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Exploring barriers to corneal donation in Nigeria: Implications for healthcare delivery and access: A mixed-methods study

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Abstract

Background: Corneal opacity is a significant cause of blindness worldwide, accounting for an estimated 5.5 million people who are bilaterally blind or have moderate to severe visual impairment. In Nigeria, corneal opacities contribute to 7.9% of blindness, with trachoma alone accounting for an additional 4.2%. Despite the high prevalence, the availability of donated corneas remains critically low, with only one cornea available for every seventy individuals in need globally. This mixed-methods study explores the barriers to corneal donation in Lagos, Nigeria.

Methods: We conducted a cross-sectional study at the Eye Bank of Nigeria and the outpatient department of Lagos State University Teaching Hospital (LASUTH) in 2023. We administered a structured questionnaire to adult patients to assess knowledge, attitudes, and perceptions regarding cornea donation. We conducted In-depth interviews with healthcare workers, key decision-makers, and potential donors to understand the experiences, perceptions, and challenges of corneal donation. Data was analysed using descriptive analysis for quantitative data and thematic analysis for qualitative data.

Results: Among the 97 participants of the KAP survey, the mean (SD) age was 53 (±14) years, with 67% having heard about organ donation but only 9% being aware of corneal donation. Qualitative interviews identified five main themes: information and awareness, perceptions and beliefs, organisational challenges, possible solutions, and potential donors' experiences. Key barriers included a lack of awareness, cultural beliefs surrounding death, and organisational constraints related to training and funding.

Conclusion: This study identifies key barriers to corneal donation in Lagos, Nigeria, underscoring the importance of improving public awareness, education, and stakeholder engagement to enhance access to corneal transplantation services. Tackling these challenges is crucial for strengthening healthcare delivery and reducing the burden of corneal blindness in the region.

Keywords: Corneal donation; Barriers; Corneal blindness; Knowledge; Attitudes and perception; Mixed-methods study.

Introduction

Corneal opacity is an important cause of blindness worldwide, affecting an estimated 5.5 million people who are bilaterally blind or have moderate to severe visual impairment, with an additional 6.2 million unilaterally blind from corneal opacity. The global age-adjusted prevalence of blindness from non-trachomatous corneal opacity in people aged 40 years and older was 0.081% (95% CI, 0.049%-0.315%), with the Sub-Saharan Africa region accounting for 0.14%-the second most affected region after North Africa and the Middle East [1]. In Nigeria, corneal opacity contributes to 7.9% of the cause of blindness, while trachoma-related corneal opacity adds another 4.2%, making it the third leading cause of blindness after cataract and glaucoma [1]. Corneal blindness disproportionately impacts individuals during their most economically productive years, leading to substantial social and economic burdens and a higher number of disability-adjusted life years (DALYs) compared to cataract [2]. Corneal transplantation offers a reliable and effective means of restoring vision, but the global availability of donated corneas remains critically low [3]. It is estimated that only one cornea is available for every 70 people in need of a corneal transplant globally [5,6]. The burden is even more pronounced in low and middle-income countries (LMICs) [4]. In Nigeria, the Eye Bank has recorded only two Indigenous cornea donors and three beneficiaries over the past two decades (Eye Bank manager, Personal communication, November 11, 2022). However, approximately 300,000 individuals in Nigeria could potentially benefit from corneal transplantation to restore their vision [2-6]. Barriers to corneal donation vary by sociodemographic and geographic contexts. Studies from Asia and high-income countries have reported barriers such as lack of information and awareness [5,7-9], concerns about facial disfigurement [9], religious and cultural beliefs [9,10], family objection [9], and mistrust in the healthcare system. Conversely [11], studies from Africa have highlighted factors such as low levels of education [5,12,13] concerns about disfigurement [5,13], and lack of awareness [12] as key barriers. A study among medical students in Nigeria identified limited knowledge as the primary obstacle to corneal donation [14]. This study aims to explore barriers to corneal donation among healthcare professionals and the general population in Lagos, Nigeria, with a focus on understanding the systemic, cultural, and individual factors that impede access to corneal transplantation services.

Methods

We conducted a mixed-methods cross-sectional study in 2023 at the Eye Bank of Nigeria and the outpatient department both within the Lagos State University Teaching Hospital (LASUTH). The Eye Bank of Nigeria is a non-governmental organisation that was established in 2004. It is responsible for harvesting, processing donor corneas, and distributing them to trained corneal graft surgeons. The eye bank adopted the Hospital Corneal Retrieval Program (HCRP) in 2017 to improve indigenous corneal donation. The program involved training hospital nurses working in the wards and clinics of government hospitals on grief counselling so that they can counsel and encourage families of the deceased in the hospitals to consider eye donation. LASUTH is one of the two tertiary hospitals in Lagos state, and the outpatient department serves the people of Lagos state and neighbouring states.

