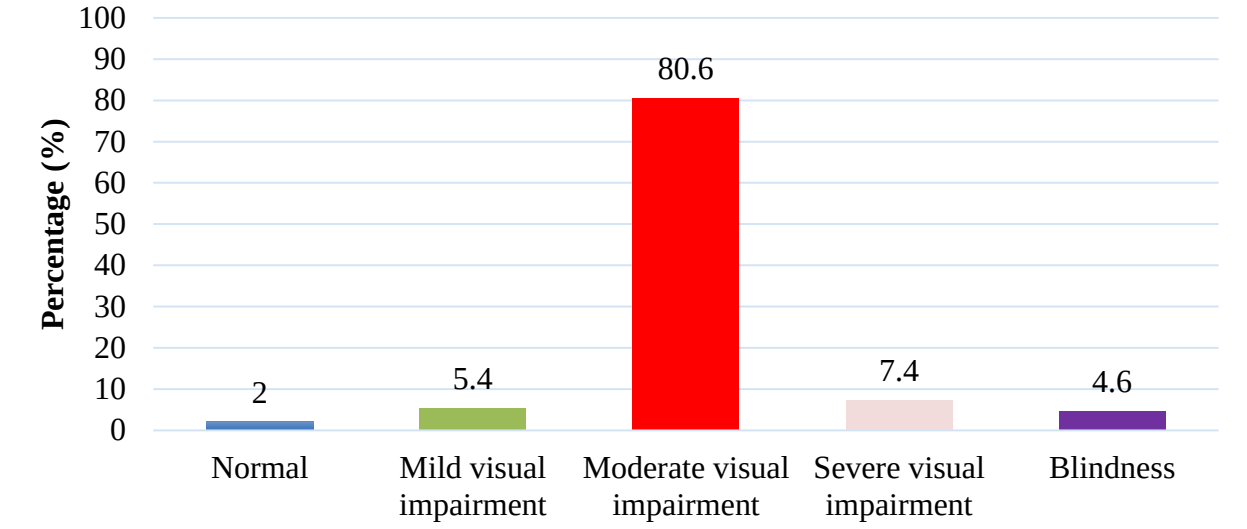

Figure 5: Visual acuity in the better eye after best subjective correction (n=108)

A paired t test was conducted to investigate whether there was a significant difference in the presenting visual acuity and the visual acuity with best correction in the better eye. The findings showed that before correction, the mean visual acuity was (M =0.94, SD =0.29) while the mean visual acuity was (M =0.81, SD =0.25) with best correction. The difference was statistically significant.

Table 3: Presenting visual acuity and visual acuity with best correction in the better eye (n=108)

Visual acuity in the better	Mean (logMAR)	SD	N	t	df	P-value
Presenting visual acuity	0.94	0.29	108	9.648	107	p<0.001
Visual acuity with best correction	0.81	0.25	108			

The most common types of refractive errors found were hyperopic astigmatism 86 (39.1%) and myopic astigmatism 57 (26.0%). 6 eyes had an opaque media (4 had cataracts and 2 had cornea scars). The spherical equivalent yielded a mean of + 0.45 D representing low hyperopia.

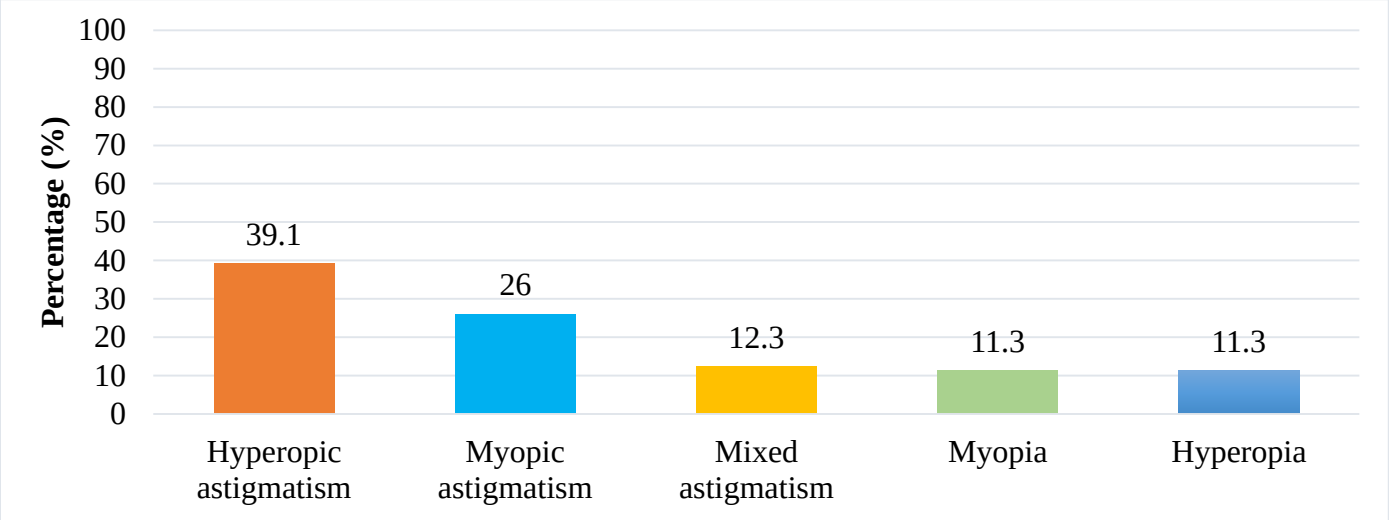

Figure 6: Patterns of refractive errors (n=214 eyes)

Majority of the participants had nystagmus (96.4%).

