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Specific unwillingness to donate eyes: the impact of disfigurement, knowledge and procurement on corneal donation

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Abstract

While willingness, attitudes and beliefs surrounding solid organ donation have been extensively investigated, much less is known about corneal donation. Despite evidence that a substantial number of families who agree to multi-organ donation also specifically refuse corneal donation, it is unclear why this occurs and what can be done to increase rates of corneal donation. We conducted a survey of 371 Australian adults regarding their views on

corneal donation. While willingness to donate corneas generally reflected a person's willingness to donate all of one's organs, unwillingness to donate corneas appeared to be due to other factors. Specifically, decisions not to donate appear to be driven by a range of concerns surrounding disfigurement. The survey also provides eye banks with reassurance about the acceptability of whole globe procurement, and recognition that research into blindness is a highly valued part of corneal donation. Finally, the survey identifies that many individuals see benefit in having their family engaged in the decision making process, suggesting that decisions about donation are more complex than a simple appeal to the autonomy of the deceased.

Introduction

While willingness, attitudes and beliefs surrounding solid organ donation have been extensively investigated, much less is known about corneal donation. This is important as rates of corneal donation are much lower than those for solid organs, suggesting there is something different about corneal donation. A large US study of over 10,000 patient charts demonstrated that while consent for organ donation was 47%, consent for corneas was only 24%(1). Similarly in Australia, there is evidence that while virtually all families who agree to multi-organ donation consent to kidney donation, 28% specifically refuse to donate corneas(2). It is important to note that the number of potential corneal donors is much greater than the number of potential solid organ donors, as corneas may be procured up to 12 hours after cardiac death and therefore a declaration of brain death is not a precondition of donation.

Despite this apparent difference in consent between organs, no studies have been published that specifically investigate the general public's willingness to donate corneas. As part of more general investigations of organ and tissue donation a US survey of 445 adolescents registering for a driving licence found that while 49% of respondents had favourable donation intentions, 33% of these individuals specifically indicated that they would not allow their eyes to be removed after death(3). Other studies have suggested individuals are most willing to donate kidneys, and least willing to donate corneas, skin and bone(4, 5).

Surveys of willingness to donate corneas among health care workers suggest that these individuals also hold similar biases and reservations. A survey of UK nurses found that while 80% were willing to sign a donor card, 25% of respondents specifically indicated they would not be willing to donate their corneas, while only 3% were unwilling to donate their heart(6). Similar surveys of donation coordinators have found they were least likely to want to donate bone and corneas, while hospital health care staff were least likely to want to donate corneas and skin(7, 8).

A further source of investigating willingness to donate is through registries of donation intention. Many countries encourage registration of wishes as a method of maximising the number of donors. In Australia there are two systems for registering donation preferences: the national online Australian Organ Donor Register, and the New South Wales (NSW) Roads and Traffic Authority (RTA) database.

As part of licence renewal in Australia's most populous state NSW, all individuals are asked to indicate their preferences concerning organ and tissue donation. The RTA offers possible responses of yes or no to all organs, or individuals may specify which particular organs they are willing to donate. As at 30 June 2008 there were 4.6 million individuals who held a NSW driving licence (personal communication NSW RTA, Nov 2008). Of these 44% indicated willingness to donate all organs and tissues, 30% were unwilling to donate anything, 20% did not respond to the question, and 6%, (270,000 individuals) chose to specifically identify which organs they were willing to donate. The most common organs and tissues that were refused by this final group were skin 86%, bone 71% and corneas 70%. Unwillingness to donate the pancreas was indicated by 35% of respondents, heart and lung 23%, liver 18%, and kidney 8%. It appears that when individuals chose to selectively indicate particular organs they are willing to donate, they most commonly use this opportunity to express unwillingness to donate skin, bone and corneas.

The exact reasons why so few people consent to corneal donation are unclear, but there is some evidence to suggest that negative sentiments regarding corneal donation may be due to concerns about disfigurement(9-11), the association of eyes with identity or the soul(6, 7), the physical visibility of the eyes(6), and concerns about the need for eyes in an afterlife(12). This existing evidence derives from either small studies, or research where investigation of corneal donation was of secondary concern. The aim of this study was to describe the attitudes to corneal donation held by an Australian adult population, identify those factors that determine corneal donation decisions, and describe the impact of concerns regarding disfigurement, method of procurement and decision-making responsibility on donation decisions.

