

https://dspace.org/

Public attitudes to corneal tissue donation in an urban South African population

Hajee, Faheema

2023-08
University of the Witwatersrand, Johannesburg
https://hdl.handle.net/10539/43959
Hajee, Faheema. (2023). Public attitudes to corneal tissue donation in an urban South African population. [Masters dissertation, University of the Witwatersrand, Johannesburg]. WIReDSpace. https://hdl.handle.net/10539/43959

Downloaded from a DSpace repository. https://dspace.org/

PUBLIC ATTITUDES TO CORNEAL TISSUE DONATION IN AN URBAN SOUTH AFRICAN POPULATION

Faheema Hajee

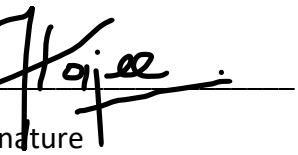


A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Medicine in the branch of Ophthalmology.

Johannesburg, 2023

i) DECLARATION

I, Faheema Hajee, declare that this research report is my own unaided work. It is being submitted for the degree of Master of Medicine at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at any other University.



Signature

_28_____ day of _August__ _2023____ in

_Johannesburg_____

ii) ABSTRACT

Background: Corneal pathology is the second leading cause of preventable blindness in Sub-Saharan Africa. Corneal disease is the cause of visual loss in 11% of blind or severely visually impaired children and 4% of blind adults in South Africa. In majority of cases, a corneal transplant or keratoplasty can restore or significantly improve vision. South Africa has an immense shortage of donor corneas, causing the burden of corneal disease requiring transplantation to continually rise[1].

Aim: The aim of this study was to determine the public attitude towards corneal tissue donation in an urban South African population.

Setting: The study was conducted at St John's Eye Hospital, Soweto, South Africa.

Method and Design: This was an observational, cross-sectional quantitative study of the current attitude of an urban South African population towards corneal tissue donation. A self-designed questionnaire was developed. The participants were asked about reasons for both willingness and unwillingness to donate their corneas. The study population included patients or escorts attending the out-patients clinic at Saint John's Eye Hospital

Results: A total of 100 participants (60 females and 40 males) completed the questionnaire. The mean age (±SD) of the study participants was 41.26 (±14.7) years. Seventy-six percent of participants did not know about corneal donation. Sixty four percent of participants were willing to donate their corneas, whereas 25% were not willing to do so. The main reason for unwillingness to donate their corneas was cultural reasons. In this study there was no statistically significant correlation between the willingness to donate corneal tissue and age, gender, level of education and employment status. There was a statistically significant difference between the willingness to donate one's solid organs as compared to the willingness to donate one's cornea (*p*-value 0.029). Participants were more willing to donate their solid organs than they were willing to donate their corneas.

Conclusion: There is a decreased level of awareness of corneal tissue donation in this urban South African population. However, many of the participants had a positive attitude towards corneal donations. Increasing the awareness of donation and its benefits may help increase the supply of corneal tissue.

Keywords: organ donation, cornea, South Africa, corneal transplant

iii) ACKNOWLEDGEMENTS

To my Supervisor Dr Roland Hollhumer, thank you for all your time, insight, and guidance.

To Dr Thariq Bagus, thank you for assisting me with the statistical analysis.

Thank you to all the participants for their agreement to take part in this study.

Contents

i) DECLARATION
ii) ABSTRACT
iii) ACKNOWLEDGEMENTS
iv) LIST OF FIGURES
v) LIST OF TABLES

CHAPTER 1

1. INTRODUCTION

CHAPTER 2

2. METHODS
2.1 Study design
2.2 Study population
2.3 Exclusion criteria
2.4 Ethics approval
2.5 The questionnaire
2.6 Statistical analysis

CHAPTER 3

3. RESULTS
3.1 Demographic characteristics of participants
3.2 Willingness to donate cornea
3.3 Awareness and general attitude towards corneal donation
3.4 The association between willingness to donate the cornea and study variables
3.5 Reasons for refusal or unwillingness to donate the cornea
3.6 Willingness to donate solid organs
3.7 Willingness to donate the cornea of family members and willingness to donate the solid organs of family members
3.8 Willingness to accept a corneal transplant
3.9 Awareness regarding the shortage of corneal tissue donation in South Africa

CHAPTER 4

4.DISCUSSION
4.1 Demographics of study population
4.2 Awareness and general attitude toward corneal donation
4.3 Willingness to donate corneal tissue
4.4 Willingness to donate corneal tissue and demographic factors
4.5 Reasons for refusal or unwillingness to donate corneal tissue
4.6 Willingness to donate solid organs
4.7 Willingness to donate the solid organs and cornea of deceased family members
4.8 Willingness to accept a corneal transplant
4.9 Preference of an opt-in and opt-out law system

5.CONCLUSION

6. REFERENCES

Appendix 1: Approved Protocol

Appendix 2: Survey Questionnaire

Appendix 3: Study Information Sheet

Appendix 4: Informed Consent

Appendix 5: Data Collection Sheet

Appendix 6: Consent to Collect Data – Head of Department Permission

Appendix 7: Consent to Collect Data – CEO Hospital Management Permission

Appendix 8: Ethics Clearance Certificate

Appendix 9: Turnitin

iv) List of Figures

Figure 1

Reasons for unwillingness to donate the cornea after death

v)List of Tables

Table 1

Demographics and characteristics of participants (n=100)

Table 2

Characteristics of participants willing to donate their corneas and the influence of study variables (age, gender, level of education and status of employment) on willingness towards corneal donation.

Chapter 1

1. Introduction

Corneal pathology is the second leading cause of preventable blindness in Sub-Saharan Africa. Corneal disease is the cause of visual loss in 11% of blind or severely visually impaired children and 4% of blind adults in South Africa[1]. Studies have shown that low vision is associated with the loss of ability to work, a reduced quality of life and can trigger depression[1].

In majority of cases, a corneal transplant or keratoplasty can restore or significantly improve vision. Reversing corneal blindness with a corneal graft can prove to be of great benefit to the patient, the family, and society[2]. Studies have shown that corneal transplants not only restore vision, but also reduces pain caused by an injured or diseased cornea[2].

Keratoplasty is a surgical technique where damaged or diseased cornea is replaced by donated corneal tissue. Advances in surgical techniques and surgeon expertise have resulted in improved visual outcomes with these procedures[1]. Corneal transplantation is the most frequently performed transplant procedure worldwide[6].

In recent years, the availability of corneal tissue in South Africa has been significantly reduced. The shortage of supply of corneal tissue is apparent in both the private and public sector[4].

For the majority of South Africans imported corneas are not affordable. Patients in the public sector who require corneal transplants are often placed on long waiting lists and it may be months or even years before a graft becomes available. Most recent published data from the Gauteng Cornea Eye Bank showed that there were 1 884 persons in South Africa on a waiting list for a corneal graft in the year 2008 and an estimated 330 corneal transplant surgeries were performed in the same year.[5] As compared to the USA which had no patients on their waiting list in 2008 and performed 41 652 corneal transplant surgeries during that year[1].

Population groups with low donor rates may have cultural and other objections to tissue donation[1]. Cultural factors regarding organ and tissue donation within other population groups and minority groups in South Africa have been studied previously[1,4]

There has been a progressive year-on-year decline in corneal donors, from 565 per year in 2002 to 89 in 2016. As a result, there has been an 85.5% decrease in the number of corneal transplants per year using locally donated corneas. The reasons given for the progressive decline in donations were threefold: legislative changes in South African mortuaries, rising rate of infectious diseases in donors and lack of public awareness.[1]

The rapid decline in corneal donors from 2005 to 2008 coincided with a legislative change affecting South African forensic mortuaries. Prior to 2006, the South African Police Services controlled and managed forensic mortuaries in the country. During this period, Eye Bank directors were privy to information on deceased persons in the mortuaries and therefore could identify potential donors and contact their next of kin[1]. This made mortuaries the main source of corneal donors at that time. Currently, state forensic mortuaries are under the governance of the National Department of Health. This has brought additional confidentiality and ethical considerations that are governed by the National Health Act and Protection of Personal Information Act[1].