Table 4: Prevalence of Nystagmus (n=110)

		Frequency (n)	Percentage (%)
Nystagmus	Yes	106	96.4
	No	4	3.6

The prevalence of strabismus was 63.6%, consisting of horizontal deviations.

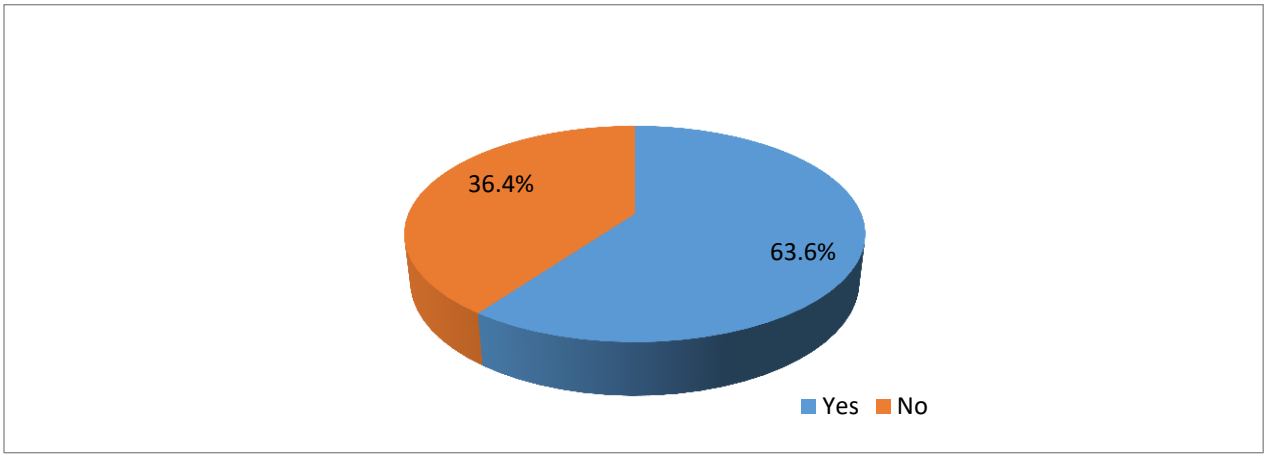

Figure 7: Prevalence of strabismus (n=110)

More than half of the participants with strabismus had esodeviation.

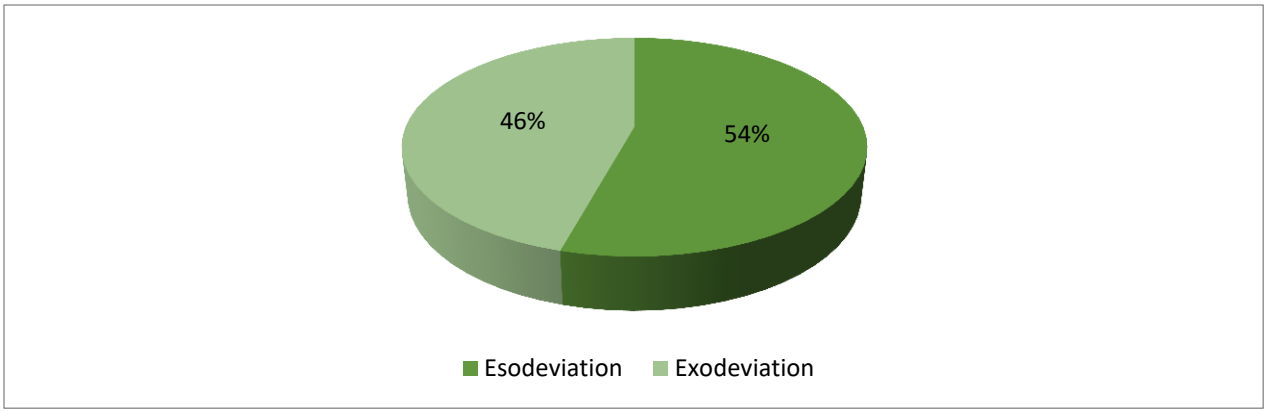

Figure 8: Patterns of strabismus (n=70)

Majority of the participants didn't have stereopsis. Only 2 participants had gross stereopsis (3600 sec of arc). 14 participants couldn't respond to subjective testing of stereoacuity.

Table 5: Presence of stereopsis (n=96)

		Frequency (n)	**Percentage (%)**
Stereopsis	Present	2	2
	Absent	94	98

The Amsler grid test was normal in the majority (75%) of the participants. 11 (22 eyes) participants couldn't cooperate with the test.