Materials and Methods

In New South Wales (NSW), Australia's most populous state of 7 million people, residents renew their licenses every 1-5 years at offices of the Roads and Traffic Authority (RTA). At this time, each applicant is asked about their wishes concerning donation. In this study each individual entering an RTA branch was approached with a standard request asking whether they would be willing to complete a questionnaire whilst waiting to be served. Data was collected during the first half of 2008 and respondents came from 5 geographically separated branches of the RTA in Sydney, Australia. Research ethics approval was granted from the University of Sydney Human Research Ethics Committee.

The questionnaire consisted of 18 questions that covered 5 areas thought to impact upon corneal donation: (1) knowledge of corneal donation and transplantation, (2) willingness to donate corneas, (3) reasons for willingness or unwillingness, (4) attitudes regarding decision making responsibility and (5) socio-demographic factors.

Survey responses of reasons for willingness or unwillingness to donate were developed from review of both published surveys of eye and of solid organ donors, and of non-empirical literature on eye donation.

Results were tabulated, and associations between categorical responses analysed using chisquare tests. Comparisons of perceived disfigurement, measured using a five-point Likert scale, were conducted using the Wilcoxon signed-rank test.

Results

The overall survey response rate was 88% with a total of 371 respondents completing the survey.

Knowledge questions

The first section of the survey contained knowledge questions. They were placed first to avoid inadvertent education from other questions in the survey. Table 1 demonstrates respondents understanding of the use of donated eyes. While 86% correctly identified it was to replace a damaged cornea, 57% of respondents incorrectly felt that a donated eye could be used to replace an entire damaged eye.

Table 2 illustrates responses to a series of factual questions about donation and transplantation. The term 'eye cornea' was used to reflect the terminology used by the RTA when registering donation preferences. While there was relatively wide variation in the percentage of correct answers, for the most part less than 50% of respondents could identify the correct response. In addition, for most questions one-third to one-half of respondents indicated that they did not know the answer.

Of particular note is the finding that 44% of individuals indicated that corneal donation was only possible once a person had been declared brain dead. This suggests that there is limited awareness that corneal donation occurs under quite different circumstances to that of heart-beating solid organ donation.

Willingness to donate

Of the 369 participants who responded to the question regarding their willingness to donate corneas, 216 (59%) indicated that they would be willing to donate their corneas, while 153 (41%) indicated that they would not. Of those who were willing to donate their corneas, almost 80% indicated that this decision was a part of their more general willingness to donate *any* organs and tissues, while 58% felt that it was important that eyes were available for research. (Table 3)

The responses of those willing were also analysed according to whether they wanted to donate all their organs and tissues. The only statement that showed a significant difference between the groups was that individuals who wanted to donate all their organs and tissues were significantly more likely to make the decision quickly without much thought (40% v 22%, p=0.002).

Table 4 illustrates the reasons that individuals suggest played a role in their unwillingness to donate corneas. Half of respondents indicated that this was part of a more general unwillingness to donate any of their organs and tissues. This suggests that the other half of

respondents are not opposed to donation completely, but that they had specific concerns about corneal donation. A substantial minority also did not feel they had enough information to agree to donation. The next three most common responses involve either explicit recognition that the reasons were not known, or were associated with discomfort with thoughts of death, or the physical or mental associations with donation. Religious objections and medical contraindications to donation were uncommonly cited as reasons for not wanting to donate.

The responses were also analysed according to whether the individuals did not want to donate any of their organs and tissues. The only significant difference identified between these groups was that individuals unwilling to donate corneas but not unwilling to donate all other organs and tissues were significantly more likely to state they did not have enough information to agree (54% v 27%, p=0.001).

These data demonstrate that in contrast with those willing to donate corneas, those unwilling to donate corneas are significantly more likely to hold this independent of reservations about donation in general. Seventy nine percent of those willing indicated this was part of more general willingness to donate all organs and tissues, while only 49% of those unwilling indicated this was part of a more general unwillingness to donate any organs or tissues (79% v 49%, p<0.0001).

Disfigurement

Disfigurement associated with donation of particular organs was investigated by asking respondents to indicate on a Likert scale of 1-5 the amount of disfigurement they felt was caused by removal by each of heart, bones, skin, corneas and kidneys. One indicated 'not at all disfigured' and five indicated 'very disfigured'. The percentage of individuals responding with 3 or more for each organ was skin 75%, bones 66%, corneas 47%, kidneys 32% and heart 35%. Comparisons of disfigurement for the removal of each organ with cornea found that skin (p<0.0001) and bones (p<0.0001) are significantly more disfiguring than corneas, while kidneys (p=0.0001) and hearts (p=0.0003) are significantly less disfiguring than corneas.