South Africa currently adopts an 'opt-in system' for organ donation. Countries that adopt an 'opt-out system', which implies that all persons are presumed to be organ and tissue donors unless they explicitly state their wishes against it, have shown to have significantly higher donation rates[1].

A review of 55 published studies across 13 different countries showed that the most mentioned reason for not being a registered eye donor was lack of awareness about eye donation and not knowing how to pledge one's eyes for donation after death[9]. Awareness about eye donation and knowledge about corneal transplantation is one of the modifiable factors associated with an increased willingness to donate[9].

Currently in South Africa the final decision to donate corneal tissue lies with the family members of the deceased, even if the deceased was a registered organ donor . International studies show family refusal rates of corneal tissue donation to be between 29 and 59%. The rate of corneal tissue donation refusal is higher than that of multiple organ donation[15]. The most frequent reason for refusal is family members being unaware of the desire of the potential donor. Another frequently cited reason is a delay in the release of the body, family members lack of knowledge regarding the time required for donation leads them to believe that there will be a delay for the religious rituals[15].

There is a specific unwillingness to donate eyes or the cornea. A previous study of an adult South African population showed respondents were more willing to donate solid organs compared to corneas[14].

South Africa has an immense shortage of donor corneas, causing the burden of corneal disease requiring transplantation to continually rise. This study will assess the level of knowledge and current attitude toward corneal donation among an urban population of South Africans. In addition factors that might influence the willingness and unwillingness to donate corneal tissue will be investigated. It would be beneficial to study the public attitudes toward corneal tissue donation and therefore identify the barriers and possible solutions to overcome them.

Chapter 2

2. Methods

2.1 Study design

A cross-sectional study using mixed methods was performed, using a structured questionnaire that was developed to obtain information about attitude toward corneal tissue donation and identify factors that might affect corneal donation in urban South Africa. The study was conducted at Saint John Eye Hospital in Soweto between November 2021 and December 2021.

2.2 Study population

The study participants were selected randomly from patients or escorts attending the out-patients clinic at Saint John Eye Hospital. South African born adults aged ≥ 18 years were invited to complete a self-administered questionnaire on knowledge of corneal donation and reasons of willingness and unwillingness toward corneal tissue donation.

2.3 Exclusion criteria

Participants speaking a language other than English that could not be translated by the nursing staff were excluded from the study.

2.4 Ethics approval

Ethics approval was granted by the Human Research Ethics Committee of the University of the Witwatersrand. Permission to conduct research at Saint John Eye Hospital was granted by Professor I Mayet – Head of Ophthalmology Department at Saint John's Eye Hospital.

Participant confidentiality was ensured by not including any identifiers on data sheets. Each participant was assigned a unique reference number to maintain anonymity. Data was stored in a password protected computer.

Study information sheets were handed out to all participants (See Appendix 3) and all those who agreed to participate in the study signed an informed consent form (See Appendix 4)

2.5 The questionnaire

A self-designed questionnaire was developed (See Appendix 2). Possible reasons for willingness or unwillingness to donate corneal tissue in an urban South African population was taken into consideration when designing the questionnaire.

To ensure that the questionnaire was clear and easy to comprehend, a pilot group of five subjects from the patients or escorts at Saint John's Eye hospital were randomly selected to perform the questionnaire interview. There were no further changes made to the questionnaire. The data from the pilot group were not included the final data analysis.

The questionnaire consisted of 17 questions. The first 8 questions obtained the sociodemographic details of the participants, such as age, gender, population group, ethnicity, religious denomination, level of education and occupation.

The subsequent questions were multiple-choice type questions with options given. The options given were directed by information gathered by previous studies on corneal tissue donation[1,16]. Participants were asked about their awareness of corneal tissue donation. All participants were given

information and an explanation on corneal transplantation. Participants were then asked whether they would accept a corneal transplant if they needed one.

The participants were then asked about reasons for both willingness and unwillingness to donate their cornea, as well as their willingness and unwillingness to donate their organs. Listed reasons included religious, cultural, and ethical reasons, which may affect the subject's decision regarding corneal tissue donation and organ donation. Participants were also asked if would agree to donate their family members solid organs after they passed on and whether they would agree to donate their family members corneal tissue after they had passed on.

Finally, participants were asked whether they favored an opt-in or an opt-out law regarding corneal tissue donation and if they thought there was a shortage of corneal tissue available in South Africa.

The questionnaire was administered to 100 participants. All the questionnaire interviews were carried out by the principal investigator. A brief explanation regarding the purpose of the study was given prior to participation and certain concepts about corneal tissue donation were explained to ensure all participants had a similar level of understanding.

2.6 Statistical Analysis

Data was analysed using Statistical Package for Social Sciences (SPSS) software (IBM Corp. Released 201. IBM SPSS Statistics for Windows, Version 25.0 Armonk, NY: IBM Corp). Descriptive statistics including frequencies and percentages were calculated to summarise the categorical data. Parametric data were compared using *independent t*-test and reported as mean ± SD and non-parametric data were compared using the Wilcoxon Signed-Ranked test and reported as median ± IQR. A p-value of <0.05 was considered statistically significant.

Chapter 3

3. Results

3.1 Demographic characteristics of participants

A total of 100 participants (40.0% males and 60.0% females) completed the questionnaire. The mean age of the study participants (± SD) was 41.26 (±14.23) years and ranged from 20 to 80 years. Demographics of all participants are shown in the table 1.

Table 1 Participants' characteristics (n=100)

Variable	No (%) of respondents
Gender	
Male	40 (40.0)
Female	60 (60.0)
Race	
Black	95 (95.0)
White	3 (3.0)
Mixed Race	2 (2.0)
Ethnicity	
Zulu	31 (31.0)
Sotho	25 (25.0)
Setswana	21 (21.0)
Sipedi	2 (2.0)
Venda	2 (2.0)
Xhosa	8 (8.0)
Ndebele	1 (1.0)
Swati	4 (4.0)
Tsonga	2 (2.0)
Other	4 (4.0)
Religion	
Christianity	90 (90.0%)
Traditional African	9 (9.0)
Jewish	1 (1.0)
Highest Level of Education	
Primary	6 (6.0)
Secondary	68 (68.0)
Tertiary	25 (25.0)
Occupation	
Unemployed	29 (29.0)
Employed	53.0 (53.0)
Student	4 (4.0)
Pensioner	14 (14.0)

3.2 Willingness to donate cornea

Sixty four percent were willing to donate their cornea, 25 % were unwilling and 11% were unsure. Characteristics of participants willing to donate their corneas and the influence of study variables

(age, gender, level of education and status of employment) on willingness towards corneal donation are shown in Table 2.

3.3 Awareness and general attitudes toward corneal donation

Seventy-six percent of participants did not hear about corneal donation previously. All participants were explained to what corneal transplantation is and thereafter were asked about their willingness and unwillingness to donate their corneal tissue. Willingness to donate cornea after death was confirmed by 64,0% of participants, whilst 25,0% were unwilling and 11,0% were unsure.

3.4 The association between willingness to donate the cornea and the study variables

The influence of the study demographics on the willingness of the participants to donate their corneas are shown in Table 2. Age, gender, level of education and status of employment did not significantly influence participants willingness to donate their corneas after death ($p > 0.05$ for all variables)

Table 2 Characteristics of participants willing to donate their corneas and the influence of study variables (age, gender, level of education and status of employment) on willingness towards corneal donation.

Demographics	Willingness to donate cornea		
	Yes	No	Unsure
Total	64	25	11
Age (years)			
18-29	16	7	2
30-50	35	9	7
>50	13	9	2
Gender			
Male	24	9	7
Female	40	16	4
Education			
Primary	4	3	0
Secondary	46	14	8
Tertiary	14	8	3
Employment			
Employed	36	12	5
Unemployed	24	7	2
Pensioner	6	8	0

3.5 Reasons for refusal or unwillingness to donate the cornea

The participants who were unwilling to be corneal tissue donors cited the following to be reasons for refusal. Fifty-three percent were unwilling due to cultural reasons, 33% gave their reason for refusal to be a fear of disfigurement, 10% due to religious reasons and 3% had a fear of organ trade.

