# Willingness to donate eyes and associated factors among adults in a rural community in Central Ethiopia

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#### **ABSTRACT**

Objective: To assess the willingness on corneal donation among rural adults in Central Ethiopia.

Design: A community based, cross sectional study.

Setting: The study was conducted in Wolkite town, Central Ethiopia.

Methods: Data collection was through a house to house visit with face to face interviews. Systematic random sampling method was used. A total of 492 residents aged 18 years or older living in the randomly sampled housing units were included in the study.

Results: The mean age of respondents was 33 years (range 18-60) and 55.3% were females. From all adults, 57.9% were willing to pledge to donate eyes while only 30.9% were aware of eye donation. On multiple logistic regression, willingness to donate was associated only with previous awareness on eye donation (adjusted OR 0.434, 95 % CI: 0.266 - 0.709). The main reason given for being willing to donate (73.7%) was the feeling that they will be pleased to help the blind. The main reason for unwillingness (59.4%) was the belief that it was important to have an intact body after passing away (dislike to separate the eye from the body).

Conclusion: A good proportion of participants were willing to donate their corneas while the awareness level was low. Previous awareness on eye donation was the major factor associated with willingness to donate.

Key words: Eye donation, Willingness, Cornea transplantation, Eye bank, Ethiopia

## **INTRODUCTION**

Corneal diseases are second only to cataract as major causes of blindness worldwide<sup>1</sup>. According to a national survey done in 2006, 1.6% of Ethiopians were found to have blindness and 3.7% had low vision. Trachomatous and other corneal opacities ranked as the second leading causes of blindness (19.3%) next to cataract (49.9%) and the third leading cause of low vision<sup>2</sup>.

Corneal transplantation is the major option for restoration of vision for these large numbers of corneal blind people. The success of corneal transplantation service is, however, dependent on many factors. Establishment of an efficient eye bank and acquiring the qualified professionals is the basic one. Furthermore, procurement of the adequate and quality donor corneas is a challenge, which depends on the availability of suitable donors and requires the presence of voluntary eye donation<sup>3</sup>.

Currently, there is only one eye bank in the country involved in collection and storage of donor corneas, the Eye Bank of Ethiopia. Corneal transplantation is performed in three university referral hospitals in the country, with the same eye bank expected to provide the available corneas for the institutions. Between 130 and 150 corneas are harvested every year and used in 90–120 transplants. However, the annual harvesting rate of corneas for transplantation is minimal compared with

the requirement, and this has hampered the effective utilization of the service. Understanding the reasons why people do or do not donate is critical to devise policies to address this undersupply.

The health practice of an individual is influenced by the cultural milieu in which one lives. Among many factors that can affect this include religion and traditional beliefs and practices. It is therefore important to understand whether these factors would affect their willingness to donate their organs. Ethiopia is geographically, culturally, ethnically diverse country. There are more than 80 ethnic groups and Christianity and Islam are the chief religions.

There is scarcity of information on public attitudes towards eye donation and associated factors in the developing world, particularly in sub Saharan Africa. According to studies done in the developed nations, the decision to be an organ donor may be influenced by multiple factors; relational ties, religious beliefs, cultural influences, family influences, body integrity, previous interactions with the health care system<sup>4</sup>.

In this study, we aimed to assess the awareness on and willingness of adults in a rural community in Central Ethiopia to donate their corneas and to determine the factors influencing their willingness. To date, there is no published study in our country on this topic done at the community level. The information about distribution and demographic associations of

willingness for eye donation could help in developing strategies to increase the harvesting of corneas for dealing with corneal blindness.

#### **MATERIALS AND METHODS**

A community based cross sectional study was conducted in Wolkite town, Gurage zone, central Ethiopia. It is located 155 km West of Addis Ababa, the capital city of Ethiopia (Central Statistical Agency of Ethiopia, 2007). According to the National Census, it has a population of 28,856 divided in two kebeles (the smallest administrative unit in urban or rural areas). There is no significant difference in population characteristics in distribution among the kebeles (economic, ethnic, educational, etc.). One of these was selected for the study by a lottery method.

The total sample size was calculated using one proportion formula. Taking an estimated proportion of 30% of people willing to donate eyes and allowing an error of 4% of detecting the estimated prevalence by chance alone with 95% confidence interval, and adding a non-response rate of 10%, the total sample size calculated was 554. One of the adults aged 18 years or above and living in the sampled household was randomly selected and included in this study.