Method of corneal removal

Respondents were also prompted that corneal donation can either involve whole globe donation, or removal of the cornea only. A question then asked whether the method of removal of corneas would influence their willingness to donate. Overall 59% of respondents indicated their decision would not be influenced by the method of removal. Of those who indicated corneal only procurement would make them more likely to donate, 19 (5.9% of total) had indicated they were unwilling to donate, while 7% of respondents indicated unwillingness to donate at all if the whole eye was removed. Only 1.2% of respondents were initially willing to donate, but then indicated they would not do so if the whole eye were removed.

Family decision making

Respondents were asked whether they felt that a family member should be able to override an explicit decision about donation made by the deceased individual prior to their death. Thirty five percent of respondents indicated a family member should definitely not be able to override, 22% indicated they should probably not be able to override, 13% were not sure, and 30% thought that either maybe or definitely they should be able to override. These results were not significantly different between those individuals willing and those unwilling to donate corneas.

Demographic associations

Demographic data is provided in Table 5. This data demonstrated that willingness to donate corneas significantly decreased with education; while 73% of those not completing high school were willing to donate, only 47% of those with postgraduate degrees were willing. Women were also significantly more willing to donate than men (66% vs 54% p=0.03). Religion was also significantly associated with willingness to donate (p=0.03); followers of Islam and Judaism were less likely to be willing, and those of no religion or a non-listed religion more likely to be willing to donate. There was weak evidence that willingness to donate increased with age (p=0.2). Level of income was not related to willingness to donate (p=0.5), nor was there a significant difference between the consent rate at the different locations in which the survey was administered (p=0.24).

Contact with eye related health care also appears related to willingness to donate corneas. For individuals who wore glasses or contact lenses willingness was 58%, for those who had seen an optometrist within the last 2 years 63%, seen an ophthalmologist within the last 2 years 78%, and for those who have had previous eye surgery 81% (p=0.03).

Discussion

This study provides the most comprehensive published account of attitudes to corneal donation. The findings suggest that willingness to donate corneas is generally part of a broader commitment to organ and tissue donation, whereas unwillingness to donate appears to be related to factors specific to corneal donation, most notably concerns about disfigurement. It has also found that whole globe enucleation is unlikely to significantly affect consent, and that a significant minority of individuals would have concerns if donation policy excluded families from decisions about donation.

The main limitation of this study is that the quantitative methodology restricted responses to those provided in the survey (12% of those unwilling to donate corneas indicated that they had a reason for this unwillingness that was not an option in the survey instrument) and did not allow a deep exploration of the values and reasons underpinning donation decisions, which would have required the use of qualitative methods, such as in-depth interviews.

The results of this survey suggest that knowledge of most aspects of corneal donation is poor, with many respondents unable to correctly answer questions about corneal donation. It was particularly noteworthy that 57% of respondents felt that a donated eye could be used to replace an entire damaged eye, and that 44% believed that a donor must be

declared brain dead in order to become a corneal donor, as each of these misunderstandings could have a substantial impact upon rates of corneal donation. While the literature is replete with evidence that the concept of brain death is poorly understood(13), in this setting it is important because it suggests that there is limited awareness that corneal donation occurs under quite different circumstances to that of multi-organ donation.

This relatively low level of health literacy is likely to be either because of poor knowledge of specific aspects of corneal donation, or low general health literacy. While this suggests that there may be a role for education about organ donation and transplantation it cannot be assumed that this will lead to increased donation, as other studies have clearly demonstrated that the translation from increased knowledge about donation to increased donation rates is very low(14). It also cannot be assumed that ignorance about corneal donation predicts unwillingness to donate, as those who are well educated and knowledgeable about donation, including donation coordinators and health care staff, appear also to have reservations about donating particular organs and tissues. Finally, while previous surveys have suggested a positive association between level of general education and willingness to donate(15, 16), we found that at least for corneal donation, an increased level of education was associated with greater unwillingness to donate.

The results of this survey suggest that it may be concerns about disfigurement, rather than ignorance or intelligence, that drive decisions to donate. Of the top eight reasons given for not wanting to donate corneas, one was discomfort without an identifiable reason, while four others involved notions of discomfort surrounding the physical act of donation or explicit concerns about disfigurement or mutilation. Respondents also indicated that they found the idea of corneal donation significantly more disfiguring than both kidney and heart donation, although less so than skin and bone donation.

This is unsurprising, as removal or incision of the eyes, skin or bone would likely be regarded as leading to observable disfigurement. Differences regarding the degree to which each of these procedures are thought to be disfiguring may reflect awareness of the utility of transplantation of these tissues and organs, familiarity with the process of procurement, or beliefs about what the body may look like following donation. The external eyes and skin may be imagined as absent, and a lay understanding of bone donation may raise concerns about a shapeless body bereft of its normal human form. While this understanding of bone procurement is not accurate, it is likely to be the perception by individuals who have not previously encountered it. These concerns about bone donation appear reaffirmed by evidence that fear of mutilation in bone donation is heightened in organ procurement staff who have actually witnessed the procedure[8].