The following graph shows the reasons for unwillingness to donate the cornea after death.

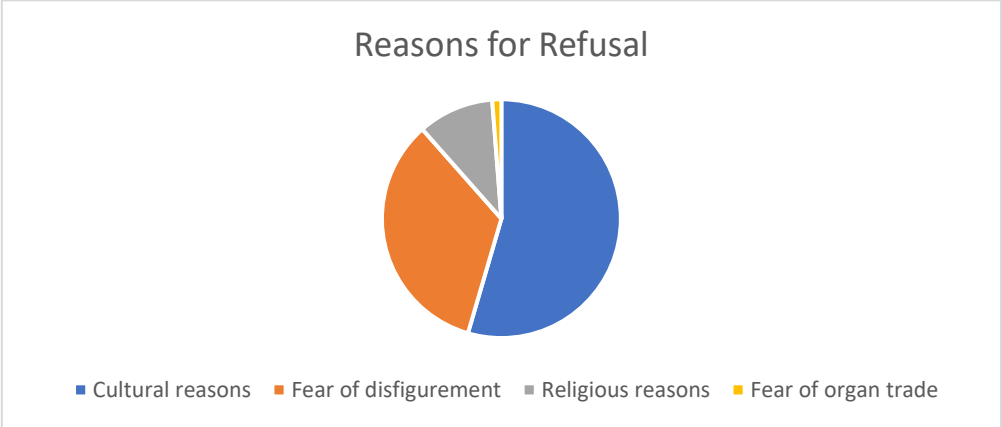


Figure 2: Reasons for unwillingness to donate the cornea after death

3.6 Willingness to donate solid organs

There was a statistically significant difference between the willingness to donate one's solid organs as compared to the willingness to donate one's cornea with a *p*-value 0.029. Sixty-nine participants were willing to be organ donors, 19% were unwilling and 12% were unsure.

3.7 Willingness to donate the cornea of family members and willingness to donate the solid organs of family members

The response to whether participants were willing to donate the cornea of their family members (who have expressed their will to be a corneal tissue donor prior to death) were as follows: 84% of participants were willing to go ahead with their family members request, 13% were unwilling and 3% were unsure.

The response to whether participants were willing to donate the solid organs of their family members (who have expressed their will to be an organ donor prior to death) were as follows: Eighty four percent were willing to fulfil the wishes of the deceased and agree to have their family members solid organs donated, 12% were not agreeable to donating their family members organs and 4% were unsure.

3.8 Willingness to accept a corneal transplant and preference to an opt-in or opt-out law system for organ and corneal tissue donation

Responses about willingness to accept a corneal transplant were investigated by asking participants if they would accept a corneal transplant if they required one to improve their vision. Eighty percent of participants responded that they would accept a corneal transplant. Twelve percent responded in the negative and 8% were unsure.

Sixty-nine percent of participants favoured an opt-in system for organ and corneal tissue donation and 31% were in favour of an opt-out system.

3.9 Awareness regarding the shortage of corneal tissue donation in South Africa

Participants response regarding whether they perceived a shortage of corneal tissue donation in South Africa were as follows: 82% responded yes, there is a shortage of corneal tissue donation, 16% were unsure and 2% responded, no, there is no shortage of corneal tissue donation.

Chapter 4

4. Discussion

Corneal pathology is the second leading cause of preventable blindness in Sub-Saharan Africa. In majority of cases, a corneal transplant or keratoplasty can restore or significantly improve vision[1].

In recent years, the availability of corneal tissue in South Africa has been significantly reduced. The shortage of supply of corneal tissue is apparent in both the private and public sector. The reasons given for the progressive decline in donations were threefold: legislative changes in South African mortuaries, rising rate of infectious diseases in donors and lack of public awareness[1]. For the majority of South Africans imported corneas are not affordable. Patients in the public sector who require corneal transplants are often placed on long waiting lists and it may be months or even years before a graft becomes available.

The objective of this study was to determine the current attitude of a South African urban population towards corneal tissue donation.

4.1 Demographics of study population

The study population comprised of more females (60.0%) than males (40.0%). Majority of the participants were black (95.0%) with few white (3.0%) and mixed-race (2.0%) participants and no Indian or Asian participants. A 15-year review of corneal donations in South Africa showed that despite black South Africans making up 79,2% of the population they comprised 6% of the corneal donor pool, whereas White donors made up 77% of corneal donors in South Africa.[1]

It is a recognised limitation of this study that the participants were a hospital-based sample. Responses from individuals in a population-based sample may have differed.

4.2 Awareness and general attitudes toward corneal donation

Several studies across different communities in the world have shown that persons with higher knowledge scores correlate with an increased willingness to donate. Similarly, lower level of socio-economic status, formal education and knowledge regarding corneal donation have been associated with a lower likelihood of believing the justification of corneal and organ donation and a lower likelihood of corneal donation[9].

The current study showed a poor level of awareness and knowledge among the studied population. Most participants (76,0%) did not hear of corneal tissue donation previously.

This contrasts with studies carried out elsewhere in the world, that reported a high level of public awareness of corneal donation[16].

4.3 Willingness to donate corneal tissue

The current study reported that more than half of the participants (64.0%) of subjects expressed willingness to donate their corneas after death. This figure falls within the range presented for other populations[16].

4.4 Willingness to donate corneal tissue and demographic factors

In this study there was no statistically significant correlation between the willingness to donate corneal tissue and age, gender, level of education and employment status.

Several studies have shown that demographic factors such as age of participants, gender and socioeconomic status did not influence the willingness to donate the cornea.[17] Other studies have shown only religion and ethnicity to have influenced the willingness to donate corneas.[18] Although, there were representations from all the African ethnic groups in this study population, most of the participants belonged to the Zulu (35.0%), Sotho (25.0%) and Setswana (21.0%) ethnic groups. Ninety percent of the participants followed the religion of Christianity. The study population was not representative of all the religions followed in South Africa. It was not possible in this current study to assess the correlation between the willingness to be a corneal tissue donor and ethnicity and religion.

4.5 Reasons for refusal or unwillingness to donate the cornea

The participants who were unwilling to be corneal tissue donors cited the following to be reasons for refusal. Fifty-three percent were unwilling due to cultural reasons, 33% gave their reason for refusal to be a fear of disfigurement, 10% due to religious reasons and 3% had a fear of organ trade.

Population groups with low donor rates may have cultural and other objections to tissue donation[1]. Cultural factors regarding organ and tissue donation within other population groups and minority groups in South Africa have been extensively studied in previous studies[1]. A recognised limitation of this study is that the questionnaire was designed as a multiple-choice survey, with no opportunity for participants to provide open-ended answers. This limited the ability of this study to elaborate on specific reasons for unwillingness to donate corneal tissue.

Within the Black African Culture, organ and tissue donation is a complex subject. The belief is held that the deceased will join his or her ancestors in the afterlife, and that it is important that the body of the deceased remains whole for this transition. There is the concern that if tissue or organs are removed, the ancestral spirits will be displeased and not able to rest. It is believed that the spirit may then return to those living to seek retribution for the removal of tissue and organs[8].

Human organs have apparently been used by sangomas (traditional healers) to make muti (traditional medicine to ward off spells) and 'witches', 'wizards' and 'sorcerers' for black magic. Although this is a separate issue, the association may adversely affect attitudes toward tissue donation[8].

A study by Lawlor and Kerridge explored the reasons why individuals decide whether to donate corneas. The main concerns that contributed to refusal of corneal donation were disfigurement and loss of identity[14].

Religion is an influential factor in the decision making of organ and tissue donation. There are some striking differences between the major faiths, but also a common theme, namely the dilemma between religious concerns and altruism[15].

