

A Method to Increase Corneal Tissue Worldwide: A Survey on Organ Donation

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Abstract

Corneal transplantation is the world's most frequently performed transplant surgery and has the potential to restore vision in patients with damaged or diseased corneas. Despite the volume of procedures done worldwide, a significant global gap exists between supply and demand, with an estimated 53% of the world's population lacking access to corneal transplantation. The United States, one of only two countries with a surplus of eye tissue, is uniquely positioned to help address this shortage. This study explores attitudes in the U.S. toward organ donation in general versus corneal donation specifically, aiming to identify factors that may influence willingness to donate corneal tissue.

A survey of 378 individuals, modeled after a 2019 National Survey of Organ Donation Attitudes and Practices, assessed demographic variables and attitudes toward organ and corneal donation. Of the 318 fully completed surveys, 14% of respondents indicated unwillingness to donate organs, yet over half of that subgroup expressed willingness to donate their corneas. Statistical analysis revealed three key factors significantly associated with corneal donation willingness despite general opposition to organ donation: beliefs about burial with intact body parts, family support for donation, and support for presumed consent policies.

The study also identified religion, particularly within the Islamic community, as a significant factor in overall attitudes toward donation.

These findings suggest that offering individuals the option to donate specific organs-such as corneas-rather than presenting organ donation as an all-or-nothing choice at the DMV, could increase tissue availability. This shift in approach could potentially result in millions more corneas becoming available for transplant. The survey results also suggest that a continued effort for education and outreach to the Islamic community could increase organ donation generally, and corneal donation specifically within that demographic.

Further research is needed to explore these trends in a more diverse population with a greater sample size. However, the study provides compelling evidence that changing the way donation options are presented could be a practical step toward increasing the global supply of corneal tissue.

Keywords: Cornea; Organ Donation; Attitudes; Tissue Donation

Abbreviations

DMV: Department of Motor Vehicles; IRB: Institutional Review Board; U.S.: United States; LDS: Church of Jesus Christ of Latter-Day Saints

Introduction/Overview

Corneal transplantation can restore a person's vision when damage and/or disease has rendered the person's original cornea non-functional. It is widely accepted as the world's most frequently performed transplantation surgery. While corneal transplantation is performed often, one estimate reports that 53% of the world has no access to the procedure for a variety of reasons, including lack of access to equipment or facilities for the treatment and lack of readily available eye tissue [4]. Another estimate states that for every 70 corneas needed worldwide, only 1 cornea is available [2]. The U.S. and Sri Lanka are the only countries in the world that consistently have more supply of eye tissue than demand and export a significant number of corneas to be used in other countries [4].

While the U.S. currently meets its own needs for corneal transplantation, increasing the number of corneas donated and banked in the U.S. would both improve the quality of corneas available for use and allow for the U.S. export to help close the gap between supply and demand for corneas worldwide. In the U.S., organ donation follows an "opt-in" system, meaning citizens must opt into being an organ donor for their tissue to be used following their death. This process most commonly takes place at the Department of Motor Vehicles (DMV), where individuals get their driver's license [3]. Some data suggests that more than 90% of all organ donors in the U.S. were first registered at the DMV [7]. Other countries follow what is termed "presumed consent," meaning that people must opt out of being an organ donor [3]. Roughly 60% of U.S. adults have opted in and registered to be organ donors [9].

Aim of the Study

The aim of this study is to evaluate whether there is a difference in attitudes among Americans between organ donation generally and corneal donation specifically.

Materials and Methods

A survey based on the 2019 National Survey of Organ Donation Attitudes and Practices was conducted amongst 378 individuals to evaluate attitudes toward organ donation [8]. The survey included seven demographic questions and eighteen questions assessing attitude. The survey was administered by the authors through multiple routes, including distribution to participants at health fairs. Inclusion criteria required respondents to be at least 18 years of age and live within the United States. Institutional Review Board (IRB) approval was obtained from the University of Texas Health Science Center at San Antonio prior to survey distribution.

Key variables assessed include willingness to donate organs, willingness to donate corneal tissue, and attitudes toward presumed consent. Demographic data including sex, age, race, religion, zip code, and occupation were also collected. Additional questions addressed belief surrounding body parts, willingness to discuss wishes with family, willingness to honor family members' donation wishes, and personal experiences with organ donation. Responses were measured using a 1-5 Likert scale and participants were given the option to select "Prefer not to answer".