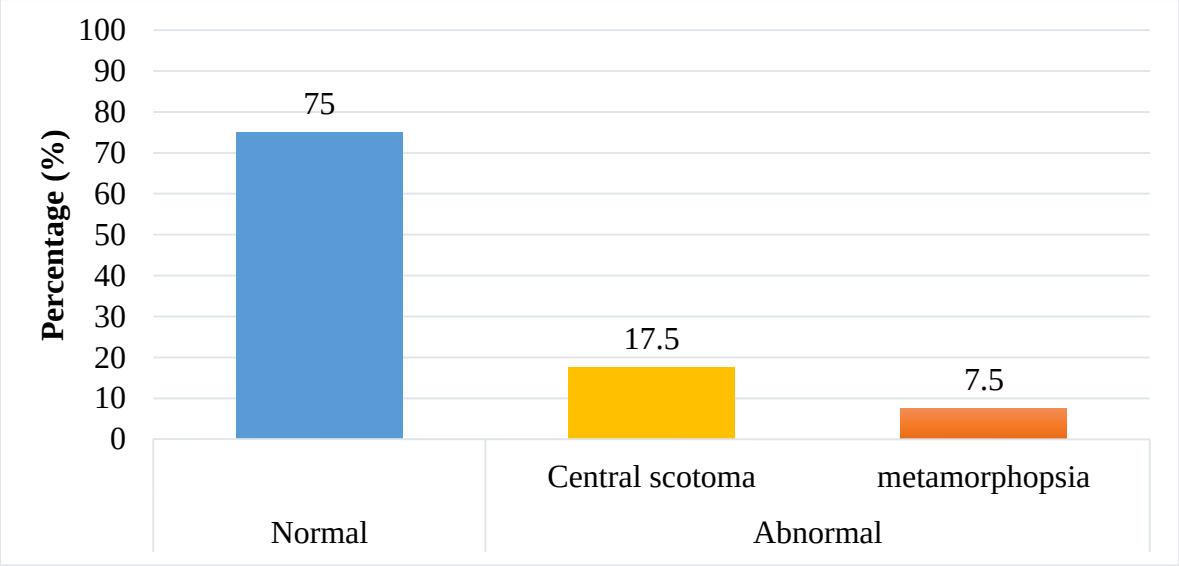

Figure 9: Amsler Grid assessment (n=198 eyes)

The most common anterior segment finding was iris transillumination (88.2%). Other abnormal findings were eyelid mass, ectropion, conjunctiva papillae and lesions, cornea scars and cataracts.

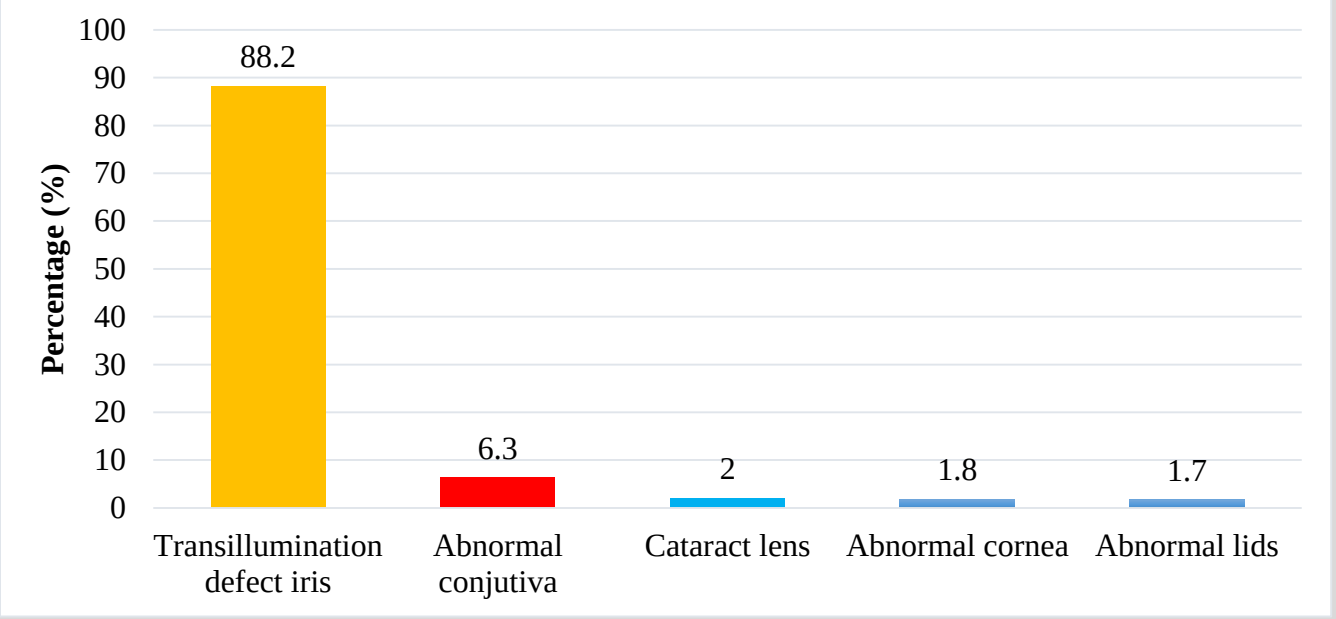

Figure 10: Anterior segment examination (n=220 eyes)

Foveal hypoplasia was the most common posterior segment finding with 97.3%.