The above cultural reasons for unwillingness to donate corneal tissue are findings of previous studies and it is a recognised limitation of this study that these factors were not investigated further in this study.

4.6 Willingness to donate solid organs

In this current study there was as a statistically significant difference between the willingness to donate one's solid organs as compared to the willingness to donate one's cornea. Participants were more willing to donate their solid organs than they were willing to donate their corneas. A previous study of an adult South African population showed respondents were more willing to donate solid organs compared to corneas[14].

4.7 Willingness to donate the solid organs and cornea of deceased family members

Approximately 30 percent of families agreeing to multi-organ donation in Australia, specifically refuse corneal donation, and a similar disparity is noted in large studies in the USA[9]. The physical alteration or disfigurement by removing the eyes or corneas of the deceased was a significant source of distress for family members. For some there were concerns about the appearance of the body at a viewing, for others the symbolism associated with the eyes caused concern that by removing the eyes, the human aspect of the deceased will be diminished.[14]

Currently in South Africa, state forensic mortuaries are under the governance of the National Department of Health. This has brought additional confidentiality and ethical considerations that are governed by the National Health Act and Protection of Personal Information Act. As a result, family members have the final say on whether corneal tissue of the deceased can be donated[1].

In this study most of the participants stated that they would fulfill the wishes of their deceased family members with 84.0% of participants agreeing to their family members solid organ donation and 84.0% agreeing to their family members corneal tissue donation.

4.8 Willingness to accept a corneal transplant

In the current study 80.0% of participants were willing to accept a corneal transplant if needed. Of note, in this study some participants were willing to accept a corneal transplant, however, were not willing to be corneal tissue donors. It has been widely reported that the demand on healthy corneas exceeds the actual supply of donated corneas.

4.9 Preference of an opt-in or opt-out law system

South Africa currently adopts an ‘opt-in system’ for organ donation. Countries that adopt an ‘opt-out system’, which implies that all persons are presumed to be organ and tissue donors unless they explicitly state their wishes against it, have shown to have significantly higher donation rates. Wales is the first country in the United Kingdom that has shifted to an opt-out system and has shown a 24% increase in donations in their first year[1].

In this study sixty-nine percent of participants favoured an opt-in system for organ and corneal tissue donation and 31% were in favour of an opt-out system.

Implementing an opt-out system may not be that simplistic in South Africa, due to varying cultural and religious beliefs, as well as level of awareness and education regarding organ and tissue donation. A change in this legislation, however, would prove to be beneficial for not only corneal tissue donation, but other organ donations as well[1].

5.0 Limitations of the Study

A recognised limitation of this study is that the questionnaire was designed as a multiple-choice survey, with no opportunity for participants to provide open-ended answers. This limited the ability of this study to elaborate on specific reasons for unwillingness to donate corneal tissue.

Another limitation of this study that the participants were a hospital-based sample. Responses from individuals in a population-based sample may have differed.

The study population was not representative of all the religions followed in South Africa. It was not possible in this current study to assess the correlation between the willingness to be a corneal tissue donor and ethnicity and religion.

5. **Conclusion**

This study showed that participants demonstrated a decreased level of awareness about corneal tissue donation in South Africa. However, most of the participants were willing to donate their corneas. The main reason for unwillingness to donate their cornea was cultural reasons. This study highlighted that there is a specific unwillingness to donate eyes or corneas as compared to the donation of solid organs. South Africa has an immense shortage of donor corneas, causing the burden of corneal disease requiring transplantation to continually rise. This study emphasized the need to create an increased awareness of corneal donation. Thereby, reducing the misconceptions related to corneal donation and increasing the supply of local donor tissues.

6. References

1. York NJ. Corneal donations in South Africa: A 15-year review. SAMJ.2017; 107(8):697-701

2. Rock D, Wude J, Yoereuk E *et al*. Evaluation of factors limiting corneal donation. Annals of Transplant. 2016; 21: 701-707

3. Meyer D, The new challenge of corneal transplantation in South Africa.(Editorial) SAMJ. 2007; 97 (7): 512

4. Etheredge HR, Turner RE, Kahn D. Public attitudes to organ donation among a sample of urban-dwelling South African adults: a 2012 study. Clinical Transplantation. 2013; 27(5): 684-692

5. *Pickering L. 2019. Cornea and Eye donation. Date viewed 13/07/2019* <www.gautengcorneaeyebank.co.za>

6. Makgotle AM, Carmichael TR. Plummeting corneal donations at the Gauteng Cornea and Eye Bank. (Editorial) SAMJ. 2009; 99(11): 797

7. McQuoid M. Human Tissue and organ transplant provisions: Chapter 8 of National Health Act and its regulations in effect from March 2012. What doctors must know. SAMJ. 2012; 102(9): 733-735

8. Bhengu BR, Uys HHM. Organ donation and transplantation within the Zulu culture. Curationis. 2004. 8: 24-33

9. Williams AM,Muir KW. Awareness and attitudes toward cornel donation: challenges and opportunities. Clinical Ophthalmology. 2018; 12: 1049-1059

10. Hermann KC, Pagnussato F, de Oliveira MLB *et al.* Reasons for family refusal of ocular tissue donation. Transplantation Proceedings. 2014; 46: 1669-1671

11. Wale J, Arthur A, Faull C. An analysis of knowledge and attitudes of hospice staff towards organ and tissue donation. BMJ Supportive and Palliative Care. 2014; 4:98-103

12. Wong KH, Kam KW, Chen LJ et al. Corneal blindness and current major treatment concern – graft scarcity. International journal of Ophthalmology. 2017; 10(7):1154-1162

13. Pike RE, Odell JA, Kahn D. Public attitudes to organ donation in South Africa. SAMJ. 1993; 83: 91-94

14. Lawlor M, Kerridge I. Understanding selective refusal of eye donation. Identity, beauty and interpersonal relationships. Journal of Bioethical Inquiry. 2014; 11 (1): 57-64

15. Oliver M, Woywodt A, Ahmed A *et al.* Organ donation, transplantation and religion. Nephrology Dialysis Transplant. 2011; 26: 437-444

16. Haddad M, Khabour O, Alzobier K *et al.* Public attitudes towards corneal donation in northern Jordan. Clinical Ophthalmology. 2018; 12: 1973-1980

17. Tandon R, Verma K, Vanathi M *et al.* Factors affecting eye donation from postmortem cases in a tertiary care hospital. Cornea. 2004; 23(6): 597-601
18. Yew YW, Saw SM, Pan JC *et al.* Knowledge and beliefs on corneal donation in Singapore adults. British Journal of Ophthalmology. 2005; 89 (7): 835-840

Appendix 1

Approved Protocol

PUBLIC ATTITUDES TO CORNEAL TISSUE DONATION IN URBAN SOUTH AFRICAN POPULATION

Dr Faheema Hajee

BSC Hons (Wits) MBBCh (Wits)

Registrar

Division of Ophthalmology

Department of Neurosciences

Faculty of Health Sciences

University of the Witwatersrand

Student Number: 0304468W

Registered for Degree: MMED Ophthalmology, January 2019

Candidate's Signature:

Supervisor: Dr Roland Hollhumer

Consultant

Division of Ophthalmology

Department of Neurosciences

Faculty of Health Sciences

University of the Witwatersrand

Supervisor's Signature:

DEPARTMENT OF NEUROSCIENCE$

Neurology, Neurological Surgery, Ophthalmology, Otorhinolaryngology: Psychiatry

School of Clinical Medicine, Faculty of Health Sciences, 7
York Road, Johannesburg 2193, South Africa

Tel: +2711 717-2774 · Fax: +27117172775

Plagiarism declaration for written work

I, Faheema Hajee as a postgraduate student registered for a MMed at the University of the Witwatersrand declare the following:

- I am aware that plagiarism is the use of someone else's work without their permission and or without acknowledging the original source.
- I am aware plagiarism is wrong.
- I confirm that this written work is my own work except where I have stated otherwise.
- I have followed the required conventions in referencing the thoughts and ideas of others.
- I understand that the University of the Witwatersrand may take disciplinary action against me if there is a belief that this is not my own unaided work or if I have failed to acknowledge the ideas or writing of others.