Survey questionnaire

A structured questionnaire was administered to adult (aged ≥18 years) patients attending the general outpatient department (other than the eye clinic) of LASUTH via a systematic sampling method. The sample size for the survey was calculated using the formula for estimating the proportion of binary outcomes in descriptive studies. The considered proportion willing to donate was 6% [16], and the desired level of absolute precision was 0.05 i.e. 5%, giving a total of 97 participants, inclusive of 10% of non-response [15]. Each patient in the outpatient clinic was given a number as they arrived. At the start of each survey day, a random naira was chosen and the first digit of its serial was used as the starting number. After this, every second patient from the patient's list was selected. The selected patients were informed about the study. The principal investigator administered the questionnaire to the patients who consented and were eligible to participate. Data was collected using the Open Data Kit central database (ODK Collect version 2023.1.2) in English. The questions were translated into the local language for those who did not understand English. The questionnaire explored their knowledge, attitudes and perceptions regarding corneal donation. After completing the questionnaire, the participants were educated on corneal donation services and offered leaflets on corneal donation. The questionnaire was pretested before the commencement of this study. This process helped refine the last version used in this study.

In-depth Interviews

In-depth interviews were conducted with healthcare workers, key decision-makers and potential corneal donors using purposive sampling. Healthcare workers consisted of ophthalmologists who had been trained to retrieve corneas and perform transplantation with ≥3 years of experience and grief counsellors who are certified nurses trained to offer grief counselling on corneal donation. Key decision-makers included members of staff of the Eye Bank. The potential corneal donors at the Eye Bank of Nigeria included only those who consented to be contacted. The list of names and contact details of the potential donors who had consented to be contacted was obtained from the administrative office of the Eye Bank of Nigeria. Participants were contacted and informed about the study via a phone conversation. In-depth interviews were conducted either in person at the eye bank or via a Zoom call as per participants' preferences and availability. The interview guide consisted of socio-demographic information and open-ended questions on perceptions of corneal donation, factors influencing cornea donation services, and possible solutions to cornea donation in Nigeria.

Ethical considerations

Approval to conduct this study was obtained from the Medical and Health Research Ethics Committee of LASUTH and the London School of Hygiene and Tropical Medicine. Informed consent and permission to audio record the interview were obtained. Participants were identified using a unique ID number, and personal identifiers were removed from the transcripts. After the interviews, audio recordings were saved on a password-protected computer and immediately deleted from the audio recorder. All data were kept confidential. The study was conducted under the ethical principles of the World Association

Declaration of Helsinki.

Data analysis

A descriptive analysis of the survey data was done using Stata 17.0, June 2017, Stata Corp LP USA software. The knowledge and perception questions were categorised into two groups, each assigned a score: one for affirmative answers and zero for non-affirmative answers. Participants who had a score equal to and above the mean score were considered to have 'good' knowledge or perception regarding corneal donation, while those below the mean score were classified as having 'poor' knowledge or perception regarding corneal donation. Categorical variables were reported as frequencies and percentages, while continuous variables were reported as means + standard deviation. Qualitative data was transcribed verbatim from audio recordings into text. Transcripts were coded using an inductive approach guided by the objectives and interview guide. Using thematic analysis, emerging themes were summarised, and the resulting summaries were checked across participants' transcripts to check for similarities and differences.

Table 1: Socio-demographic characteristics of the study participants (N=97).

Variable	Grouping	n	% of N
Sex	Female	60	61.86
	Male	37	38.14
Age grouping	19 to 39 years	20	20.62
	40 to 59 years	43	44.33
	≥ 60 years	34	35.05
Employment	Employed	70	72.16
	Not employed	27	27.84
Education	College or university	57	58.76
	Secondary school	21	21.65
	No/little formal education	19	19.59
Ethnicity	Yoruba	45	46.39
	Ibo	30	30.93
	Others	22	22.68
Religion	Christian	87	89.69
	Muslim	10	10.31
Residence	Urban	88	90.72
	Rural	9	9.28

Results

Survey: The mean (SD) age in our study was 53 (±14) years and the age range was 19 to 79 years. More of the participants were females (60,62%), middle-aged i.e. 40 to 59 years (43,44%), employed (70,72%), had attained college or university education (57,59%), Yoruba tribe (45,46%), Christians (87,90%); and resides within the urban area (88,91%) as shown in Table 1 below.