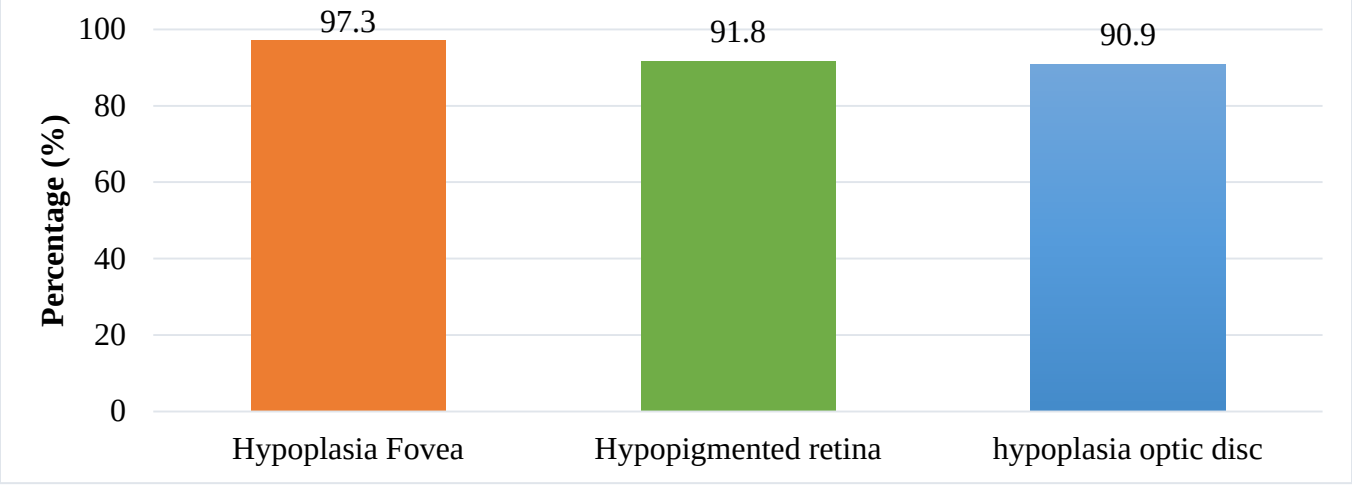

Figure 11: Posterior segment examination (n=220 eyes)

7.0. DISCUSSION

The study sought to investigate the patterns of ocular findings in persons with albinism in Bujumbura, Burundi. Out of 120 participants contacted, 110 responded and were enrolled in the study, giving a response rate of 91.6%. There were a relatively high number of males comparing to females with 56 males (50.9%) and 54 females (49.1%). The median age was 18 years, with the common age group being 11 to 20 years. These findings are consistent with Mokaya et al. cross-sectional study conducted in Kenya. The study recruited 101 persons with albinism, from which 52 were male and 49 were female.(7) The median age was 12 years. The difference in the age group could be attributed to the fact that the latter was a school-based study where majority of the students were much younger.

Photophobia (96%) and reduced vision (89%) were the most common ocular complaints, while itchy eyes, foreign sensation, painful eyes, and tearing were some of the other complaints reported by the participants. Photophobia is mainly attributed to the lack of uveal and retinal pigment, which results in high levels of retinal irradiance. However, these findings were higher than those obtained by Mokaya et al. in 2010 in kenya, who found that 91% of the participants had photophobia and 78% had reduced vision.(7) Similarly, a study conducted in Oman by Sreelatha et al. found that the common ophthalmic manifestations in patients with albinism were photophobia, nystagmus, defective vision, and squint.(23) Because of the absence or deficiency in melanin which has a photoprotective role in the eye, persons living with albinism are at risk of eyelid malignancy. That is why they should have glasses for vision, to reduce photophobia and for protection against UV rays.

General examination of the participants found that 36.4% had an abnormal head posture and 18.2% were using spectacles. Among those who used spectacles, majority of them (70%) didn’t have appropriate correction. These findings are comparable to a study conducted in Nigeria by Ezinne and Machine in 2018, who asserted that inappropriate correction despite using visual aid is a major problem in low-income settings due to limited expertise in the field.(24) The present study further identified that the common reasons given by respondents who did not use spectacles included high cost, not been informed about the use of visual aid, and using them but not helping.

Majority of the participants had moderate visual impairment both before and after best subjective correction. There was an improvement in visual acuity after best subjective correction from 71.3% with moderate visual impairment and 16.7% with severe visual impairment before correction to 80.6% with moderate visual impairment and 7.4% with severe visual impairment after spectacle correction but still the majority remained visually impaired. The mean visual acuity before correction was 0.94±0.29 (logMAR) and after correction 0.81±0.25 (logMAR). The difference in visual acuity before and after correction was statistically significant ($p<0.001$).

These findings are very high comparing to the prevalence of visual impairment in the general population. A study done in Kenya by Muma et al. in 2019 on the prevalence and causes of visual impairment among children in Kenya - the Kenya eye study found that 2.4% were visually impaired.(25)

A retrospective study conducted in Brazil among 77 patients with albinism found increased visual acuity with optical devices between 20/25 – 20/160.(26) Thus, optical resources assisted in the improvement of visual function and quality of life of patients with ocular albinism. Further, Wildsoet et al., in assessing clinical manifestations in patients with albinism, found that all of them had reduced visual acuity, with the majority showing moderate visual impairment.(4) In a study conducted in South Africa by Jhetam and Mashige , an optical correction was essential in improving visual acuity, contrast sensitivity, and reading rate among patients.(19)

In this study, none of the subjects was emmetropic. After refraction, the common types of refractive errors were hyperopic astigmatism (39.1%) and myopic astigmatism (26%). Also most of the participants were highly astigmatic. These findings are consistent with a cross-sectional study conducted in Congo brazaville by Geraud et al. in 2018 in which all the children had astigmatism, of whom 56.25% had hyperopia and 37.5% myopia.(20) These findings illustrate that managing refractive errors is essential in reducing eye morbidity associated with low vision in oculocutaneous albino patients.