Signature

Date 05/06/2020

Table of Contents

1. Introduction
2. Literature Review
3. Aim
4. Study Objectives
5. Hypothesis
6. Materials and Methods
7. Data Analysis
8. Ethics Approval
9. Funding
10. Presentation Plans
11. Authorship
12. Timeline
13. References
14. Appendices

1. Introduction

Corneal pathology is the second leading cause of preventable blindness in Sub-Saharan Africa. Corneal disease is the cause of visual loss in 11% of blind or severely visually impaired children and 4% of blind adults in South Africa[1]. Studies have shown that low vision is associated with the loss of ability to work, a reduced quality of life and can trigger depression.

In majority of cases, a corneal transplant or keratoplasty can restore or significantly improve vision. Reversing corneal blindness with a corneal graft can prove to be of great benefit to the patient, the family, and society[2]. Studies have shown that corneal transplants not only restore vision, but also reduces pain caused by an injured or diseased cornea[2].

Keratoplasty is a surgical technique where damaged or diseased cornea is replaced by donated corneal tissue. Advances in surgical techniques and surgeon expertise have resulted in improved visual outcomes with these procedures[1].

Corneal transplantation is the most frequently performed transplant procedure worldwide[6]. They have the highest success rate of all organ and tissue transplants, achieving up to 93% of mean 1-year graft survival rate in low risk patients and 77% in high risk patients who have inflamed or vascularized corneas.[1]

Corneas that are used for transplant are derived from eye banks. There are five regional eye banks in South Africa, which obtains and harvests corneal tissue and supplies it to ophthalmic surgeons:[3]

1. The Eye Bank foundation of South Africa which is based in Cape Town. For several decades this was the only eye bank in Southern Africa.
2. Gauteng Cornea and Eye Bank in Johannesburg
3. Pretoria Eye Bank
4. KZN Eye Bank in Durban and the

5. Port Elizabeth Eye Bank

In recent years, the availability of corneal tissue in South Africa has been significantly reduced. The shortage of supply of corneal tissue is apparent in both the private and public sector[4].

Approximately 21.3 % of individuals in urban areas in South Africa belong to a medical scheme and therefore access healthcare in the private sector, which can be comparable to first world or developed countries. The remaining 78.6% access healthcare in the state sector which is reminiscent of developing countries[4].

For the majority of South Africans imported corneas are not affordable. Patients in the public sector who require corneal transplants are often placed on long waiting lists and it may be months or even years before a graft becomes available. Most recent published data from the Eye Bank showed that there were 1 884 persons in South Africa on a waiting list for a corneal graft in the year 2008 and an estimated 330 corneal transplant surgeries were performed in the same year. As compared to the USA which had no patients on their waiting list in 2008 and performed 41 652 corneal transplant surgeries during that year[1].

Currently, in Gauteng alone there are 700 patients awaiting a corneal graft, 100 of which are children under the age of 12. This prolongs visual disability in patients with a treatable cause[5].

There has been a progressive year-on-year decline in corneal donors, from 565 per year in 2002 to 89 in 2016. As a result, there has been an 85.5% decrease in the number of corneal transplants per year using locally donated corneas. The reasons given for the progressive decline in donations were threefold: legislative changes in South African mortuaries, rising rate of infectious diseases in donors and lack of public awareness.[1]

2. Laws pertaining to organ donation in South Africa

1. National Health Act No.61 of 2003

2. Protection of Personal Information Act No.4 of 2013
3. Opt-in organ donation system

The rapid decline in corneal donors from 2005 to 2008 coincided with a legislative change affecting South African forensic mortuaries. Prior to 2006, the South African Police Services controlled and managed forensic mortuaries in the country. During this period, Eye Bank directors were privy to information on deceased persons in the mortuaries and therefore could identify potential donors and contact their next of kin. This made mortuaries the main source of corneal donors at that time. Currently, state forensic mortuaries are under the governance of the National Department of Health. This has brought additional confidentiality and ethical considerations that are governed by the National Health Act and Protection of Personal Information Act. As a result, information on deceased individuals and thier next of kin is restricted. Furthermore, new protocols in the mortuaries state that telephonic consent is no longer adequate, and that a family member that had identified the deceased must give written consent for corneal tissue donation. This is very seldomly possible, since the time of death to harvesting of corneas should ideally be 12 hours.[1]

South Africa currently adopts an 'opt-in system' for organ donation. Countries that adopt an 'opt-out system', which implies that all persons are presumed to be organ and tissue donors unless they explicitly state their wishes against it, have shown to have significantly higher donation rates. Wales is the first country in the United Kingdom that has shifted to an opt-out system and has shown a 24% increase in donations in their first year. Implementing an opt-out system may not be that simplistic in South Africa, due to varying cultural and religious beliefs, as well as level of awareness and education regarding organ and tissue donation. A change in this legislation,

however, would prove to be beneficial for not only corneal tissue donation, but other organ donations as well.[1]

3. Rising levels of infected donors

Tissue from donors who are positive for hepatitis B or C or HIV cannot be used for transplantation. The following graph illustrates the negative impact that the rise of infectious diseases has on useable corneas at just one of the national eye banks[3].

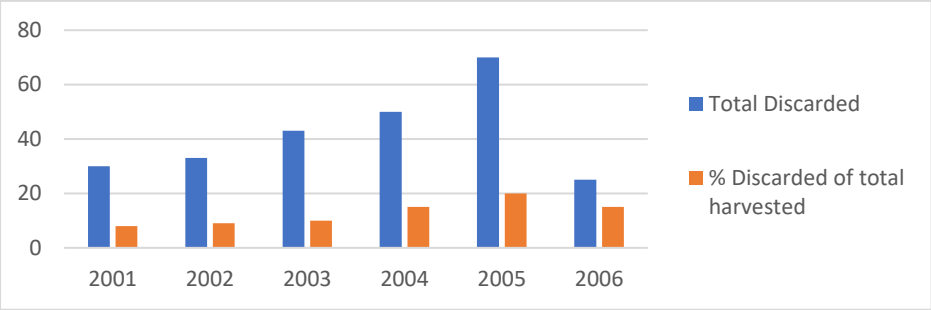


Fig. 1. Rising number (and % of total) corneas harvested from donors positive for hepatitis B and C and HIV from the Cape Town-based Eye Bank Foundation of South Africa from 2001-2006

4. Donor Characteristics and Public Awareness

4.1 Demographics and corneal tissue donation

A 15-year review of corneal donations in South Africa showed that despite black South Africans making up 79,2% of the population they comprised 6% of the corneal donor pool, whereas White donors made up 77% of corneal donors in South Africa. The low number of Indian/Asian donors is most likely due to religious beliefs (Figure 1).[1]

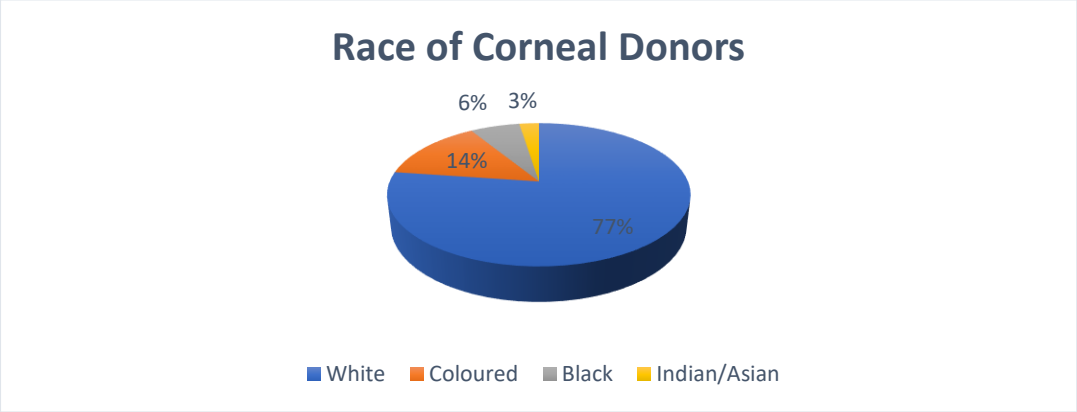


Figure 1: Race of corneal donors over a 15-year period

South Africa has a history of racial discrimination and prejudice. This may still be reflected in the views regarding organ and tissue donation. In the United States, African Americans who have registered as organ donors, have reported a fear of compromised health care during critical times[9].