Our results support existing research that shows that potential donors often have concerns about disfigurement, with many donors expressing fears that they 'wouldn't want their body cut up' or that they 'would want to be buried as a whole person' (15). Disfigurement appears an even more important influence in corneal donation with some research suggesting some individuals express difficulty rationalising their position yet remaining emotionally repelled by the idea; "How do you look afterwards? I know it is irrational – your eyes are closed, of course, it's an emotional fear I have" (17).

Concerns about disfigurement need not be an intractable barrier to donation as potential donors and family members may be persuaded by reassurances that physical disfigurement (particularly of the face) is not evident after donation and that a viewing is still possible (9-11, 18). But while the body may not appear disfigured after donation, the very fact that it has been physically altered appears to invoke fears about mutilation and a desire to maintain bodily integrity and bury the body whole. These concerns are quite common and appear to be relatively difficult to overcome in the donation discussion (18). This suggests that there is possibly a role for a broader discussion with the public that is concerned not with correcting a deficit of knowledge about transplantation but with respectfully addressing the very real fears and concerns that people may have about this aspect of organ donation.

Our study also provides important data about the question as to whether the method by which corneas are procured influences decision about donation. Corneal procurement can either involve direct corneal excision from the deceased, or the globe can be enucleated and the cornea excised ex-vivo. While claims have been made that whole globe enucleation leads to a lower consent rate than cornea only excision, to date there is little direct evidence to support this(19), and centres that exclusively use enucleation maintain relatively high consent rates(20). Cornea only excision also has limitations; it is a technically more demanding procedure and requires a sterile preparation at the bedside. Importantly, cornea only excision also does not give the donating family an opportunity to donate eye tissue for research and deprives researchers of a critical resource(21). Our results provide some reassurance that procurement by enucleation rather than corneo-scleral excision is unlikely to alter the consent rate, as the method of removal appears unlikely to sway the decisions individuals have already made. While a small group of respondents indicated that they would be more willing to donate corneas if only the cornea was removed, the majority of these individuals had already indicated willingness to donate. And while 5.9% (19 of 323) of those who were unwilling to donate indicated that they might be more likely to donate if only the cornea was removed, it is not clear whether this increased likelihood would be sufficient to persuade them to become a corneal donor. Importantly, only 1.2% (4 of 323) of respondents were initially willing to donate but then indicated they would not do so if the whole eye were removed. While this finding may appear contrary to the discussion of disfigurement above, it could be that concerns about disfigurement among the general public do not extend to the nuances of medical procurement techniques. For those concerned about disfigurement, the discomfort they feel may be present irrespective of the procurement method employed.

One of the most striking findings arising from this research concerns the attitude towards the role of the family in decision making surrounding organ donation. Most countries encourage individuals to make a decision about donation prior to their death, both to ensure that decisions made by a person about their own body are respected after their death, and as a strategy to increase the number of organ donors(22). Australia has always had an 'opt-in' system of organ donation. But while there is general support for the idea that an individual's expressed wishes regarding donation should be respected, in practice health professionals invariably discuss donation with the remaining family and generally respect the family's decision. Despite evidence that relatively few families override the

clearly expressed wishes of the deceased regarding organ donation(22), there has been ongoing debate as to whether families should ever be able to override an individual's decision to donate. Our results provide evidence that many individuals see benefit in having their family engaged in the decision making process. While the most common response was that a family member should definitely not be able to override a stated decision, this response was only given by 35% of respondents. A further 22% indicated they should probably not be able to override, while 30% thought that either maybe or definitely they should be able to override. A substantial number of respondents therefore appear to affirm that decisions about donation are more complex than a simple appeal to the autonomy of the deceased. It is unclear why people may tolerate, or even welcome their families having the 'final say' on their decisions regarding organ donation. Possible explanations include a belief that it is important to respect the emotional preferences of relatives who survive the deceased, or concerns that indicating a wish to donate may compromise one's own medical care — that doctors may not do as much to save the life of someone who has indicated a willingness to donate(23).

