RESEARCH

Eye Donation Project: Differences Between Donors Versus Refusers

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ABSTRACT

Objective: To assess factors associated with the family members' willingness to donate eyes of their deceased loved ones.

Methods

Relatives of 121 potential post-mortem eye donors were approached and by local eye bank coordinators working for Eye Donation Project in Thailand. Information was categorized into 3 parts according to: 1) general and socioeconomic status, 2) activity of daily living index (ADLI), medical conditions and causes of death, 3) reasons for donating eyes. Various factors were compared between those willing to donate (Yes group) versus those who refused (No group).

Results

From 121 cases, 27 (22.13%) came from the Yes group whereas 94 (77.68%) were from the No group. We found no difference of socioeconomic status and level of education between both groups. Marital status was statistically associated with donate rate by univariate analysis (P=0.043). Multivariate analysis showed significant relationship between ADLI and rate of eye donation (P=0.042). The reasons for donating were to obtain religious merit, fulfill the donors' wishes, and provide recipients with an opportunity to gain back vision. As for those who refused to donate, the reasons were: beliefs in reincarnations, family conflicts for making the decision, and belief that a person's body should remain intact to allow the spirit to rest in peace.

Conclusions: Socioeconomic status, level of education and medical conditions did not influence family's decision in regards to eye donations. Success of an eye donation project is possible if there is a well-planned counseling offered by an experienced team to the potential donor family.

KEYWORDS

Attitude, Eye Banks, Tissue and Organ Procurement, Thailand

INTRODUCTION

With current advances in medical technology, outcome of organ transplantation has drastically improved compared to the past 10 years. Among these surgeries, corneal transplantation is the most common transplant surgery performed worldwide with very high success rates.[1,2,3] Corneal transplantation is the only way to correct corneal blindness which is one of the leading cause of blindness worldwide and also in Thailand, following cataracts and glaucoma according to the results obtained from the National Blind Survey of 1994 and 2007.[4,5]

Data from the Thai Red Cross Eye Bank (TRCEB), an organization that is responsible for the collection and allocation of donated cornea to patients, showed that the number of recipients waiting for eye transplantation is approximately 900 cases per year whereas the number of eyes donated per year is only 600. About 7,000 patients are currently on the waiting list for the operation.[6] Because of this, many patients have to wait between 1 – 3 years for the eye transplantation which in turn, causes the patients to have a poorer quality of life and become a burden to their families and communities.

Insufficient number of eye donations is common among many countries. Therefore many studies were conducted to find factors affecting people's willingness to donate their eyes and their perspectives/attitudes towards eye donation. [7,8,9] Krishnaiah S et al.[8] assessed the awareness of eye donation among the population living outside of India and found that organ donation was significantly lower in people $\geq$ 70 years old, illiterate, had low income and were Catholic. On the other hand, a study conducted in Singapore by Yew YW et al.[9] reported that highly educated, ethic Chinese Christians and Hindus were positively correlated with being eye donors.

In Thailand, one study assessed the attitudes and needs of organ donors. (10) Anothayanon K et al. reported that variables such as age, marital status, parity, and attitudes toward life after death affected whether people would donate their organs. The study also showed that eyes were the most donated organ but due to the lack of confidence in the medical personnel, people refused to donate them.

In another study conducted in 2004, the National Statistical Office of Thailand surveyed the general public on their opinions of organ donations.(11) Most of the people surveyed agreed and were pleased to donate their organs as well as their relatives. Among those that refused to donate, the major reasons given were the beliefs in reincarnations, beliefs that a person's body should remain intact to allow the spirit to rest in peace, and inability to make a decision at time of grief. They also found that Buddhists and Christians were more willing to donate their organs.

Aim of this study was to assess the factors associated with the family members' willingness to donate eyes of their deceased loved ones. Regarding TRCEB conducted the active program for eye donation to increase number of donors. The deceased were screened whether they were potential donor or not. Then, well-trained coordinators will approach relatives of the deceased and ask for permission to donate cornea. This program was set up in many hospitals, which were network of TRCEB. The challenge of this program is timing. Our coordinators have to complete their work before 12 hours after dead.

MATERIALS AND METHODS

This is a cross-sectional, descriptive study that was conducted at the Queen Savang Vadhana Memorial Hospital, Sriracha distinct, Chonburi province, and Chaophaya Abhaibhubejhr Hospital, Prachinburi province, Thailand, between 1 April 2006 and 31 March 2007. Both of them were tertiary care center.

Population

The study included potential donors and their relatives who were responsible in making the decisions whether the eyes would be donated or not. The potential donors were selected by purposive sampling technique from patients in all age groups who died at the Queen Savang Vadhana Memorial Hospital and Chaophaya Abhaibhubejhr Hospital between 1 April 2006 and 31 March 2007. Potential donors were excluded if they were not met standard donor screening protocol of TRCEB. Two well-trained coordinators from TRCEB, one coordinator for each site, would seek the permission of the relatives of the deceased for the eyes as well as completing the questionnaires pertaining to their decision making.