Knowledge of cornea donation: While most of the participants had heard about organ donation (65,67%), only about one-tenth (9,9%) had ever heard about corneal donation. Just 1 (1%) participant knew how to donate their corneas, and close to a quarter (24%) knew corneal donation is legal. Only a few of the participants (10,10.31 %) had good knowledge about corneal donation, as shown in Table 2.

Females 7 (70%), those aged 19 to 39 years 5 (50%), those employed 8 (80%), Ibo tribe 5 (50%), Christians 10 (100%), those who had college or university education 7 (70%) and living in an urban area 10 (100%) had a higher proportion of good knowledge as indicated in Table 3.

Table 2: Knowledge of cornea donation (N=97).

Knowledge of cornea donation	Responses	n (% of N)
Ever heard about organ donation?	Yes	65 (67.01)
	No	32 (32.99)
Ever heard about corneal donation?	Yes	9 (9.28)
	No	88 (90.72)
Do you know how to pledge your cornea for donation?	Yes	1 (1.03)
	No	96 (98.97)
Is it legal to pledge your cornea for donation?	Yes	23 (23.71)
	No	74 (76.29)
Overall knowledge	Good	10 (10.31)
	Poor	87 (89.69)

Table 3: Sociodemographic data of the participants stratified by poor/good knowledge.

Variable	Knowledge category		
	Poor - 87 n (% of n)	Good - 10 n (% of n)	Total – 97 N (% of N)
Sex			
Female	53 (60.92)	7 (70.00)	60 (61.86)
Male	34 (39.08)	3 (30.00)	37 (38.14)
Age group			
19 – 39yrs	15 (17.24)	5 (50.00)	20 (20.62)
40 – 59yrs	40 (45.98)	3 (30.00)	43 (44.33)
≥60yrs	32 (36.78)	2 (20.00)	34 (35.05)
Employment status			
Employed	62 (71.26)	8 (80.00)	70 (72.16)
Unemployed	25 (28.74)	2 (20.00)	27 (27.84)
Ethnicity			
Yoruba	42 (48.28)	3 (30.00)	45 (46.39)
Ibo	25 (28.74)	5 (50.00)	30 (30.93)
Others	20 (22.99)	2 (20.00)	22 (22.68)
Religion			
Christian	77 (88.51)	10 (100.00)	87 (89.69)
Muslim	10 (11.49)	0 (0.00)	10 (10.31)
Education			
None or little formal	18 (20.69)	1 (10.00)	19 (19.59)
Secondary school	19 (21.84)	2 (20.00)	21 (21.65)
College or University	50 (57.47)	7 (70.00)	57 (58.76)
Residence			
Urban	78 (89.66)	10 (100.00)	88 (90.72)
Rural	9 (10.34)	0 (0.00)	9 (9.28)

Attitude toward corneal donation: The attitudes and beliefs regarding corneal donation were only collected from the nine participants who had heard about corneal donation. Out of these nine participants, none had considered pledging their cornea. However, all (9,100%) of these participants would be willing to receive or allow family members to receive cornea to help restore their sight if necessary. They all agreed that there is a need for increased public awareness and education regarding corneal donation.

Table 4: Perception questions (N=97).

Question	Responses	n (% of N)
Is cornea donation important?	Yes	38 (39.18)
	No	59 (60.82)
It is easily noticeable that someone has a donated cornea?	Yes	24 (24.74)
	No	73 (75.26)
Willing to donate cornea after death	Yes	20 (20.62)
	No	77 (79.38)
Will you consent to the harvesting of the cornea of a family member if in a position to do so?	Yes	15 (15.46)
	No	82 (84.54)
Willingness to participate in the corneal donation awareness program?	Yes	36 (37.11)
	No	61 (62.89)
Overall perception	Good	62 (63.92)
	Poor	35 (36.08)

Perception regarding corneal donation: Table 4 summarises the participants' perception towards corneal donation. To assess the perception regarding cornea donation, the participants were provided with information on corneal donation, as only 9,9%) had heard of corneal donation. A large majority of the participants thought corneal donation was unimportant (59,61%), with only (20,21%) of the study participants planning to donate their cornea after death. A smaller proportion of the participants (15,15%) will consent to have the cornea of their family member harvested after their death if they can do so. Just over a third (36,37%) of the study participants are willing to participate in the corneal donation awareness program. Overall, 62 (63%) of the study participants were considered to have good perception regarding corneal donation.

A trend like that seen in the knowledge categories was observed when the sociodemographic data was stratified with perception, except those participants from the Yoruba tribe showed a higher level of good perception as indicated in Table 5.

In-depth interviews: A total of nine participants were interviewed. Their sociodemographic characteristics are summarized in Table 6.