Data collection was through a house to house visit. A structured questionnaire predesigned in local language was completed after the nature of the study was explained and verbal informed consent of each individual was obtained. The length of the interview was about 20 minutes. Non-participating subjects included refusal to participate and non-contactable after three visits. Pre-test was performed in another area, which was not selected for the study. Data analysis was conducted using Statistical Package for Social Sciences (SPSS) version 15.0. Descriptive, univariate, and multivariate analyses were performed. The characteristics of those who were willing to donate eyes were compared to those who were not willing. Statistical significance was determined at the 0.05 level.

The study was approved by the Department of Ophthalmology and was done with adherence to the guidelines of the Declaration of Helsinki. The officials of the study area were approached and permission given to conduct the study. Informed verbal consent was also obtained from the participants. 'Awareness' was defined as 'having heard of eye donation' and 'Willingness' - a subject was willing if he/she was voluntary to pledge to donate eyes.

#### **RESULTS**

A total of 492 subjects were included in this study, with a response rate of 88.8%. The age of respondents ranged from 18 - 80 years with a mean of 33 years (±14). The majority 261(53%) were in the age group 18–30 years old while 169 (34.4%) were 30–50 years old, and 62 (12.2%) were aged above 51 years. There were 272 (55.3%) females making the female to male ratio 1.24:1; from all participants 283 (57.5%) were married. The completed education level of the participants was as follows: 30.5% were illiterates, 4.1% were able to read and write only, 23.6% primary school education, 32.9% secondary school education and 8.9% had college education. The majority, 225 (45.7%) were Muslims while 203 (41.3%) were orthodox Christians and 39 (7.9%) were protestant Christians.

From the total respondents, 152 (30.9%) were aware of eye donation and the major sources of information were TV (65.1%) and Radio (39.5%). In addition, 285(57.9%) of the study participants were willing to donate their eyes, while 37 (7.5%) said they needed more information to decide (Table 1). On univariate analysis, willingness to donate was not associated with age (p = 0.71), sex (p = 0.12) or religion (p = 0.12)= 0.447). Respondents who were in the secondary education or completed a tertiary education were more willing to donate their eyes (69%) as compared with the other groups (50.6%), which was statistically significant, (OR = 1.203, 95% CI: 1.056-1.370). Educational level was also significantly associated with awareness on eye donation (OR = 2.14, 95% CI: 0.133-0.185). Those who were aware of eye donation (73.7%) were also more willing compared with those who were not aware (50.9%), which was statistically significant, (OR= 2.703, 95% CI: 1.778-4.109). Since of awareness was also associated with the educational status of the participants, awareness was also entered on multiple logistic regression analysis; this showed that only awareness was significantly associated with willingness to donate, after adjusting for age, sex, educational status, ethnicity and religion (adjusted OR 0.434, 95% CI: 0.266 - 0.709). From those who were unwilling to donate eyes, 54 (26.3%) said they will be willing if their family member is to receive the benefit.

**Table 1:** Age, sex, ethnicity, religion, education and willingness to donate eyes, Central Ethiopia

Variables	Willing to donate No. (%)	Unwilling to donate No. (%)	Multivariate adjusted odds ratio*	95.0% C.I.		
				Lower	Upper	P value
Age						
18-29	153(58.6)	108(41.4)	1.00			
30 - 39	67 (60.9)	43 (39.1)	1.153	0.559	2.379	0.699
40 - 49	31(52.5)	28 (47.5)	1.718	0.817	3.615	0.154
50+	34 (54.8)	28(45.2)	1.245	0.569	2.725	0.583
Sex						
Female	149 (54.8)	123 (45.2)	1.00			
Male	136 (61.8)	84 (38.2)	0.852	0.563	1.290	0.449
Education						
Illiterate	80 ( 53.3)	70 (46.7)	1.00			
Able to read and write only	11 (55.0)	9 ( 45.0)	1.010	0.413	2.469	0.983
Primary	51 (44.0)	65 ( 56.0)	0.824	0.251	2.709	0.750
Secondary	113 (69.8)	49 (30.2)	0.592	0.259	1.349	0.212
College/University	30 (68.2)	14 (31.8)	1.396	0.635	3.067	0.407
Religion						
Muslim	122 (54.2)	103 (45.8)	1.00			
Orthodox (Christians)	126 (62.1)	77 (37.9)	2.191	0.813	5.904	0.121
Protestant (Christians) Others	24 ( 61.5) 13 ( 52.0)	15 (38.5) 12 (48)	2.080 2.154	0.823 0.657	5.262 7.062	0.122 0.205
Awareness						
No			1.00			
Yes			0.434	0.266	0.709	0.001

<sup>\*</sup>Adjusted for all other factors in the table.