The prevalence of nystagmus and strabismus in this study was 96.4% and 63.6% respectively. These findings are comparable to a study conducted by Mokaya et al. in Kenya in 2010 in which nystagmus was present in 98% and strabismus in 91% of the participants.(7) Similarly, in a study conducted in Brazaville by Geraud et al. in 2019 investigating refractive errors in albino

children, it was revealed that all children who were included in the study had nystagmus, including 2 cases (6.25%) with strabismus.(20)

Stereopsis was absent in the majority of the participants (98%), while gross stereopsis was present in only two (2%) of the participants. A hallmark of albinism is excessive decussation of retinostriate projections at the optic chiasm. This misprojection might lead to abnormalities in the retinal correspondence and may account for the usual absence of stereovision.(27)

The Amsler grid test in this study was normal in the majority (75%) of the participants, with 11 participants unable to cope with the test. Amsler grid is an essential test in the assessment of central vision in patients. However, prior studies have found major shortcomings in its application to evaluating individual vision, especially with a negative result. It is difficult to assess the patient's ability to observe and provide an accurate judgment. Similarly, defects might also occur between the gridlines.(28)

Anterior segment examination revealed that 98% of the participants had normal ocular adnexa with one case of ectropion and one with an eyelid mass. The most common anterior segment finding was iris transillumination defect (88.2%).This is comparable to a similar study by Mokaya et al done in kenya in which the most common anterior segment finding was iris transillumination defect (87%).(7)

The posterior segment findings were foveal hypoplasia (97.3%), retinal hypopigmentation (91.8%) and Optic disc hypoplasia (90.9%). These findings are consistent with findings in a similar study done in Kenya by Mokaya et al in which posterior segment findings were foveal hypoplasia (100%), retinal hypopigmentation (97.5%) and optic disc hypoplasia(97%).(7)

8.0. LIMITATIONS

Inability to get persons with albinism from Bujumbura who are not registered in the association. The unavailability and the high cost of some specific testing equipments like OCT (Optical Coherence tomography) which is an important tool in diagnosing fovea hypoplasia and low vision devices like telescope made it impossible to perfom them. Getting participants of persons with albinism from rural areas was a challenge; due to the fact most of them fear being persecuted. This study was only conducted in Bujumbura City; there at least persons with albinism feel safer than those living in the rural area.

9.0. CONCLUSION

1. The primary ocular morbidity encountered in our study population were high prevalence of visual impairment (100%), followed by Nystagmus (97.3%) and strabismus (63.6%).There were few cases of allergic conjunctivitis (6.3%) and cataracts (2%).

2. The possible anatomical causes of visual impairment were fovea hypoplasia (97.3%), optic disc hypoplasia (90.9%) and iris transillumination defect (88.2%).

3. The avoidable cause of reduced vision in our study population was mainly uncorrected refractive error.

10.0. RECOMMENDATIONS

1. An early ocular examination with appropriate refractive correction of persons with albinism is imperative and will help to improve their visual function and quality of life.

2. An eye care program from the public or private sector aiming at providing glasses both for vision and protection from UV rays free of charge or at low cost to persons living with albinism is necessary in order to help reduce the ocular morbidity they encountered.

3. Further studies including tests like OCT to diagnose fovea hypoplasia or the use of low vision devices (example: telescope) will help to get a deeper understanding of the ocular problems faced by persons living with albinism in Burundi.

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12.0. APPENDICES

Appendix I: Budget

Description	**Quantity**	**Unit cost (Ksh)**	**Total (Ksh)**
Proposal development			
Printing	**6**	**500**	**3000**
Binding	**6**	**500**	**3000**
Ethics committee fee	**1**	**2000**	**2000**
Data collection			
Printing of consents + assents + Questionnaires	**15**	**10**	**150**
Questionnaires	**400**	**5**	**2000**
Consents + assent forms	**960**	**5**	**4800**
Stationery + Torches		**5000**	**5000**
Equipment			
Lensometer (Hire)	**30 days**		**10.000**
Contracted services			
Statistician	**1**	**50.000**	**50.000**
Research Assistant	**30 days**	**2000**	**60.000**
Travel			
Air tickets (NBO-BJM-NBO)	**1**	**100.000**	**100.000**
Vehicle for transporting the participants (hire)	**30 days**	**2000**	**60.000**
Meals (snacks)	**30 days**	**500**	**15.000**
Total			**314.950**

Appendix II: WHO Classification of Visual impairment (2018)

Snellen VA	VA (LogMAR)	Classification
≥ 6/12	≥ 0.3	Normal
< 6/12 - 6/18	< 0.3 - 0.5	Mild VI
< 6/18 - 6/60	< 0.50 - 1.0	Moderate VI
< 6/60 - 3/60	< 1.0 - 1.30	Severe VI
< 3/60	< 1.30	Blindness

VA : visual acuity; LogMAR: logarithm of the minimum angle of resolution; VI: visual impairment.