Five main themes - Information and awareness, Perceptions and Beliefs, Organizational challenges, Possible solutions and Experiences of potential donors - were generated from the analysis of the transcripts as shown in Figure 1.

Information and awareness

Lack of awareness and information: A lack of awareness was attributed to a lack of information about corneal donation among the public and certain healthcare personnel. Even though some participants perceived that lack of awareness cuts across tissue donation, others thought that more people were aware of other organ donations compared to the cornea. Many of the participants revealed that people are unaware that harvested corneas can be utilized upon death for someone else to regain their sight. According to one of the participants

"*…so, I know people are aware of kidney transplants, even liver but when it comes to it [the cornea], it's not very popular like the rest*"" – Potential donor 08.

Table 5: Sociodemographic data of the participants stratified by poor/good perception.

Variable (N=97)	Perception category		
	Poor - 35 n (% of n)	Good - 62 n (% of n)	Total - 97 N (% of N)
Sex			
Female	22 (62.86)	38 (61.29)	60 (61.86)
Male	13 (37.14)	24 (38.71)	37 (38.14)
Age group			
19 – 39yrs	8 (22.86)	12 (19.35)	20 (20.62)
40 – 59yrs	14 (40.00)	29 (46.77)	43 (44.33)
≥60yrs	13 (37.14)	21 (33.87)	34 (35.05)
Employment status			
Employed	25 (71.43)	45 (72.58)	70 (72.16)
Unemployed	10 (28.57)	17 (27.42)	27 (27.84)
Ethnicity			
Yoruba	20 (57.14)	25 (40.32)	45 (46.39)
Ibo	7 (20.00)	23 (37.10)	30 (30.93)
Others	8 (22.86)	14 (22.58)	22 (22.68)
Religion			
Christian	29 (82.86)	58 (93.55)	87 (89.69)
Muslim	6 (17.14)	4 (6.45)	10 (10.31)
Education			
None or little formal	9 (25.71)	10 (16.13)	19 (19.59)
Secondary school	11 (31.43)	10 (16.13)	21 (21.65)
College or university	15 (42.86)	42 (67.74)	57 (58.76)
Residence			
Urban	33 (94.29)	55 (88.71)	88 (90.72)
Rural	2 (5.71)	7 (11.29)	9 (9.28)

The eye bank uninformed of death: The family or next of kin of the potential donors are unaware of their intention to donate their corneas upon death so they do not inform the eye bank when these donors die. Therefore, their corneas are not harvested. Two of the participants highlighted that some of the donors may have informed their family members about their commitment to donate their corneas upon their death but the family members may have forgotten due to the circumstances surrounding the death. One of the Eye Bank staff said:

"*…especially when it has to do with when the person is not old and it is an unfortunate incident… So, most of them even forget, or they do not feel it is important enough. So that is one of the challenges*" - Eye Bank staff 01.

Attitude of beneficiaries: Some of the participants revealed that people who had received transplanted corneas are typically not willing to let people know because of the perceived fear of stigmatization that they may face from people around them. This stigma may be a result of poor knowledge of corneal donation amongst the populace. One of the Eye Bank staff mentioned that

…. but when people that have gotten this thing [corneal transplant] are not coming forward to say, I got this thing {corneal transplant} done. I can see now; once I was blind, now I can see. How will people know [about cornea donation]?" - Eye bank staff 02.

Table 6: Sociodemographic characteristics of the participants for the In-depth interview.

Unique ID number	Position	Age (yrs.)	Sex	Religion	Years in the current position
01	Eye bank staff	36	Female	Christian	3
02	Eye bank staff	74	Female	Christian	14
03	Grief counsellor	55	Female	Christian	5
04	Grief counsellor	42	Female	Muslim	3
05	Grief counsellor	54	Female	Christian	5
06	Ophthalmologist	69	Male	Muslim	20
07	Ophthalmologist	64	Male	Christian	17
08	Potential donors	56	Female	Christian	7
09	Potential donors	-	Female	Christian	8