In the same study the gender of corneal donors was recorded as 69% males and 31% female. This approximate 2:1 ratio male preponderance may be because 49% of corneal tissue was obtained from forensic mortuaries. In South Africa, males are three times more likely to die of unnatural death than females. It is not known whether gender itself influences attitudes toward organ and tissue donation[1].

There was a bimodal peak in donor age at 25 and 55 years of age. The number and quality of corneal endothelial cells decrease with age. To ensure primary graft survival, corneal tissue is discarded if there is an inadequate number and quality of endothelial cells[9].

4.2 Level of Education

Several studies across different communities in the world have shown that persons with higher knowledge scores correlate with an increased willingness to donate. Similarly, lower level of socio-economic status, formal education and knowledge regarding corneal donation have been

associated with a lower likelihood of believing the justification of corneal and organ donation and a lower likelihood of corneal donation[9].

4.3 Public Awareness

A review of 55 published studies across 13 different countries showed that the most mentioned reason for not being a registered eye donor was lack of awareness about eye donation and not knowing how to pledge one's eyes for donation after death. Individuals who were aware of the process of eye donation, cited television and the media to be the main source of their learning[9]. Awareness about eye donation and knowledge about corneal transplantation is one of the modifiable factors associated with an increased willingness to donate. This indicates the potential to increase the number of registered corneal tissue donors through educational campaigns[9].

4.4 Family refusal of corneal tissue donation

Currently in South Africa the final decision to donate corneal tissue lies with the family members of the deceased, even if the deceased was a registered corneal tissue donor. International studies show family refusal rates of corneal tissue donation to be between 29 and 59%. The rate of corneal tissue donation refusal is higher than that of multiple organ donation. The most frequent reason for refusal is family members being unaware of the desire of the potential donor. Another frequently cited reason is a delay in the release of the body, family members lack of knowledge regarding the time required for donation leads them to believe that there will be a delay for the religious rituals[15].

4.5 The role of healthcare workers

Healthcare workers play a key role in discussions about organ and tissue donation. However, studies have shown that majority of healthcare workers report that discussions would make patients, or their relatives feel uncomfortable. Those healthcare workers that have discussed

organ or tissue donation with their patients are those with more years of experience and with more knowledge regarding donation. Similarly, a lack of knowledge regarding the processes of organ and tissue donation is cited as a reason for healthcare workers not having a discussion with their patients or their relatives.[11]

4.6 Effects of Cultural beliefs on Corneal Tissue donation

Population groups with low donor rates may have cultural and other objections to tissue donation.[1]

Cultural factors regarding organ and tissue donation within other population groups and minority groups in South Africa have not yet been extensively studied.

Within the Black African Culture, organ and tissue donation is a complex subject. They hold the belief that the deceased will join his or her ancestors in the afterlife, and that it is important that the body of the deceased remains whole for this transition. There is the concern that if tissue or organs are removed, the ancestral spirits will be displeased and not able to rest, as the body is not whole. It is believed that the spirit may then return to those living to seek retribution for the removal of tissue and organs[8].

Zulus have a strong bond of interdependence between the living and the dead (the ancestors), this contributes to the fear of organ or tissue donation, because if this bond is broken the ancestors will show anger by visitation in the form of ill-health, misfortune or even death. Ritual murders for human tissue or organs for use in witchcraft may accentuate these fears. Human organs have apparently been used by *sangomas* (traditional healers) to make *muti* (traditional medicine to ward off spells) and 'witches', 'wizards' and 'sorcerers' for black magic. Although this is a separate issue, the association may adversely affect attitudes toward tissue donation[8].

It is therefore important to be cognisant of these cultural values and respect requests to maintain harmony with the ancestors. A preference to perform certain rituals before or after tissue or organ donation should be honoured[8].

A survey regarding public attitude to organ donation in South Africa showed that the Xhosa groups in both rural and urban areas were more willing to donate organs than blacks from any of the other groups. This may be as a result of extensive media campaigning aimed specifically toward Xhosa-speaking people. However, it could also represent different cultural beliefs.[9]

Of interest, whilst the Sotho group were willing to donate their own organs, they were unwilling to donate the organs of a close relative. The authors could not find a possible explanation for this, except for a possible cultural difference.[9]

This survey further showed that within all ethnic groups of black South Africans, heart and kidney donation were equally acceptable, however the donation of corneas was not.[9]

However, a previous study carried out in 2012 by Etherredge *et al* showed that 70% of the Black South African population in an urban area were willing to donate their own organs. It was hypothesized that since the study population was urban, it is possible that Westernised worldviews and familiarity with modern medicine were influential in viewpoints. This same study population, however, were not willing to donate their corneas.[4]

The specific unwillingness to donate eyes or corneas is a phenomenon expressed by populations throughout the world.[6]

5. Religion

Religion is an influential factor in the decision making of organ and tissue donation. There are some striking differences between the major faiths, but also a common theme, namely the dilemma between religious concerns and altruism.[15]

5.1 Christianity

Christianity has been demonstrated as a positive motivator to organ donation.[15]

The Christian faith generally endorses tissue and organ donation, however, there are clearly different nuances in opinion. Most Anglican, Catholic and Protestant scholars view organ donation as an act of selflessness and endorse transplantation. The Church of England took its support for organ donation even further and declared organ donation a Christian duty in 2007. The Mormon Church does not object formally to organ donation but believe that organ donation and transplantation should be left to the individual's decision.[15]

Jehovah's Witnesses are a non-Trinitarian Christian denomination distinct from mainstream Christianity and deserves special consideration. The issue of organ transplantation is not straight forward and is compounded by the refusal of blood products. Religious guidance from the 1960's stated that organ transplantation from another human is akin to cannibalism and was not allowed. However, review of this guidance in the 1980's allowed for organ transplantation, provided no blood is transplanted and the decision for or against organ transplantation is the individual's choice.[15]

5.2 Islam

Violating the human body, whether living or dead is forbidden in Islam. However, altruism is also an important principle of Islam, and saving a life is placed with high regard in the Quran – 'Whosoever saves the life of one person, it would be as if he saved the life of all of humanity'(Chapter 5:32). In this dilemma, the principle that reconciles the two are 'necessity overrides prohibition' *(al-darurat tubih al mahzurat*).[15]

Most Islamic scholars endorse organ donation, however, many individuals within the faith are still reluctant, particularly regarding deceased donation. It is premature to conclude that this is due to

religious factors alone, as logistical problems play a major role. Muslim burial customs deserve consideration as well, it is traditional for Muslims to be buried within 24 hours, or as soon as possible. A lengthy organ retrieval may raise concerns. Due to these ongoing uncertainties, Muslims may seek the advice of the local Imam, and ultimately the decision/advice of this scholar is respected.[15]

5.3 Judaism

The Jewish faith places great importance on avoiding any unnecessary interference with the body after death, and requirement of burial of the complete body must be fulfilled within 24 hours. There are three prohibitions concerning cadavers that may seem to preclude organ or tissue donation (i) desecrating a cadaver (ii) delaying burial of a cadaver and (iii) receiving benefit from a cadaver. These considerations have led some Jewish scholars to disagree with deceased donation. However, many Jewish scholars feel that these concerns are overridden by the principle to save lives. Saving a life is a fundamental value in Judaism. Jewish law demands that one should violate almost all other commandments to save a life. This guidance has been used to solicit organ donation. Jewish scholars have discussed the issue of corneal transplantation, although not strictly lifesaving, it was felt that blindness was like death, and that corneal transplantation was acceptable.[15]