Appendix III: Questionnaire

A. DEMOGRAPHIC DATA

1. Identification number _____
2. Sex: M___ F____
3. Age in years _____

B. GENERAL EXAMINATION

4. Does the participant have an abnormal head posture? Yes ___ No ___
5. Does the participant use glasses or a low vision aid? Yes___ No___

   5.1 If yes, is it an appropriate correction? Yes ___ No ___

   5.2 If No, reason:

   a) Don't need
   b) Not been informed
   c) Parent/guardian cannot afford
   d) Other (specify) _____

C. OCULAR COMPLAINTS

Ocular Complaints	**RE**		**LE**	
	Yes	**No**	**Yes**	**No**
Photophobia				
Strabismus				
Others (specify)				

D. OCULAR FINDINGS

	RE	**LE**
VA (sc)		
VA (cc/PH)		
Refraction		

	RE		LE	
	Yes	**No**	**Yes**	**No**
Nystagmus				
Strabismus				

Stereoacuity, Titmus Fly Test: 1. Present 2. Absent

Amsler Grid Test	RE		LE	
	Yes	**No**	**Yes**	**No**
Central scotoma				
Metamorphopsia				

Anterior Segment Examination:

	RE	**LE**
Lids	1. Normal 2. Abnormal a) Mass b) Scar c) Others ….	1. Normal 2. Abnormal a) Mass b) Scar c) Others ……
Conjunctiva	1. Normal 2. Abnormal a) Discharge b) Injection c) Mass d) Others …..	1. Normal 2. Abnormal a) Discharge b) Injection c) Mass d) Others ……

Cornea	1. Normal 2. Abnormal a) Opacity b) Others …..	1. Normal 2. Abnormal a) Opacity b) Others …..
Anterior Chamber	1. Normal 2. Abnormal a) Hyphema b) Hypopyon c) Others ……	1. Normal 2. Abnormal a) Hyphema b) Hypopyon c) Others ……
Iris	1. Normal 2. Abnormal a) Transillumination defect b) Posterior synechiae c) Aniridia d) Others …..	1. Normal 2. Abnormal a) Transillumination defect b) Posterior synechiae c) Aniridia d) Others ….
Pupil	1. Normal 2. Abnormal a) RAPD b) Fixed NRTL c) Others …..	1. Normal 2. Abnormal a) RAPD b) Fixed NRTL c) Others …..
Lens	1. Normal 2. Abnormal a) Cataract b) Pseudophakic c) Aphakic	1. Normal 2. Abnormal a) Cataract b) Pseudophakic c) Aphakic

Posterior Segment Examination:

	RE	**LE**
Vitreous	1. Normal 2. Abnormal a) Vitritis b) Hemorrhage c) Others ……	1. Normal 2. Abnormal a) Vitritis b) Hemorrhage c) Others ……
Retina	1. Normal 2. Abnormal a) Hypopigmented b) Other ……	1. Normal 2. Abnormal a) Hypopigmented b) Other ……
Fovea	1. Normal 2. Hypoplasia	1. Normal 2. Hypoplasia
Optic disc	1. Normal 2. Abnormal a)Hypoplasia b)Atrophic b) Others …..	1. Normal 2. Abnormal a)Hypoplasia b)Atrophic b) Other …..

Appendix IV : Consent Information and Consent Form

Introduction

My name is Dr. Jean Junior Nkuyubwatsi. I am a post graduate student in the Department of Ophthalmology at the University of Nairobi. I am conducting a study on*: **Ocular Findings in Persons with Albinism in Bujumbura, Burundi***

Purpose of the Study

1. To determine the magnitude of ocular morbidity among persons with albinism in Bujumbura.
2. To identify the anatomical causes of visual impairment in the study population.
3. To determine the possible avoidable causes of reduced vision in the study population.

Basis of Participation

Your participation will be voluntary. You are free to withdraw at any time during the course of the study period. Your refusal to participate or withdrawal at any time during the study period will not in any way affect the quality of your treatment.

Confidentiality

All information obtained in the study will be treated with utmost confidentiality. I shall not use your name in any of my reports.

Benefits

The results of this study may be published in a medical book or journal for teaching purposes; or may be given to the community for better understanding of this topic.

Description of Study Procedure

Approval of the Burundi “Albinos without Borders” association will be obtained and presented to the participants. With the help of the administration of the group, the participants will be

contacted in advance to make arrangement for examination. All the tests will be conducted in a selected health facility within Bujumbura. Informed consent will be issued with a brief explanation of the procedure and will be given to the participants prior to examination. A demonstration of key tests like taking the visual acuity will be done. All participants present on the day of examination with consent given will be recruited into the study. A research assistant (ophthalmic nurse) will be recruited to help in collecting of the data. Registration of each participant and findings will be recorded in individual questionnaires. Any known history and complaints that is related to an ocular problem will also be noted.

Risk and Discomfort

Any examination process that will be conducted by the researcher will cause no damage to the participant.

Request for Information

You may ask more questions about the study at any time or at this moment. You will be informed of any significant findings.

You may contact Dr. Jean Junior Nkuyubwatsi through telephone _____ and email, _____, Department of Ophthalmology (University of Nairobi), or KNH/UoN Ethical Review Committee Secretariat P.O. Box 20723 – 00202, Nairobi, Telephone Number: +254 2726300 Ext. 44102 and email address: uonknh_erc@uonbi.ac.ke

Consent

Having read this consent form, all my questions have been answered, my signature below indicates my willingness to take part in this study and my authorization to use and share with others.

I _____ after reading and having the study purpose explained to me by Dr. Jean Junior, do hereby give informed consent to participate in the study.

Signed _____ Date _____

I confirm that I have explained to the Principal the above statement.