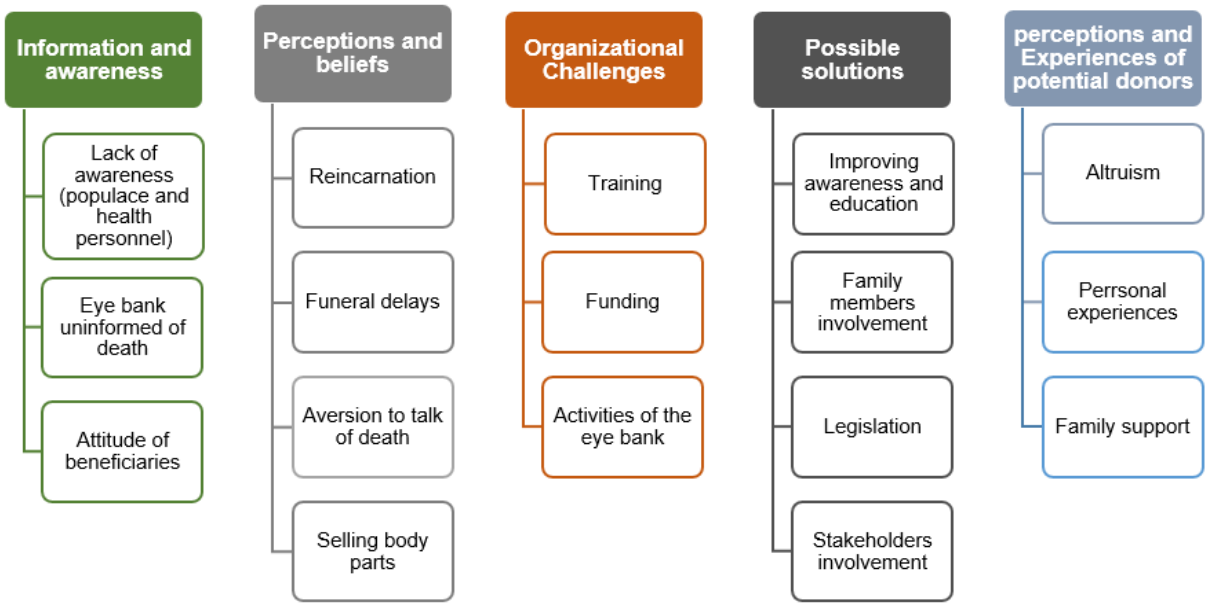

Figure 1: Summary of the themes and subthemes of interviews.

Perceptions and beliefs

Reincarnation: Most of the participants highlighted that people believed that they would come again in another life after their death and because of this, they do not want any of their body parts to be mutilated or removed. It is believed that the body part that was removed may be missing in their other life. The study participants expressed mixed opinions on whether reincarnation was a cultural or religious belief. One of the participants thought that reincarnation was perceived to be prevalent even among those identifying as Christian or Muslim; the two main religions in Lagos state.

Funeral delays: Some people believed that cornea harvesting may delay funeral arrangements. Islamic religious practices believe in the burial of the deceased within 24 hours of death to protect the living from sanitary issues. As a result, the family of the deceased may be unwilling to entertain any process that is perceived to delay the funeral arrangements of the deceased.

Aversion to talk of death: Findings revealed that people were averse to hearing or talking about death and therefore discussions of corneal donation after their death were not entertained. Death was regarded as a taboo subject. Even though it was admitted that death was inevitable, people were averse to talking or planning around it. One of the ophthalmologists reported that a pastor said

"Please doctor do not come back and be talking about such things [donating your cornea after death] to us [the church] because what we tell our people are positive things... So, you cannot come and be talking to them that when you die, you donate your eyes and things like that" – Ophthalmologist 07

Selling body parts: Many of the participants emphasised the general misconception about the use of body parts for money-making rituals. It has been speculated that good fortune and fame can be made by consuming or using human parts for sacrifices. This concept of acquiring wealth through sacrifices with body parts has become a recurrent theme for many Nigerian movies and religious institutions and this may have propagated this erroneous belief amongst people. It has also been speculated that the submission of body parts upon death is a practice by some fraternity groups, so people are not willing to donate their body parts, including the cornea because they do not want to be perceived to belong to these groups. Three participants thought that people believed that their families should receive monetary compensation if they decide to pledge their corneas for donation. One of the Ophthalmologists said

"The main problem we are having is because of our{people's} belief in that human parts can be used to make money. So that is why nobody wants to submit their human part or parts of their body even at death. -Ophthalmologist 06

Organizational challenges

Training: The grief counsellors highlighted that the quality of training they received was adequate, however, they emphasised the need for ongoing refresher training rather than the one-off training that they had received as some of them could no longer remember the details. The principal investigator initially contacted some of the grief counsellors to participate in the study, but they were no longer working for the institution. The participants revealed that having a dedicated person for grief counselling may be more appropriate as most of the nurses selected have other primary responsibilities such as looking after patients and as such may not devote the needed time for counselling. According to one of the health workers

"When we were given the training then we were really satisfied but it's been a while, it's been a long time, so I feel there should be retraining because you [people] get new information daily and this will actually enhance our performances as grief counsellors" -Grief counsellors 04