Questionnaire

The questionnaire was developed by both the ophthalmologist and psychiatrist and was divided into three parts. The first part would gather the background information of the potential eye donor. Information collected were: sex, age, education, religion, occupation, income, marital status, cause of death, and physical dependency of the potential donors before death by using

Barthel Activities of Daily Living Index (ADLI) which consists of 10 items that measure a person's daily functioning specifically the activities of daily living and mobility. [12]

The second part collected the general information of the relative of the deceased as well as their relationship to the deceased. The last part assessed the relative's attitude towards eye donation. This part consisted of open-ended questions assessing their perspectives towards eye donation and their decision process.

The research proposal and questionnaire were approved by the Research Ethics Committee of the Queen Savang Vadhana Memorial Hospital. Completed questionnaires were divided into two groups: willing to donate (Yes group) and refusers (No group).

Data Analysis and Statistics

Data analysis was performed using Statistical Package for Social Science (SPSS) version 17.0. Univariate analysis was conducted by using chi-square test for categorical data and t-test for continuous data. Logistic regression model was used for multivariate analysis. A p-value < 0.05 was considered statistically significant.

RESULTS

Information was collected from people who died at the Queen Savang Vadhana Memorial Hospital and Chaophaya Abhaibhubejhr Hospital between 1 April 2006 and 31 March 2007. Out of 121 potential donors, eyes were donated from only 27 cases (22.3 %).

Potential Donor

There were 90 potential male (74.4 %) and 31 potential female donors (25.6 %). The average age was 43.9 years old. 64.5 % of them were married. Almost all of them were Buddhist (98.3%). As for their educational level, most of them had completed primary school (57.4 %), followed by high school (32.8 %). Most of the potential donors were laborers or blue-collar workers (74.4 %), followed by unemployment (10.7 %). About two- thirds of them had revenue of less than 310 USD per month, followed by revenue between 155 and 310 USD per month (48.4 %) and less than 155 USD per month (30.3 %). 39.5 % of the potential donors died from chronic conditions such as cancer, lung infections, kidney disease, congestive heart failure, renal failure and other chronic conditions whereas 60.5 % died from acute deaths. These deaths included accidents (mostly traffic accidents), acute myocardial infarction, sudden cardiac arrest, acute cerebrovascular accident, etc.

We did not find any association between willingness to donate and gender, age, religion, education, occupation, income, and cause of death of the potential eye donor (P > 122 0.05). When the univariate analysis was performed, marital status was statistically associated 123 with

the willingness to donate (P = 0.043) but was no longer significant with multivariate 124 analysis (P = 0.098).

The dependencies of the potential eye donors measured with ADLI were interpreted as low dependence (score 12-20), moderate dependence (score 9-12), severe dependence (score 5-8), and total dependence (score 0-4). Analysis was done between group of low and moderate dependence and group of severe and total dependence. According to the multivariant analysis, the ADLI was statistically significant (P = 0.042). Results are 1summarized in Table 1.

Relatives of the Deceased

The relative of the deceased was usually the person who would give his/her permission whether the eyes would be donated or not. In the study, 46.3 % and 53.7 % of the relatives were males and females, respectively. The average age was 39 years old. 76 %, 17.4 %, and 6.6 % were married, single, and divorced, respectively. Almost all of the relatives were Buddhists (98.3 %). As for their relationship with the deceased, most of them were the children (26.5 %) followed by siblings (24 %), caretakers (24 %), parents (14.9 %), and spouses (10.8 %). Majority of them had primary (44.3 %) and secondary school educations (36.1 %). Most of the relatives of the deceased were laborers or blue-collared workers (72.7 %). Most of the subjects had income of less than 310 USD per month. 51.6 % had revenue between 155 and 310 USD per month and 23.8 % had revenue of less than 310 USD per month.

There were no significant association between willingness to donate the deceased's eyes and gender, age, religion, marital status, education, occupation, and income of the relatives ($P > 0.05$). When caretakers were excluded from the model because they were not considered as the relatives of the deceased and therefore could not make any real decisions regarding the donation, we detected a higher ratio of the siblings (Yes: No = 11: 18) compared to the spouses (Yes: No= 3: 10) willing to donate but this was not statistically significant. Results are summarized in Table 2.