Respondents who indicated they were not willing to be an organ donor were asked a follow-up question regarding their willingness to donate their corneas.

Of the 378 responses, 318 were selected for evaluation based on full completion of the survey.

Data was analyzed using Chi-squared tests and pairwise z-tests. 95% confidence intervals were then calculated to determine the significance of results.

Results

Three hundred and seventy-eight individuals took the survey. Of respondents, 42% were male and 58% female, with an age range of 18 to 86.

Only 318 surveys were fully completed, and their data was selected for analysis. Forty-six of the 318 responses (14%) indicated not wanting to be an organ donor.

Across demographic categories, the only criteria that was significantly correlated with an overall desire to donate organs was religion. While only 19% of respondents were Muslim, 59% of the population who were unwilling to donate organs were Muslim (p-value < .0001).

Desire to Donate Own Organs					
		N	% "Yes"	95% CI Lower	95% CI Upper
Total		380	<div><div></div></div> 76.6%	72.3%	80.8%
Sex	Female	195	<div><div></div></div> 87.7%	83.1%	92.3%
	Male	147	<div><div></div></div> 81.0%	74.6%	87.3%
Age	18-29	218	<div><div></div></div> 87.2%	82.7%	91.6%
	30-39	35	<div><div></div></div> 68.6%	53.2%	84.0%
	40-49	29	<div><div></div></div> 69.0%	52.1%	85.8%
	50-59	40	<div><div></div></div> 87.5%	77.3%	97.7%
	60-69	9	<div><div></div></div> 77.8%	50.6%	100.0%
	70+	8	<div><div></div></div> 87.5%	64.6%	100.0%
	Race/Ethnicity	Asian	50	<div><div></div></div> 64.0%	50.7%
Black or African American		29	<div><div></div></div> 82.8%	69.0%	96.5%
Hispanic		49	<div><div></div></div> 89.8%	81.3%	98.3%
Middle Eastern		24	<div><div></div></div> 50.0%	30.0%	70.0%
White		219	<div><div></div></div> 92.2%	88.7%	95.8%
Other		12	<div><div></div></div> 66.7%	40.0%	93.3%
Religion	Agnostic	29	<div><div></div></div> 93.1%	83.9%	100.0%
	Atheist	8	<div><div></div></div> 87.5%	64.6%	100.0%
	Evangelical	5	<div><div></div></div> 100.0%	100.0%	100.0%
	LDS	132	<div><div></div></div> 95.5%	91.9%	99.0%
	Muslim	55	<div><div></div></div> 43.6%	30.5%	56.7%
	Protestant	28	<div><div></div></div> 92.9%	83.3%	100.0%
	Roman Catholic	38	<div><div></div></div> 84.2%	72.6%	95.8%
	Other	37	<div><div></div></div> 89.2%	79.2%	99.2%
Education	Less than high school graduate	8	<div><div></div></div> 87.5%	64.6%	100.0%
	High school graduate	11	<div><div></div></div> 81.8%	59.0%	100.0%
	Some college	62	<div><div></div></div> 85.5%	76.7%	94.3%
	Trade/technical/vocational training	9	<div><div></div></div> 88.9%	68.4%	100.0%
	College graduate	175	<div><div></div></div> 85.7%	80.5%	90.9%
	Post graduate work/degree	77	<div><div></div></div> 81.8%	73.2%	90.4%
Profession	Healthcare professional	123	<div><div></div></div> 85.4%	79.1%	91.6%
	Non-healthcare professional	214	<div><div></div></div> 85.0%	80.3%	89.8%

Table 1: Percent answering, “Definitely Yes” or “Probably Yes” to the question, “Would you want your organs to be donated after your death?” “Total N” is the number of individuals in each group. “CI” is the confidence interval. The total “N” for each demographic category may not equal the “Total N” due to non-respondents or individuals belonging to multiple groups. Religious categories of “Buddhist,” “Jewish,” and “Orthodox” were excluded due to lack of respondents.

Fifty-three percent of individuals who did not want to be an organ donor were still willing to donate their corneas.