Funding: The Eye Bank of Nigeria is a non-governmental organisation funded by members of the board. It receives donations from the Ophthalmology Society of Nigeria (OSN) and the Federal Nigerian Society for the Blind. The donations from these organisations have not been consistent because of the low corneal retrieval and transplantation rates. This invariably has limited the activities of the eye bank in creating awareness, publicity, organising training workshops and employing dedicated staff for grief counselling. The available funds are used for office maintenance and administrative staff salaries. Some of the participants highlighted the role of funding in publicity, awareness, advocacy, and the employment of dedicated grief counsellors. According to one of the Eye bank staff,

"… because we [the eye bank] do not have fat envelopes to give [to media houses] we do not get the expected…. how will I put it now. Expected ... What is the word to use now? The publicity that we need." Eye bank staff 02

Activities of the eye bank: Findings revealed that participants had mixed views concerning how well the eye bank performed its activities. Some believed that the eye bank had put in a lot of effort despite its limited funding towards sensitization on corneal donation, through advocacy with the government, continuous engagement with religious institutions, media awareness, outreaches, and presentations at conferences to enlighten the public and healthcare professionals on corneal donation. One of the Eye Bank staff Said,

"We've been to churches…Yes, some people have come up to register to be donors" Eye Bank Staff 02.

Another Eye Bank staff added

"At the OSN (Ophthalmological Society of Nigeria) conference… we applied to them to give us a stand where we can display all our fliers and people can come and ask questions, we can create more awareness… on corneal donation. It was also part of the sub-themes of the conference" - Eye Bank Staff 01.

Others believe that the eye bank should concentrate on promoting the retrieval of indigenous corneas rather than helping hospitals source corneas overseas. According to one of the ophthalmologists

"So the problem I also see is that the eye bank is not well focused, especially on the technical parts of eye banking that is getting donors, preserving, processing, and distributing cornea. What the eye bank is doing or was doing was to get corneas from abroad and give to surgeons to use which I do not think is wrong or bad. But that should not be the focus of an eye bank" - Ophthalmologist 07.

Possible solutions

Improving awareness and education: Most of the participants repeatedly highlighted that improving awareness and education on corneal donation is an important initial step. Some participants also suggested that this would aid the efforts of the grief counsellors. Participants discussed various methods of improving awareness, particularly emphasizing the need to educate students on corneal donation at various stages of education, especially at the primary level. Other methods suggested included the use of television and radio, religious institutions, social media, newspapers, posters, and leaflets, involving the beneficiaries, having a dedicated day for cornea donation awareness, involving health associations and hospitals, and engaging the community and religious leaders. One of the Eye Bank staff recalled that

"whilst growing up nobody talked about this [cornea donation]. So, I think that we need to start advocacy from schools. Let us get the children involved. Let them start to know that even at death, they can be relevant" -Eye Bank staff 02.

Family member's involvement: Some of the participants highlighted the need for the eye bank team to actively engage the families of potential donors as soon as they commit to pledging their eyes for donation. One of the participants recommended sending reminders in the form of text messages, emails, and letters to the potential donor and the next of kin that had been indicated in the donor form. One of the Ophthalmologist said

"I think anybody that has signed the papers [donor forms] should allow us [eye bank team] to have a meeting with the family members"-Ophthalmologist 06.

Legislation: Participants emphasised the need to implement the National Health Bill and for the government to show commitment to improving corneal donation. One participant suggested amending the law to the presumed consent law, which automatically makes everyone a donor unless the person opted out. According to one of the potential donors

"… if we are looking at the angle of legislation, how can we get the government to approve legislation…." - Potential donor 08.

Stakeholder's involvement: The participants highlighted the role of several stakeholders, especially government participation. One of the participants suggested having representatives from patients who had benefited from corneal donations on the board. It was highlighted that organizations should be encouraged to support corneal donations as part of their corporate social responsibility. It was also emphasized that more Indigenous corneal retrieval and transplantation needed to be done to retain the organisations that are currently supportive. One of the participants suggested that a representative of the Ministry of Health be a board member of the eye bank saying,

"I believe until the government steps in like what they did for blood bank, blood donation, then maybe there would be a bit of push forward" Eye bank staff 02.

Experiences of potential donors

Altruism: Corneal donation was perceived to improve someone else quality of life by restoring their vision and a way to set a positive legacy after passing on.

Personal experiences: According to some potential donors, personal experiences, previous or current interactions with cornea services and having lived in a country where the presumed consent law was practised had influenced their decision to become corneal donors. One of the potential donors said "My father is a retired ophthalmologist

…So growing up, we were privy to having some understanding… When my mother… passed away… her death was sudden, so everybody was in shock, but my father got someone to harvest her cornea. …the cornea is still being used by that person and the person can see. The person was blind before, but the person can see. And it was a turning point for me" -Potential donor 09.