Among those who were willing to donate their corneas, the most frequently given reason (73.7%) for this act was 'I will be pleased to help the blind', followed by 'I feel doing good to humans', (38.2%). (Table 2). The most frequent reason given for not being willing to donate corneas was 'I want my body to be buried intact (dislike to separate the eye from the body) (59.4%), while 35.9% of responders indicated that donation is against their religious belief (Table 3). Participants with Muslim religion were more likely to cite that the act of donation is against their religious beliefs (46.4%) as compared with 25.8% of orthodox and 15.4% of protestant Christians. This was statistically significant (p = 0.024).

**Table 2:** Reasons for willingness to donate eyes (n = 285)

Reasons given for willingness to donate eyes	No. who gave this response*	(%)
Pleased to help the blind	210	73.7
Doing good to humanity	109	38.2
Because I don't need my eyes after death	104	36.5
It counts for my afterlife	33	11.6

<sup>\*</sup> An individual can give more than one response

**Table 3**: Reasons for unwillingness to donate eyes (n = 170)

Reasons given for	No. who	(%)
unwillingness to donate	gave this	(, -)
eyes	response*	
I want my body to be	101	59.4
buried intact		
It's against my	61	35.9
religious beliefs		
My family might be	35	20.6
upset/ Not approve		
Unsuitable to donate	4	2.4
due to health problem		
I have no reason	3	1.8

<sup>\*</sup> An individual can give more than one response

From the 152 individuals who were aware of eye donation, 130 (85.5%) had positive attitude in that they believed eye donation could help someone blind to see again. Moreover, 108 (83.1%) of those with such positive attitude were willing to donate eyes as compared to only 18.2% of adults who believed eye donation could not help someone blind to see again. This was also statistically significant, (OR= 22.1, 95% CI: 6.8-71.6). When asked whether or not there is eye bank in Ethiopia, only 82 (16.7%) of all participants responded there is an eye bank in the country.

## **DISCUSSION**

There is scarcity of information on the factors influencing corneal donation in different geographic areas and in populations from varied cultural, social, religious, and economic backgrounds<sup>5</sup>. This is more evident in developing nations, despite the fact that they are the major areas with the burden of corneal blindness<sup>3</sup>. It is therefore important to study the factors influencing willingness of the public for corneal donation for effective eye bank function. Since there is scarcity of published papers, particularly in sub Saharan Africa, on this topic, we have limited our comparison to studies done in Asia. This is also the first paper in Ethiopia to evaluate the willingness of adults to donate corneas at a community level.

From all respondents in our study, 57.9% were willing to donate their corneas even though only 30% of adults had heard about eye donation. In comparison, a study done in a rural population of Andhra Pradish, Southern India, only 32.9% of adults were willing to donate their corneas while 30.7% had heard about eye donation<sup>6</sup> and 52% of adults in North Western (NW) India were found willing to donate with 70.5% of the total respondents having heard about eye donation<sup>7</sup>. In a study done among Singapore adults, 80.7% were aware of eye donation, while 67% were found to be willing to donate corneas8. These studies may not be directly comparable with that of ours as the age; ethnicity and religion distribution of all these studies is different from that of ours. Nonetheless, the proportion of rural adults who are willing to donate their eyes in our study is high when it is weighed against the lower level of awareness.

The influences of various socio- demographic factors (like age, gender, religion, economic status, education level etc) on willingness to donate eyes have been described in the literature.