Signature of Principal Investigator _____

Dr. Jean Junior Nkuyubwatsi

Appendix V: Consent Information and Consent Form (in Kirundi)

Umwidondoro wanje

Ndi Muganga Jean Junior NKUYUBWATSI.
Ndi umunyeshule yiga kuri Kaminuza y'i Nairobi mu gihugu ca Kenya. Ndiko ndanonosora ivyerekeye ingwara z'amaso. Icigwa ndiko ndakora cerekeye : "*Ibimenyetso n'ibibazo vy'amaso abanyamwema baba i Bujumbura bakunda kugira''*

Intumbero y'ico cigwa

- Kwiga ingorane z'amaso abanyamwema baba i Bujumbura bakunda kugira
- Gusesangura neza ibituma abanyamwema bagira izo ngorane

Ugufasha muri kino cigwa

Gufasha kugira ngo iki cigwa kirangurwe biva ku gushaka kwawe; nta gahato karimwo. Ushobora kubiheha aho ushakiye hose kandi nta ngaruka n'imwe ikubako kubera ico.

Iki gikorwa gikorwa mw'ibanga

Ivyiyumviro vyose bizotangwa muri iri tohoza ry'iki cigwa bizokorwa mw'ibanga ntangere, ntituzovuga na hamwe uwabitubariye**.**

Akamaro ko gukora iki cigwa

Ibizova muri kino cigwa bishobora kuzokwandikwa mu bitabo kugira ngo abantu babimenye. Bizokoreshwa mu kwigisha abanyeshure vyongere bimenyeshwe abanyagihugu kugira ngo batahure neza ingorane z'amaso abanyamwema bakunda kugira.

Impanuka zoshikira ufashije muri kino cigwa

Ibizokorwa vyo muri kino cigwa, nta ngaruka mbi nimwe bizogirira uwo wese azoba yafashije kugira kigende neza

Kubaza ibijanye n'iki cigwa

Wewe uriko uriko urafasha kugira ngo iki cigwa kigende neza, ufise uburenganzira bwo kubaza ikibazo ico arico cose cerekeye kino cigwa, umwanya uw'ariwo wose.
Hagize igihinduka mu gutunganya iki cigwa, uzobimenyeshwa ku gihe.
Ushobora kunyakura Dr Jean Junior NKUYUBWATSI kuri Telefone (----------) canke ukanyandikira ku buryo ngurukanabumenyi (email): nkuj2005@yahoo.fr
Ushobora kandi kunyandikira ubucishije ku gasandugu ka posita kari i Nairobi:

Dr Jean Junior Nkuyubwatsi
Igisata c'ivyigwa vy'amaso
Kaminuza y'i Nairobi.
KNH/UoN Ethical Review Committee Secretariat
P.O. Box 20723 – 00202,
Nairobi, Telephone Number: +254 2726300 Ext. 44102
email address: uonknh_erc@uonbi.ac.ke

Kwemeza gufasha mw'itohoza ry'iki cigwa

Jewe ……
Maze gusoma no gusigurirwa na Muganga Jean Junior ingene iki cigwa kizokorwa, ndemeye ata gahigihigi gufasha kugira ngo ayo matohoza ajanye n'ico cigwa agende neza .

Umukono_____ Igenekerezo ryo kuwa_____

Jewe, Muganga Jean Junior Nkuyubwatsi,
Ndemeje ko nasiguriye neza Mr/Mrs_____ ibi muri kino cigwa vyose
Umukono _____. Igenekerezo ryo kuwa ----------

Appendix VI: Parental Consent (English)

Dear Parent.

My name is Dr. Jean Junior Nkuyubwatsi. I am a post-graduate student of Master of Medicine in the Department of Ophthalmology, University of Nairobi, Kenya. I am conducting a study on ***"Ocular findings in persons with Albinism in Bujumbura, Burundi"***

I have explained the nature of the study to your son/daughter. Participation will be voluntary. Your child is free to withdraw at any time during the course of the study period. All information obtained in the study will be treated with the utmost confidentiality. I shall NOT use any name in any of my reports. Assent will be obtained from your son/daughter after your final consent.

All the examination processes that will be conducted by the researcher will cause no damage or harm to your child.

For any question, you may contact Dr. Jean Junior Nkuyubwatsi at (Phone: _____)

Consent:

I _____ the parent of _____ after reading the consent form, and all my questions answered, do hereby give informed consent to allow my child to participate the study.

Signed _____ Date _____

I confirm that I have explained to the parent the above statement.

Signature of the Investigator _____

Dr. Jean Junior Nkuyubwatsi

Appendix VII: Parental Consent (in Kirundi)

Ndi Muganga Jean Junior NKUYUBWATSI.

Ndi umunyeshule yiga kuri Kaminuza y'i Nairobi mu gihugu ca Kenya. Ndiko ndanonosora ivyerekeye ingwara z'amaso. Icigwa ndiko ndakora cerekeye : "*Ibimenyetso n'ibibazo vy'amaso abanyamwema baba i Bujumbura bakunda kugira''*

Nasiguriye neza umwana wawe iki cigwa tugiye gukora.Gufasha kugira ngo iki cigwa kirangurwe biva ku gushaka kwawe.Umwana wawe ashobora kuva muri kino cigwa aho abishakiye hose. Ibikorwa vyo muri kino cigwa bikorwa mw'i banga.Ntahantu nahamwe hazokwandikwa amazina y'umwana canke ayanyu. Mukaramuka muduhaye uruhusha yuko umwana wanyu afasha muri kino cigwa nawe nyene turaheza tumusabe icemezo yuko yemeye gufasha muri kino cigwa ata gahato.