Attitudes of the relatives of the deceased

From 121 potential donors, 26 decisions were made by one relative (21.6 %) whereas 84 decisions were made by all of the family members (69.4 %). The reasons for the donation were to obtain religious merit (77.8 %), fulfill the donors' wishes (29.6 %), fulfill the family's will (63 %), and provide recipients with an opportunity to gain back their vision (66.7 %). As for those who refused to donate, the reasons were: beliefs in reincarnations (39.5 %), family conflicts for making the decision (32.6 %), belief that a person's body should remain intact to allow the spirit to rest in peace (28 %) and unable to make a decision due to grief. None of the respondents mentioned that they refused to donate because they did not trust the medical staff in how the eyes were going to be used after it has been harvested.

DISCUSSION

From the 121 potential eye donors, 22.13% of the relatives agreed to donate the eyes of their deceased loved ones. This percentage is comparable to the rate of organ donors (21%) (10) from a previous study conducted in Thailand in 2002. However, this rate is far much lower compared to India (41.5%) (13) and Germany (71.5%) (14). We speculate that it is because of the

differences in social and cultural structure. In our country, we lived in extended family. So, relatives of the deceased were involved in the decision-making process. The second reason influencing to the decision of body donation was next life belief and reincarnation. Missing body part in next life was highly concerned.

There were no differences between both groups in regards to causes of death, gender, age, religion, education, occupation, and income of the relatives. From the multivariate analysis, the scores of ADLI of the deceased showed an association with the relatives' willingness to donate (P = 0.042). If the deceased was more dependent on the relatives for ADLI, this factor was significantly associated with a higher proportion of the relatives' willing to donate (Yes: No = 24: 92) compared to those less dependent (Yes: No = 3: 2). Since majority of the deceased were in low and moderate dependence group (116 out of 121 potential eye donors), we cannot confirm with absolute certainty that ADLI of the deceased is associated with the relatives' willingness to donate. Further study is necessary to evaluate this factor and its direct effect on the relatives' willingness to donate.

Interestingly, there was a higher proportion of divorced spouses (Yes: No = 4: 6) willing to donate compared to those that were still married to the deceased (Yes: No = 12: 66). Even though that this was not statistically significant, but the trend shows that the decision process of the relatives lies in the degree of physical closeness of both parties. The close relationship of married couple seems to have a higher possessive feeling towards their love's bodies.

There were no associations between the rate of eye donation and the relative's gender, age, religion, marital status, education, occupation, income, and relationship to the deceased between both groups. However, when caretakers were controlled for in the analysis, we noticed that siblings of the deceased were more willing to donate (Yes: No = 11: 18) compared to the spouses (Yes: No = 3: 10). This observation is in line with the physical closeness of the deceased and the relative as previously mentioned. For instance, spouses may have a stronger emotional bond to the deceased and therefore it is harder for them to donate the eyes of their deceased loved ones. This can explain why there is a lower donation rate in the relatives that are currently married to the deceased.

Another factor affecting the rate of eye donation is the relatives' beliefs and religious background. Those that believed in reincarnation of life after death were highly unlikely to donate. Therefore it is important to consider the influence of the relatives' religion and beliefs in eye donations. Perhaps if they knew more about the benefits of eye donations, then it is possible that this factor can be reversed. Aside from that, another important factor affecting the decision making process is strongly rooted in the virtues of a strong hold of the family. In Thailand, family is considered very important and many decisions are always done as a family.

Culture and knowledge of eye donation has not been deep-rooted in Thailand. Small numbers of pledge donor informed their wishes known to their family prior to death. Topic of organ donation

represented the death and bad luck for the family. In addition with strong influence of religious background as formerly discussed had emphasized us the role of eye bank coordinators who were on the front row dealing with relatives during grief period.

There are some limitations in this study. Because we had to immediately approach the relatives after their loved ones died, it is very difficult for the relatives to make any decisions during this period of grief. There really is no way to overcome this factor unless we do a mass advertisement in the newspapers, radios, televisions, internet, billboards, magazines and through word of mouth the benefits of eye donation, perhaps only then will people be more willing to donate even at times of grief. Without educating people on the benefits of eye donations, people cannot make informed decisions. Moreover, this study was conducted in the rural area of Thailand and will not be applicable to large cities such as Bangkok where a higher proportion of the population will have a university degree or higher. Furthermore, majority of our study participants were Buddhists and therefore it would be difficult to assess whether people of other religions would react in the same way or not. Even though the study participants represented majority of the population in Thailand but caution is warranted in interpreting these results because the sample size was small and it is possible that we were unable to see any significant associations between the variables studied and eye donation.

In conclusion, the physical dependency of the deceased may have played an important role in the relatives' willingness to donate the eyes of their loved ones. Socioeconomic status, level of

education and medical conditions did not influence or affect the family's decision making process in regards to eye donations. It is possible to have a successful eye donation project if we know what influences the family's decision to donate their loved ones' eyes. Perhaps a well-planned counseling should be offered to the potential donor family by an experienced team.

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Table 1: Characteristics of potential eye donors possibly influencing the willingness to donate their eyes

Table 2: Characteristics of the relatives of the deceased