This study confirms suggestions that individuals have differing levels of comfort with the idea of donating specific organs and tissues. While willingness to donate corneas is associated with willingness to donate all of one's organs, unwillingness to donate corneas is due to other factors, most notably concerns about disfigurement. Concerns about disfigurement in donation follow a hierarchy, with donation of corneas raising more concerns than solid organ donation, and bone and skin donation are thought to be more disfiguring than corneal donation. In order to minimise refusal rates of solid organ and corneal donation, our results suggest that the range of factors that may influence decisions to donate, particularly those relating to disfigurement, should be identified and clarified through further research and should then be explicitly included in discussions regarding organ donation. The results of this research should also reassure eye banks that whole globe procurement may be socio-culturally acceptable and that research into blindness is highly valued and plays a part in the decision of a majority of those individuals willing to donate corneas.

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Table 1: Knowledge of corneal transplantation: the uses of donated eyes (correct answer in brackets)

True False No response A donated eye is used for: % % % n n Replacing an entire damaged eye (F) 190 51% 142 39 11% 38% Replacing part of a damaged eye (T) 232 63% 98 26% 41 11% Replacing the cornea of a damaged eye (T) 7% 299 81% 47 13% 25 Research into diseases of the eye (T) 236 64% 99 27% 36 10%

Table 2: Knowledge about corneal donation (correct answer in brackets)

	True		False		Don't know		No response	
	n	%	n	%	n	%	n	%
Eye corneal transplants are usually successful (T)	160	43%	32	9%	163	44%	16	4%
There are great benefits for the recipients of eye corneal transplants (T)	285	77%	13	4%	61	16%	12	3%
There are many people in need of an eye corneal transplant (T)	226	61%	9	2%	121	33%	15	4%
Wearing glasses means you can not donate eye corneas (F)	16	4%	233	63%	104	28%	18	5%
Previous eye surgery means that you can not donate eye corneas (F)	49	13%	137	37%	166	45%	19	5%
Eye corneal donation means collection of the whole eye (T)	80	22%	112	30%	159	43%	20	5%
Eye corneal donation means collection of the cornea of the eye (T or F)	184	50%	40	11%	129	35%	18	5%
Eye corneal donation requires the donor to be declared brain dead (F)	154	42%	76	20%	123	33%	18	5%

Table 3: Statements that play a role in willingness to donate corneas

	N	% (of 216)
I would want to donate all of my organs or tissues	171	79%
Corneal donation allows something positive to come out of the donor's death	147	68%
I would feel good about myself because of having made the decision to donate	132	61%
It is important that eyes are available for research into diseases causing blindness	126	58%
I would make the decision quickly without much thought	86	40%
Corneal donation helps families of the deceased to grieve	61	28%
Other reasons	14	6%

Table 4: Statements that play a role in not being willing to donate

Table 4. Statements that play a role in not being willing to donate		
	n	% (of 153)
I would not want to donate any of my organs or tissues		49%
I don't feel I have enough information to agree to donation		41%
I am uncomfortable with the thought of someone cutting into my eyes		35%
I am not sure of the reason, I would just not feel comfortable about		35%
donating my corneas		
The thought of donating my corneas gives me a yucky feeling	43	28%
I do not like thinking about death	34	22%
I am short sighted or long sighted	28	18%
Corneal donation would cause mutilation or disfigurement of my body	28	18%
Donation would interfere with funeral arrangements	27	18%
I am concerned corneas are being bought and sold on the black market	21	14%
I do not trust the system of corneal donation in Australia	19	12%
Other reasons	18	12%
I don't want to give up such an important part of my physical appearance	17	11%
Corneal donation is against my religious beliefs	16	10%
There is no guarantee that corneal transplants are successful	16	10%
Corneal transplants are sight saving, but not life saving	10	7%
I don't want to donate my eyes in case I need them in the afterlife	10	7%
I have a medical condition unrelated to my eyes that means that I can		3%
not donate		
I have had laser surgery to improve my eyesight without glasses		3%
I have had other laser treatment or surgery to my eyes/retinas		1%
I am too old to donate my corneas		1%

Table 5: Respondent demographics

Table 5. Respondent	n
Λαο	
Age <= 19	12 /40/\
_	13 (4%)
20-30	159 (44%)
31-40	100 (28%)
41-50	45 (12%)
51-60	37 (10%)
61-70	6 (2%)
71+	3 (1%)
Religion	
Christianity	181 (50%)
Judaism	2 (1%)
Islam	16 (4%)
Hindu	20 (6%)
Buddhism	21 (6%)
None	99 (28%)
Other	21 (6%)
Education	
< Year 12	33 (9%)
Year 12	61 (17%)
Diploma	53 (15%)
Bachelor	123 (34%)
Postgrad	93 (26%)
Income (\$)	
<20,000	25 (7%)
20,001-40,000	61 (17%)
40,001-80,000	163 (46%)
80,001-120,000	69 (19%)
>120,000	39 (11%)
Sex	······································
Female	140 (39%)
Male	223 (61%)
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