Family support: The participants emphasised that they received sufficient encouragement and support from their families when they informed them that they had pledged their corneas for donation, and this provided reassurance and validated their decisions. One of the potential donors concluded that

'I'm a donor and they {my family} know that am a donor and anything acceptable by me is acceptable by all and all my family are in it with me." -Potential donor 08.

Discussion

Information and awareness

According to the results, most participants during the in-depth interview expressed a lack of awareness and information as barriers to corneal donation. This was similar to the findings from other studies from Nigeria [17], Ghana [12], Ethiopia [5], Saudi Arabia [9,18], United Kingdom [19] and Poland [18]. It was revealed that there was relatively more awareness on other organ donations as compared to corneal donation. This was comparable to the findings from our survey, which showed a greater awareness of other organ donation (two-thirds) compared to corneal donation (9%) among the participants. And only an abysmal 1% of the population knew how to pledge their corneas for donation. This finding was lower than the report from the study from Saudi Arabia, where 10.5% of the population knew how and where to pledge for corneal donation [20]. This may be because eye banking and transplantation activities in Saudi Arabia started earlier than in Nigeria, or they just have a more established system and more acceptance at the national level, or the people are more aware of corneal donation than in Nigeria. The proportion of those who had overall good knowledge about corneal donation was also very low (10%). This percentage was similar to the study in Ghana (8.4%) [12] and Ethiopia (8.4%) [13]. However, it was higher than another study from Saudi Arabia (4.3%) [9] but lower than studies from Singapore by (16.8) % [7], Ethiopia (23.7%) [5], Poland (57.56%) [18] and Nigeria (33.3%) [17]. The wide variation in the knowledge on corneal donation may be attributed to the different benchmarks for determining knowledge by the different studies, literacy of the participants and level of education. In our study, the proportion of good knowledge about corneal donation decreased with increasing age. A study by Runda et al [16] showed no association between the participant's knowledge and sociodemographic characteristics. Another study found higher educational status, ethnicity and age[12] to be associated with better knowledge of corneal donation.

Perceptions and beliefs

A significant obstacle to corneal donation is cultural beliefs that have permeated religion. There is a belief that the dead should be buried completely to meet their creator intact, and a belief in reincarnation. Even though the holy books (the bible and the Quran) of the two major religions in Lagos state reject the concept of reincarnation, [12,22] it is still regarded by some as a religious belief. Some studies have reported wanting to be buried intact to be a reason for the lack of willingness to donate corneas [5,12]. Other studies have found religious [5,9,13,18] and cultural beliefs [10] to be reasons for poor corneal donation. In Islamic practice, the deceased is usually buried on the same day of demise. The incorrect assumption was that the procedure for retrieving the cornea might cause the funeral to be delayed. In our survey, similarly, none of the participants had considered pledging their corneas for donation (data not shown), although about one-fifth (21%) would be willing to donate their cornea after demise. Some of their reasons were delays in funeral arrangements, cultural, religious, trust in the health system and lack of family support. These findings were also similar to reasons reported from other studies that included cultural, religious, [5,13,18] delayed funeral arrangements, [13] and lack of family support [18].

Organizational challenges

The training of grief counsellors is central towards the implementation of the HCRP. The development of the HCRP is crucial for boosting corneal donation and retrieval rates [3]. Most of the trained grief counsellors were enthusiastic about the training and stated that it was of good quality. However, the training had been irregular and infrequent, thus hindering their confidence and motivation to perform their roles. It was suggested that having trained, dedicated grief counsellors is preferable, as the trained nurses have their primary role in taking care of patients in the hospital and can only dedicate limited time to grief counselling. This was similar to the findings by Tandon et al [23] that showed a higher corneal retrieval rate with dedicated grief counsellors as compared to trained hospital staff. One study recommended that the eye bank should have the authority to hire dedicated grief counsellors and give appropriate appraisals and incentives based on their performance [23].