5.4 Hinduism

Hindus believe in reincarnation and the physical integrity of the dead body is not seen as crucial to reincarnation of the soul. Organ donation is encouraged within the Hindu faith.[15]

6. Specific unwillingness to donate eyes/cornea

A previous study of an adult South African population showed respondents were more willing to donate solid organs compared to corneas.[14]

Approximately 30 percent of families agreeing to multi-organ donation in Australia, specifically refuse corneal donation, and a similar disparity is noted in large studies in the USA.[9]

A study by Lawlor and Kerridge explored the reasons why individuals decide whether to donate corneas. The main concerns that contributed to refusal of corneal donation were disfigurement and loss of identity. The physical alteration or disfigurement by removing the eyes or corneas of the deceased was a significant source of distress for family members. For some there were concerns about the appearance of the body at a viewing, for others the symbolism associated with the eyes caused concern that by removing the eyes, the human aspect of the deceased will be diminished.[14]

Health care professionals and organ procurement staff addressed these concerns by explaining that the operative wound is small, and an artificial cornea or eyeball will be replaced after procurement.[9]

Care must be taken not to equate ethnicity with religion. Detailed analysis is required to dissect the various factors associated with decision-making regarding organ and tissue donation[15].

7. Conclusion

South Africa has an immense shortage of donor corneas, causing the burden of corneal disease requiring transplantation to continually rise. The general public in South Africa are not organ or tissue transplant conscious. There is an increased need for an awareness regarding the need for donor tissue.

Healthcare professionals in South Africa should be aware of the need for organ and tissue donation. We should sensitise government and decision makers to this national challenge and put together steps that can alleviate this challenge.

It would be beneficial to study the public attitudes toward corneal tissue donation and therefore identify the barriers and possible solutions to overcome them.

Aim

The aim of this study is to determine the public attitude towards corneal tissue donation in an urban South African population.

Study Objectives

- To determine the current attitude of a South African urban population towards corneal tissue donation
- To correlate the willingness to donate corneal tissue with age, gender, ethnicity, religion and level of education
- To identify barriers to corneal transplant donation in an urban dwelling population of South African adults

Hypothesis

- There are religious and cultural barriers that contribute to decreased corneal tissue donation in South Africa

Materials and Methods

Study Design

- This is an observational, cross-sectional quantitative study of the current attitude of an urban South African population towards corneal tissue donation

Study Population and Sample

- Patients or escorts attending the out-patients clinic at the Saint John's Eye Hospital. Using a hospital-based sample is a recognized limitation of this study.

- A sample size of 100 participants were determined with the assistance of a statistician
- Based on a population of 50 million, to obtain a confidence interval of 95% a sample size of 96 will be required
- I have rounded off the sample size to 100

Inclusion criteria

- South African born adults who are 21 years and older

Exclusion criteria

- Patients speaking a language other than English that cannot be translated by nursing staff

Data Collection

- Patients attending the clinic at St John Eye Hospital will be approached to participate in the study
- If a language barrier is present, clinic nursing staff will be requested to assist with translation
- Patients will be given an information pamphlet that describes the study (appendix B). They will be able to ask questions before commencing with informed consent.
- Informed consent will be obtained from all participants before commencing data collection (appendix C). As this is a cross-sectional study, participants will have a study number and no identifiers will be included in the questionnaire. This will ensure confidentiality.
- Data will be collected prospectively from interviews carried out with participants and recorded on a questionnaire.
- All information from the interviews will be captured electronically on an Excel spreadsheet (appendix E).

- Data will be stored in a password protected computer which can be accessed by the principal investigator.

Data Analysis

Statistical analysis will be performed using Statistical Package for Social Sciences (SPSS) (IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM Corp). Categorical data such as gender, population group, ethnicity, religious denomination and level of education will be compared with the willingness to donate corneal tissue. Data will be analysed using simple descriptive statistics. Parametric data will be reported as a mean, standard deviation and 95% confidence interval. Non-parametric data will be reported as median and interquartile range. Relationships between different variables will be assessed using a Spearman's correlation test.

Ethics Approval

Application for ethics approval will be submitted to the Wits Human Research Ethics Committee

- Participant confidentiality will be ensured by not including any identifiers in the research report or data sheets
- Each participant will be assigned a unique reference number
- Data will be stored in a password protected computer which can be access by the principal investigator.

Funding

- This study involves interviewing participants and then analyzing the information obtained. The stationery and travel costs will be covered by the researcher.

Presentation Plans

- Present at Ophthalmology departmental meeting

- Publish in a scientific journal
- Provide strategy recommendations regarding positive influence on attitudes and awareness.

Authorship

First Author – Dr Faheema Hajee

Second Author – Dr Roland Hollhumer

Timeline – Gant Chart

	April 2020	May 2020	June 2020	July 2020	Aug 2020	Sept 2020	Oct 2020	Nov 2020	Dec 2020	Jan 2021	Feb 2021
Literature Review											
Protocol											
Corrections											
Protocol Assessor meeting											
Ethics											
Data Collection											
Data Analysis											
Write -up											
Submission											

Appendix 2

Survey questionnaire

Public Attitudes to Corneal Tissue Donation in an Urban South African Population

To ensure anonymity, I will provide you with a study number

Please complete the following questions:

1. **Study Number**

2. **Gender**
   - ☐ **Male**
   - ☐ **Female**

3. **Age _____**

4. **Population Group**
   - ☐ **Black**
   - ☐ **White**
   - ☐ **Mixed ancestry**
   - ☐ **Indian/Asian**
   - ☐ **Other**

5. **Ethnicity**
   - ☐ **Zulu**
   - ☐ **Sotho**
   - ☐ **Setswana**
   - ☐ **Sipedi**
   - ☐ **Venda**
   - ☐ **Other _____**

6. **Religious Denomination**
   - ☐ **Christian**
   - ☐ **Muslim**
   - ☐ **Jewish**
   - ☐ **Hindu**
   - ☐ **Traditional African Religion**
   - ☐ **Atheist**
   - ☐ **Other_____**

7. **Highest Level of Formal Education_____**

8. **What is your Occupation?_____**

9. **Have you heard of Cornea donation before?**
   - ☐ **Yes**
   - ☐ **No**

10. **Would you accept a corneal transplant if you needed one?**

- ☐ **Yes**
- ☐ **No**
- ☐ **Unsure**

11. **Would you be willing to have your organs eg: heart, liver, kidneys donated to other people after you die?**
    - ☐ **Yes**
    - ☐ **No**
    - ☐ **Unsure**

12. **Would you be willing to donate your cornea after you die?**
    - ☐ **Yes**
    - ☐ **No**
    - ☐ **Unsure**

13. **If answered no above, which of the following best describes your reason for refusal**
    - ☐ **Religious reasons**
    - ☐ **Cultural reasons**
    - ☐ **Fear of disfigurement**
    - ☐ **Other**

14. **If a close family member had a fatal accident, would you be willing to donate his or her organs?**
    - ☐ **Yes**
    - ☐ **No**
    - ☐ **Unsure**

15. **If a close family member had a fatal accident, would you be willing to donate his or her corneal tissue?**
    - ☐ **Yes**
    - ☐ **No**
    - ☐ **Unsure**

16. **Would you favour an opt-in or an opt-out system to organ and tissue donation?**
    - ☐ **Opt – in**
    - ☐ **Opt out**

17. **Do you think there is a shortage of corneas available for transplantation in South Africa?**
    - ☐ **Yes**
    - ☐ **No**

Appendix 3

Study Information Sheet

STUDY INFORMATION DOCUMENT

Study title: <u>Public Attitudes toward corneal tissue donation in an urban South African population</u>

Good Day

I, Dr Faheema Hajee am doing research on people's attitude toward corneal tissue donation. Research is a process used in seeking new knowledge. In this study we want to learn how people feel about donating corneal tissue.

I am inviting you to take part in this research study.

What is involved in the study?