Ibizokorwa vyo muri kino cigwa, nta ngaruka mbi nimwe bizogirira uwo wese azoba yafashije kugira kigende neza

Ushobora kwakura Dr Jean Junior NKUYUBWATSI kuri Telefone (----------) mugihe mufise ibibazo.

Kwemeza gufasha mw'itohoza ry'iki cigwa

Jewe ……

Maze gusoma no gusigurirwa na Muganga Jean Junior ingene iki cigwa kizokorwa, ndemeye ata gahigihigi ko umwana wanje yofasha kugira ngo ayo matohoza ajanye n'ico cigwa agende neza .

Umukono_____ Igenekerezo ryo kuwa _____

Jewe, Muganga Jean Junior Nkuyubwatsi,

Ndemeje ko nasiguriye neza Mr/Mrs_____ ibi muri kino cigwa vyose

Umukono _____. Igenekerezo ryo kuwa ----------

Appendix VIII: Assent Form (for under 18 years old)

My name is Dr. Jean Junior Nkuyubwatsi, I am a post-graduate student of Master of Medicine in the Department of Ophthalmology, University of Nairobi, Kenya. I am conducting a study on ***"Ocular findings in persons with Albinism in Bujumbura, Burundi"***

A research study is when people like me collect a lot of information about certain things in the society to find out more about it. Therefore, before you decide to participate in this study, it is very important for you to understand why we are doing the research and what is involved.

Why am i doing the study?

I am doing this study because I want to find out the ocular problems that people with albinism usually encounter.

What will happen if you participate in this study?

I will check your vision, one eye at a time. The eye that is not being tested will be covered either by your hand or by an occluder. After I will conduct a series of eye examination which will help me to identify the causes of ocular problems faced by persons with albinism.
All the procedures that I am going to do will have NO RISK or HARM to you.

Beside you, your parents and the researcher no one else will know the details of your study participation. We will not use your personal identification during the course of the study. You will not be paid for taking part into this study

If you don't want to be in the study?

Please be informed that your participation is absolutely voluntary. If you don't want to be in this study, you are free to withdraw from the study at any anytime.

Finally I would like to invite you to take part in my research study.

If you would like to participate in this study, please sign your name below

Child's Name & Signature _____ Date _____

Appendix IX: Assent Form (for under 18 years old) (in Kirundi)

Ndi Muganga Jean Junior NKUYUBWATSI.
Ndi umunyeshule yiga kuri Kaminuza y'i Nairobi mu gihugu ca Kenya. Ndiko ndanonosora ivyerekeye ingwara z'amaso. Icigwa ndiko ndakora cerekeye : "*Ibimenyetso n'ibibazo vy'amaso abanyamwema baba i Bujumbura bakunda kugira''*
Itohoza nkiri rikorwa iyo dushaka kuronka amakuru yerekeye ibibazo bitandukanye abantu bahura navyo.Nico gituma bikenewe ko umenya igituma iryo tohoza ririko rirakorwa imbere yo kwemera kuja muri ryo.

Igituma dukora iri tohoza?

Dushaka gukora iri tohoza kubera dushaka kumenya igituma abanyamwema bagira ibibazo vy'amaso.

Ibiza gukorwa muri rino tohoza

Ubwambere turapima ukubona kw'amaso yawe.ijisho rimwe rirapimwa irindi ripfunze hanyuma duhindure dupime irindi nkuko twapimwe iryambere.Turaheza dukore ibipimo vy'amaso bitandukanye.Ivyo navyo biza kudufasha kumenya igituma abanyamwema bagira ibibazo vy'amaso.

Ibizokorwa vyo muri kino cigwa, nta ngaruka mbi nimwe bizogirira uwo wese azoba yafashije kugira kigende neza.
Ivyiyumviro vyose bizotangwa muri iri tohoza ry'iki cigwa bizokorwa mw'ibanga ntangere, ntituzovuga na hamwe uwabitubariye**.**
Gufasha kugira ngo iki cigwa kirangurwe biva ku gushaka kwawe; nta gahato karimwo. Ushobora kubiheha aho ushakiye hose.

Mugihe mwemeye gufasha muri rino tohoza, nimushireko umukono hano
Amazina _____ Igenekerezo _____

Appendix X: Ethical Approval Certificate

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

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/288

3rd September 2020

KENYATTA NATIONAL HOSPITAL APPROVED 03 SEP 2020 KNH/UoN-ERC P. O. BOX 20723 - 00202 NAIROBI

Dr. Jean Junior Nkuyubwatsi
Reg. No.H58/12309/2018
Dept. of Ophthalmology
School of Medicine
College of Health Sciences
University of Nairobi

Dear Dr. Nkuyubwatsi

RESEARCH PROPOSAL – OCULAR FINDINGS IN PERSONS WITH ALBINISM IN BUJUMBURA, BURUNDI (P331/06/2020)

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 3rd September 2020 – 2nd September 2021.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. 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.
d. 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.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. 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*).
g. 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.

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 Senior 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. Nyenze Emmanuel Muindi, Dept .of Ophthalmology, UoN
Dr. Mukuria Mukiri, Dept.of Ophthalmology, UON
Pr. Levi Kandeke, Dept.of Ophthalmology, University of Burundi