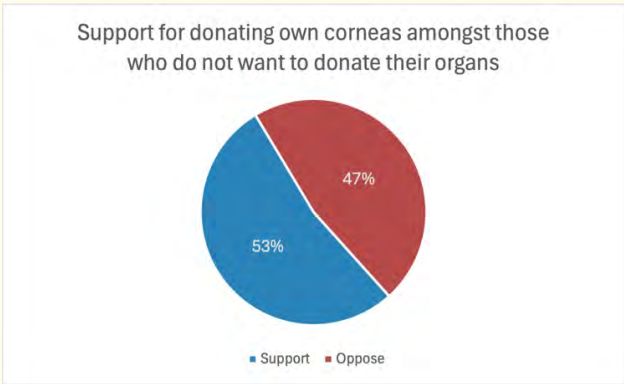


Figure 1: Of those who were unwilling to become organ donors, how many responded that they would be willing to donate their corneas.

Three of the survey questions were correlated significantly with a willingness to donate corneal tissue despite not wanting to donate organs generally. These questions addressed:

1. Whether the respondent believed it is important to be buried with all body parts ($p = .01$).
2. Whether the respondent’s family would generally support the idea of organ donation ($p = .002$).
3. Whether the respondent supported a presumed consent system for organ donation in the United States ($p = .00005$).

Eighty-three percent of people who did not believe it was important to be buried with all of their body parts were willing to donate their corneas, while only 40% of those who felt it was important to be buried with all of their body parts were.

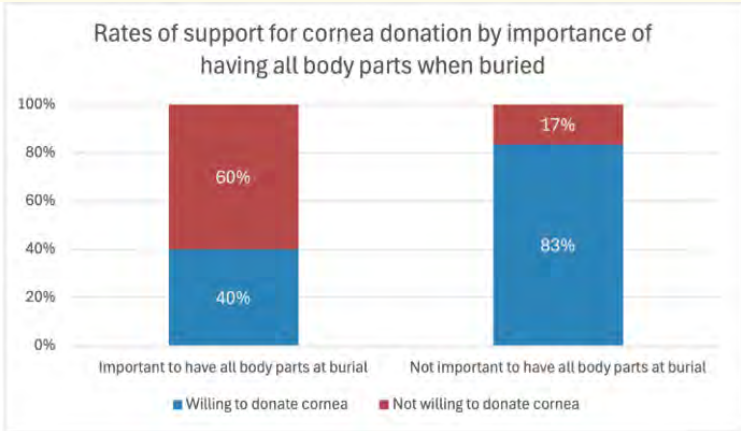


Figure 2: Comparison of the belief that it is important to be buried with all of your body parts and a willingness to donate corneal tissue.

Nearly 70% of individuals who reported that their family supports organ donation were willing to donate a cornea, compared to only 45% of those whose families were unsupportive.

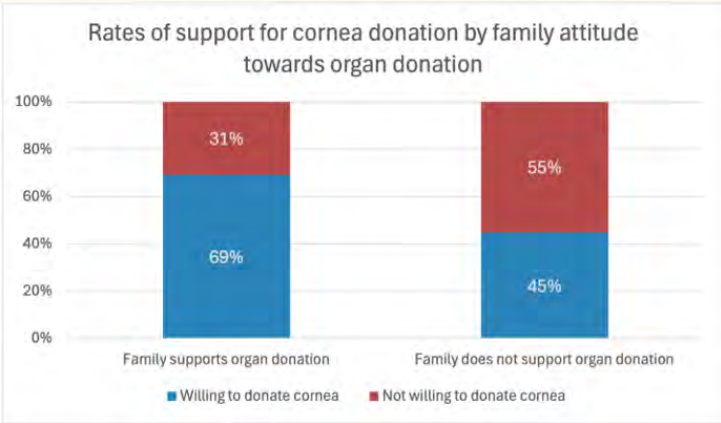


Figure 3: Comparison of the familial support for organ donation and a willingness to donate corneal tissue.

One hundred percent of respondents who supported a presumed consent model indicated willingness to donate their corneas, while fewer than half of those who opposed presumed consent were willing to do so.