1. You will be invited to fill out a questionnaire
2. A hard copy of the questionnaire will be provided to you. You will be provided with a pen to fill out the questionnaire
3. There are 7 questions regarding your personal information (eg. your age and gender) and 9 questions about corneal tissue donation,
4. It will take approximately 5-8 minutes to complete the questionnaire

Risks of being involved in the study: There are no risks in participating in this study.

Benefits of being in the study: There is no direct benefit to you participating in this study. However, the information you provide may prove to be beneficial to other persons in the future.

<u>Participation is voluntary</u>, your choice will be respected and there will be no loss to you if you wish to not participate. Refusal to not participate will not influence the treatment you or your family member will receive. You may discontinue participation at any time without penalty, or loss of benefits to which you are otherwise entitled; there is no requirement to provide a reason for withdrawing and any data collected will in default be destroyed, unless you specifically consent to its retention.

Confidentiality: Normally personal information will be treated in the strictest confidence and will only be available to the Principal Investigator (PI) and his/her Supervisor, in the case wherein the PI is a postgraduate student. The only exceptions - and all of them are rare - would normally be:

1. personal information may be disclosed if required by law
2. the Human Research Ethics Committees of the University may exceptionally require personal data to respond to a formal complaint, or for a compliance audit
3. the South African Health Products Regulatory Authority (SAHPRA), which is the successor body to the South African Medicines Control Council (SAMCC), might conceivably require access to personal data, if conducting an investigation into a drug trial

If results are published, this may, exceptionally, lead to cohort, or more rarely, individual identification. All data collected during the study will be securely retained for two (2) years, if a scientific publication arises from the study and six (6) years, if there is no publication. Thereafter it will be destroyed accordingly.

Anonymity will be ensured by the use of a study number instead of your name. Your name will not be linked directly to any data. The only person that will have access to your data is myself, and I will be storing it in a password protected computer.

Contact details of researcher/s:
Principal Investigator: Dr Faheema Hajee
Cell: 076 859 1548
Email: faheema.hajee@gmail.com

Supervisor: Dr Roland Hollhumer

Outputs

The aim of this study is to identify barriers to corneal tissue donation. If you wish, I can provide you with the outcomes of this study once it is completed.

Contact details of HREC administrator and chair – for reporting of complaints / problems. The following text is recommended:

This study has been approved by the Human Research Ethics Committee (Medical) of the University of the Witwatersrand, Johannesburg ("Committee"). A principal function of this Committee is to safeguard the rights and dignity of all human subjects who agree to participate in a research project and the integrity of the research. If you have any concern over the way the study is being conducted, please contact the Chairperson of this Committee who is Professor Clement Penny, who may be contacted on telephone number 011 717 2301, or by e-mail on Clement.Penny@wits.ac.za. The telephone numbers for the Committee secretariat are 011 717 2700/1234 and the e-mail addresses are Zanele.Ndlovu@wits.ac.za and Rhulani.Mukansi@wits.ac.za

Thank you for reading this Study Information Sheet.

July 2020

Appendix 4

Informed Consent

INFORMED CONSENT:

- I hereby confirm that I have been informed by the study doctor, Dr Faheema Hajee about the nature, conduct, benefits and risks of clinical study Protocol number_____ and Title: Public attitudes to corneal tissue donation in an urban South African Population
- I have also received, read and understood the above written information (Participant Information Leaflet and Informed Consent) regarding the clinical study.

- I am aware that the results of the study, including personal details regarding my sex, age, date of birth, initials and diagnosis will be anonymously processed into a study report.
- In view of the requirements of research, I agree that the data collected during this study can be processed in a computerised system.
- I may, at any stage, without prejudice, withdraw my consent and participation in the study.
- I have had sufficient opportunity to ask questions and (of my own free will) declare myself prepared to participate in the study.

PARTICIPANT:

Printed Name	Signature / Mark or Thumbprint	Date and Time

I, Dr Faheema Hajee, herewith confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

STUDY DOCTOR:

Printed Name	**Signature**	**Date and Time**

TRANSLATOR / OTHER PERSON EXPLAINING INFORMED CONSENT……**(DESIGNATION):**

Printed Name	**Signature**	**Date and Time**

WITNESS (If applicable)**:**

Printed Name	**Signature**	**Date and Time**

Appendix 5

Data Collection Sheet

Questions								
Knowledge of Cornea donation	Accept Cornea Transplant	Willing to donate organs	Willing to donate Cornea	Reason for refusal	Donate family members organs	Donate family members cornea	In favour of opt-in or opt-out system	Shortage of corneas in SA
(Y/N)	(Y/N)	(Y/N)	(Y/N)	(R/C/F/O)	(Y/N)	(Y/N)	(I/O)	(Y/N)
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-
-	-	-	-	-	-	-	-	-

Appendix 6

Consent to collect data – Head of Department Permission

Consent to Collect Data

To Professor I Mayet

I Dr Faheema Hajee do hereby request permission to collect data to complete my MMED research under the title:

Public attitudes towards Corneal Tissue Donation in an Urban South African Population

Data will be collected via questionnaires from individuals at Saint John's Eye Hospital.

Attached is the Patient Information Sheet and a copy of the questionnaire that would be used to collect data.

Data will be collected after approval is obtained from the Human Research Ethics Committee of the University of the Witwatersrand. This research project will be fully funded by myself. Data will be collected during my department approved research leave and will not interfere with the daily running of the Ophthalmology Department.

Head of Department Ophthalmology CHBAH

Name..... Ismail Mayet .....Date..... 22/5/2020 .....

Signature.....

Appendix 7: Consent to Collect Data – CEO Hospital Management Permission

GAUTENG PROVINCE
HEALTH
REPUBLIC OF SOUTH AFRICA

MEDICAL ADVISORY COMMITTEE

CHRIS HANI BARAGWANATH ACADEMIC HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 29th June 2020

TITLE OF PROJECT:

Public attitudes towards Corneal Tissue Donation in an Urban South African Population.

UNIVERSITY: Witswatersrand

Principal Investigator: Dr F Hajee

Department: Opthalmology

Supervisor : Dr R Hollhumer

Permission Head Department (where research conducted): Yes

The Medical Advisory Committee recommends that the said research be conducted at Chris Hani Baragwanath Academic Hospital. The CEO / management of Chris Hani Baragwanath Academic Hospital is accordingly informed and the study is subject to:-

- **Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.**
- The Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- The MAC will be informed of any serious adverse events as soon as they occur
- Permission is granted for the duration of the Ethics Committee Approval.

.....
Recommended
(On behalf of the MAC)
Date: 29/06/2020

.....
Approved/~~Not Approved~~
Hospital Management
Date: 06/07/2020

Appendix 8

Ethics Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG	HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)

Office of the Deputy Vice-Chancellor (Research & Post Graduate Affairs)

TO: Dr F Hajee
School of Clinical Medicine
Department of Neurosciences
Division of Opthalmology
St John's Eye Hospital
Chris Hani Baragwanath Academic Hospital

E-mail: faheema.hajee@gmail.com

CC: Supervisor: Dr R Hollhumer <hollhumer@gmail.com>
and <HREC-Medical.ResearchOffice@wits.ac.za>

FROM: Iain Burns
Human Research Ethics Committee (Medical)
Tel: 011 717 1252

E-mail: Iain.Burns@wits.ac.za

DATE: 2020/08/18

REF: *R14/49*

PROTOCOL NO: **M200644** *(This is your ethics application study reference number. Please quote this reference number in all correspondence relating to this study)*

PROJECT TITLE: *Public attitudes to corneal tissue donation in an urban South African population*

Please find attached the Clearance Certificate for the above project. I hope it goes well and that an article in a recognized publication comes out of it. This will reflect well on your professional standing and contribute to the Government funding of the University.



MSWorks2000/Iain0007/Clearscan.wps

PUBLIC ATTITUDES TO CORNEAL TISSUE DONATION IN AN URBAN SOUTH AFRICAN POPULATION

Faheema Hajee

Turnitin Originality Report

- Processed on: 19-Apr-2023 10:29 AM SAST
- ID: 2069173151