On this study, we found only awareness on corneal donation to be significantly associated with willingness to donate, with 73.7% of those who were aware of eye donation being willing to donate eyes, as compared with 50.9% of those who had unawareness (OR= 2.703, 95% CI: 1.778- 4.109). As having awareness on eye donation was in turn associated with education level of participants (OR = 2.14, 95% CI: 0.133-0.185), we expected those with better educational level to be more willing to donate their eyes. Positive association between level of general education and willingness to donate organs has been described in the literature<sup>7,9,10</sup>. However, on multiple logistic regression, having had heard of eye donation remained the single most important factor to be associated with the willingness of individuals to donate. Unawareness of eve donation is considered to be one of the major obstacles in the procurement of corneas<sup>11</sup>. This study confirms raising awareness among the public on eye donation and encouraging them to pledge to donate may be effective strategy for enhancing the willingness of the population towards eye donation, irrespective of education level<sup>12,13</sup>.

From the participants who were willing to donate, 73.7% cited being pleased to help the blind as a major reason for their act while 38.2% considered their act of donation is doing good to humanity after death. This shows the great sympathy the people have towards the blind and their readiness for this noble purpose. This is also in line with the principle of altruism, an unselfish concern for the welfare of others, which is said to be the basic principle why people in the west support organ donation<sup>14,15</sup>. The participants in the Singapore study (92.9%) similarly cited donating a part of themselves made them feel that they were doing good<sup>8</sup>. This was in contrast to the study done in North Western India in which the most important reason indicated was the possibility of "living on" after death, if they donated (94%), followed by doing some good to humanity after death  $(24.0\%)^7$ . On the other hand, the main reason for unwillingness to donate in our study was the belief that it was important to have an intact body after passing away (dislike to separate the eye from the body), 59.4%. This could be for cultural reasons in our society where great respect is given for the dead body and taking a part of it may result in disfigurement of the body, considered doing against the norm.

The concern of disfigurement has been described as a reason for negative sentiments regarding corneal donation<sup>5,16</sup>. In fact, this is one reason proposed for the lower rates of corneal donations than other solid organs<sup>17</sup>. The concern that the body is physically altered in some way during the procurement of cornea may invoke fears about mutilation and a desire to maintain bodily integrity and bury the body whole<sup>18</sup>. A broader discussion with the public addressing such concerns that they have about this aspect of organ donation is very important. It is essential to deliver the message that the body may not appear disfigured after donation of the cornea. Health education on the use of the donated eye and its value in sight restoration for the blind should also be employed. Similarly, the most common reason cited in the Singapore adults was that they preferred their bodies remain intact after death (73.2%)<sup>8</sup>. The belief that donation hurts the family members was the main reason for refusal to donate in the study in NW India (45.5%) followed by religious reasons  $(24.0\%)^7$ .

Religion was the second common reason given for the unwillingness (35.9%) in our study. This is a significant number. Participants with Muslim religion were more likely to cite that the act of donation is against their religious beliefs (46.4%) as compared with the others. Cultural and religious beliefs may at times be interchangeable and some people may hold strong culturally specific beliefs which are not linked to any

particular religious stance<sup>4</sup>. Furthermore, on the reasons for willingness to donate, 33 (11.6%) respondents stated that it will count for their afterlife if they donate eyes, implying donation is rather a positive act based on their religion. Addressing the religious leaders to educate people the basic teachings of their religions in relation to donations may help combat such misunderstandings. Religion was the most common one given in the study done in urban India<sup>11</sup>, while having eye problem was cited by the participants in the study in rural India as the main reason for not being willing<sup>6</sup>. From those who were aware of eye donation, 85.5% of responders had a positive attitude towards eye donation, in which they believed that corneal donation could help someone to see again. Having positive attitude was found to be a positive predictor of willingness to donate (OR= 22.1, 95% CI: 6.8-71.6).

In conclusion, our study has shown that the willingness to corneal donation of the society in this rural area of Ethiopia is relatively good while the level of awareness is very low. Willingness to donate was associated only with previous awareness on corneal donation. Having positive attitude was also found to be a positive predictor of willingness to donate. The main reasons mentioned for willingness to donate were the feeling of pleasure in helping the blind and the belief that the act of donation is doing good to humanity, while the dislike to separate the eye from the body after death was the main reason for not being willing to donate. This rural population is a good target for mobilization for pledges especially with more efforts to increase the awareness. The lack of a qualitative arm for a more detailed assessment of perceptions and attitude of the residents on corneal donation is the major limitation of the study.

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