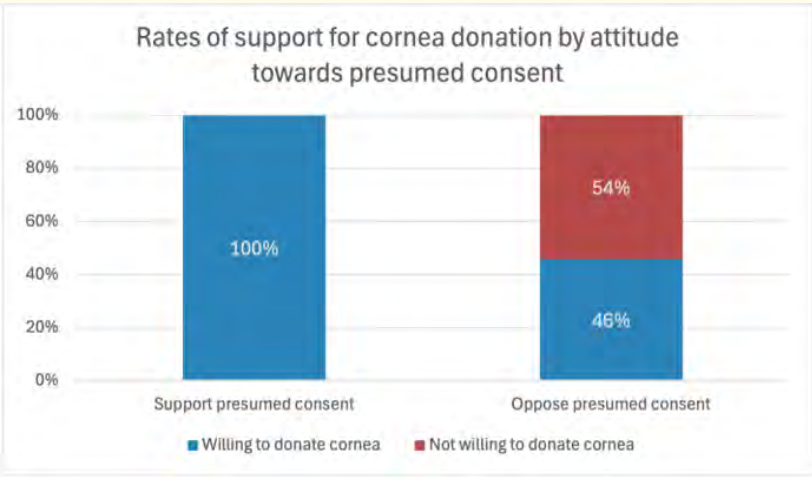


Figure 4: Comparison of support for presumed consent in the U.S. and a willingness to donate corneal tissue. Of note, no respondents who indicated support for presumed consent in the U.S. were unwilling to donate their corneas.

Discussion

The finding that 50% of individuals who oppose donating their organs generally are still willing to donate their corneas represents a potentially actionable finding to expand the corneal donor pool available in the U.S., and ultimately worldwide. To substantiate the findings of this survey, further research with a larger sample size and broader geographic representation is required. In their study about corneal donation, Williams and Muir concluded that there were more people willing to donate their corneas than were registered, consistent with the findings of our project [11]. However, their work did not compare general attitudes toward organ donation with those specifically related to eye tissue.

In the United States, there are 212 million licensed drivers. Assuming the national average of 60% being organ donors, that makes 127 million registered donors [10]. When presented with the option to be an organ donor at the DMV, drivers are essentially offered an “all-or-nothing” option. The choice of donating specific tissues is not presented. Further research into whether allowing the option to select which organs a driver would be willing to donate should be done to see whether organ donation, not just of corneas, could be increased. This survey suggests that significantly more eye tissue could be banked if potential donors were approached with the option. If 50% of the approximately 85 million licensed U.S. drivers who refused organ donation were still willing to donate their corneas, the potential supply could increase by roughly the same amount, assuming donation of both eyes.

The difference found in attitudes towards organ donation generally between Muslim and non-Muslim respondents warrants further investigation. Official declarations, called fatwas, have been released from prominent Imams in the world, including a lead Imam in the UK, explicitly stating that post-mortem organ donation is allowed according to Islam’s tenets [5]. Our findings are consistent with other studies on how religion affects organ donation attitudes [1,6]. These papers suggest that hesitancy may arise from concerns about the morality of donation, mistrust of medical systems, and unawareness of fatwas from leaders in both the Sunni and Shia sects [1]. More detailed research into Muslim attitudes towards organ donation, including potential regional differences, the influence of local leadership, and other factors, would make interesting follow up investigations.

The three aspects of the survey which correlated significantly with those willing to donate corneas despite not wanting to donate their organs are interesting. It seems logical that people who do not think it is important to be buried with all their body parts would be more willing to give their corneas after their death; however, we found those same people would be unwilling to be organ donors (Figure 2). More targeted questions, focus groups, or surveys including free-response options may provide insight into why individuals who do not consider burial with all body parts important still oppose organ donation.

It is not a surprise that more individuals with family supportive of organ donation would be willing to donate their corneas (Figure 3). Further exploration is warranted into why individuals with family support for organ donation might still hesitate to donate their own organs or corneas.

The overwhelming willingness to donate corneas when presumed consent was supported is noteworthy (Figure 4). Again, it is interesting to consider why someone might support presumed consent and yet also be unwilling to donate their organs.

One weakness of this study comes from convenience sample bias. The survey was completed by disproportionately high populations of medical workers (35% of respondents) as well as people of either the LDS (38% of respondents) or Islamic faith (17% of respondents) compared with the demographics of the U.S. population. The attitudes of respondents identifying as LDS did not differ from the attitudes of the other self-identified Christian responses.

Conclusion

While cornea transplantation is the most common transplantation procedure performed worldwide, there remains a devastating gap between the availability of corneas and the current need. The U.S. is leading the way in acquiring and banking corneal tissue, even sharing excess tissue with other countries to help meet their people's needs. Increasing the amount of eye tissue donated and banked within the U.S. could help alleviate some of the gap between supply and demand worldwide. Because a significant portion of respondents to this survey who did not want to be an organ donor were still willing to donate their corneal tissue, one possible avenue for increasing the eye tissue available is to provide the option for potential donors in the U.S. to decide which tissues they would donate specifically as opposed to an "all-in" or "all-out" approach.

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