Possible solutions

In our survey, one-fifth (21%) of the participants were willing to donate their corneas once they received some information about corneal donation. This higher percentage from our study (20.62%, 95% CI-12.57% to 28.67%) compared to the percentage anticipated based on our sample size calculation (6%) may be because of the information given to the participants before the perception question as only a few of the participants (10%) had good knowledge of corneal donation. This further emphasizes the need for improved awareness, as highlighted in the interview. This finding is lower than the study from Ethiopia (37.6%) [12] and Ghana (59.9%) [13] but higher than the study from Saudi Arabia (16.2%) [9] and India (6%) [16]. The low willingness to donate their cornea may be related to the overall poor knowledge about corneal donation or the beliefs that were previously highlighted. Other studies have shown a positive association between good knowledge and willingness to donate. This finding underscores the need to improve awareness (as we

stated in our Recommendations - Text box 1), as corroborated by the interviewed participants who indicated that increasing awareness may be a possible strategy to increase corneal donation and retrieval [5,79,10]. However, more research may be needed to explore this area. It was advised to increase awareness through a variety of channels, including teaching students in schools, involving community and religious leaders, healthcare professionals, using media institutions, social media, posters, and leaflets. This was like the findings from the survey where all participants who knew about corneal donation had thought that there should be more awareness and education on corneal donation. Other studies have shown that improved awareness was associated with willingness to donate. Sources of information on corneal donation that was reported by other studies included television, radio, newspaper and poster [9,18]. One study reported that the majority of the participants preferred to receive information on corneal donation awareness from healthcare professionals and social media [9]. This underscores the need for continuous training of health workers, dedicated grief counsellors and reinforces social media as an outlet for future awareness campaigns [9]. The legislation guiding organ donation in Nigeria is the request required law which might be due to the cultural context of the Nigerian society. The implementation of the presumed consent law was suggested; however, this will need to be assessed if it would be effective in our environment. Studies have shown that the presumed consent law increases organ donation rates [24,15]. However, in some cultures, presumed consent may present ethical dilemmas for pathologists and ophthalmologists who are uncomfortable harvesting corneas without consent. Another study reported that the existing difference in organ donation rates between the presumed consent law and the request-required law occurs only when neither the donor nor family had expressed consent to donation [26]. This places a lot of importance on the decision of the potential donor and the family [27]. The engagement of the family of the potential cornea donor with intermittent reminders of both the donors and family was considered important to improving corneal donation rates.

Experiences of potential donors

Corneal donation was perceived to improve someone else's quality of life and leave a positive legacy after dying by potential donors. This finding was like a study that reported giving to people in need and celebrating their loved ones' continued existence as motivation amongst the deceased families that consented to corneal donation. The family support that the potential donors received encouraged their decision. A study reported that families that were aware of the deceased's intention to donate their cornea found it easier to allow for corneal retrieval at the time of death [19]. Another study reported that awareness and willingness to donate the cornea was higher among organ donors than non-organ donors in a population [28].

Strengths

The Mixed-Methods approach in this study provided a comprehensive view of the barriers to corneal donation in our study population. This study addresses a critical public health issue-corneal blindness, particularly in a context (Nigeria) where the burden is high, and the cornea donation rate is abysmally low. The study population involved both healthcare professionals and the public, allowing for a diverse range of perspectives on the barriers to corneal donation.

Study limitations

The study focused on Lagos, Nigeria, while this is an important and populous region, the findings may not be generalizable to other parts of the country or Sub-Saharan Africa.

Conclusion

This study provides comprehensive and valuable information on the significant barriers to corneal donation in Lagos, Nigeria, highlighting both the awareness and attitudinal challenges faced by healthcare professionals and the public. Despite the high prevalence of corneal blindness and the potential for restoration through corneal transplantation, the willingness to donate remains alarmingly low. Most participants had minimal knowledge about corneal donation, with cultural beliefs, misconceptions, and a general lack of awareness significantly hindering the process. Perceptions about death, reincarnation, and the stigmatization surrounding organ donation contribute to the reluctance to discuss and promote corneal donation. Additionally, organizational challenges, including inadequate training for grief counsellors and inconsistent funding for awareness campaigns, exacerbate the situation.

Declarations

Ethics approval and consent to participate: The Medical and Health Research Ethics Committee of LASUTH and the London School of Hygiene and Tropical Medicine approved this study. Prior to any study procedure, all participants provided informed consent and permission to audio record the interview. The study was conducted under the ethical principles of the World Association Declaration of Helsinki.

Consent for publication: Not applicable.

Availability of data and materials: The data supporting this study's findings can be provided on request by contacting Sedoten D. Bashorun, the study lead.

Competing interest: All authors declare no competing interests.

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Authors' contributions:

SB - designed the study, lead-in study conduct, contributed to data analysis and interpretation, and wrote the first draft of the manuscript.

TM and VH- supervised study design, conduct, and review of the draft manuscripts.

CB - contributed to sample size calculation and review of the draft manuscripts.

ON - contributed to the qualitative part of the study, and review of the draft manuscripts.

AB - did the initial quantitative data analysis, and contributed to data interpretation and review of the draft manuscripts.

All authors have read through the manuscript and approved it for submission for publication.

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