

EXTENDED REPORT

Consent for corneal donation: the effect of age of the deceased, registered intent and which family member is asked about donation

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Aim: To determine whether consent to corneal donation is related to which next of kin is asked to consent, the age of the potential donor and the indication about donation made by the deceased on their driving licence.

Method: The Lions New South Wales Eye Bank (Sydney, New South Wales, Australia) provides the corneal transplantation service for Australia's most populous state. Over the 18-month period from 1 July 2004 to 31 December 2005 for all requests for donation, records were kept of which next of kin was asked for consent, the age of the deceased and the indication about donation by the deceased on their driving licence.

Results: Over the 18-month study period, 841 people were approached about corneal donation. 63.2% of those people approached gave their consent to donation. Increasing age of the deceased was significantly positively associated with consent to donation ($p=0.006$). Multivariable univariate analysis adjusting for age of deceased showed that relative type was strongly associated with consent ($p<0.001$), with mothers and fathers more likely to donate than siblings, and siblings more likely to donate than children and spouses. An indication of willingness to donate on a driving licence was strongly associated with consent ($p<0.001$).

Conclusions: Higher consent rates from older donors have implications for policies to maximise corneal procurement. The decision to donate on behalf of a deceased family member is complex and influenced by social context. Research should investigate individualised strategies to be used when seeking consent from particular categories of next of kin.

The first transplant of living human tissue was a cornea in 1905, and now >1000 corneal transplants are carried out annually in Australia, >2400 in the UK, and >30 000 in the US. In most countries, the number of corneas available does not meet the demand. The relative influence of various factors affecting this mismatch have been debated;^{1,2} however, the rate of families refusing to donate is significant.

There is evidence that consent to corneal donation is lower than that for other organs; a US retrospective chart review of over 10 000 patient deaths identified that 46.5% of those families approached for donation consented to organ donation and only 23.5% consented to corneal donation.³ Australian data indicate a similar trend, with 28.6% of families who consent to multi-organ donation specifically refusing to donate corneas.⁴

Rates of consent to corneal only donation by a face-to-face approach have been reported to be between 41.5% and 71.5%;⁵⁻⁷ however, many Eye Banks now use telephone consent, at least in part. Evidence shows that this telephone consent leads to a lower rate of consent; one study including a single requester showed a consent rate of 81.6% for requests made in person, but a consent rate of 55.2% for requests made by telephone. Despite the lower consent rate, total corneal procurement was greater using both in person and telephone consent, as this allowed the total number of families approached to be greater.

Most research of factors that are associated with donation has occurred in the context of multi-organ donation. Factors associated with the decision to consent to organ donation include families of deceased people who are young, male and white, or these who died by trauma,^{3,8,9} and families who knew that the deceased wanted to donate.^{6,8-10} There is some

evidence that consent is higher when the family respondent is older⁸ and when the deceased is younger.^{8,9,11} In the area of corneal donation it has been suggested that consent may be influenced by which next of kin is asked about donation; however, the relatively small sample sizes have not shown significance.^{5,12}

AIM

To determine whether consent to corneal donation is related to which next of kin is asked to consent, the age of the potential donor and the indication about donation made by the deceased on their driving licence.

METHOD

The Lions New South Wales Eye Bank provides the corneal transplantation service for Australia's most populous state, New South Wales (NSW). Potential donors are assessed for medical suitability, and, if appropriate, consent is requested from the senior next of kin of the deceased. NSW state legislation requires either written consent or taped telephone consent from the senior next of kin of the deceased. The senior next of kin is determined by state legislation; the order of seniority is a spouse (including a de facto partner), a child >18 years of age, a parent and finally a sibling >18 years of age. Eye Bank staff identify the appropriate next of kin by systematically working down through this hierarchy.

This study reviews all requests that were made for consent to corneal donation for the 18 months from 1 July 2004 to 31 December 2005. In most instances, consent was obtained by

Abbreviation: NSW, New South Wales

Eye Bank staff through telephone interview; however, in some cases consent was obtained in person by multi-organ donation staff or hospital-based staff. In each instance, consent included requesting whole eye donation for the purpose of corneal transplantation. The factors analysed for their relationship to consent to donation were prospectively selected: which next of kin was asked for consent, the age of the deceased and the indication about donation on the driving licence of the deceased. This information was recorded on a standard form for each individual approached.

Possible responses for which next of kin was asked for consent were son, daughter, brother, sister, husband, wife, father or mother. In 15 approaches for consent, the donation coordinator thought that they had spent considerable time in discussion with both the mother and the father of the deceased, and in these cases the next of kin was recorded as "parents".

Possible responses for indication on the driving licence were "yes" or "no" to donation, indication "not stated", "no driver's licence" or licence database "not checked". "Not checked" most commonly represented situations where the Eye Bank was not involved in seeking consent; either the families raised the issue of donation themselves or the hospitals or the multi-organ donor agency notified the Eye Bank once consent had been obtained. There is no upper age limit for potential donors to the Eye Bank, but donors <2 years of age are not accepted.

Univariate associations were summarised using odds ratios and 95% confidence intervals (CI) constructed from cross-tabulations. Multivariate logistic regression was used to adjust for the confounding effects of any inter-related variables, using a backward elimination approach.

This study investigates relationships with consent within the operational framework of the Eye Bank. As such, the consent rate determined is likely to be an overestimate; consent may not be requested if a family is perceived to be negative towards donation, or if the deceased had a formal stated wish not to donate.

RESULTS

During the study period, 841 consecutive approaches were made to individuals about corneal donation. Four records in which next of kin was not recorded were removed as the deceased consented to donation of their own corneas before their death. Of the 837 eligible records, 529 had given consent for donation, an overall consent rate of 63.2%.

Table 1 represents the univariate results. Female relatives tended to have higher consent rates than male relatives. In the 15 instances where the next of kin was recorded as "parents", the rate of consent was much lower than that of either mothers or fathers alone. Potential donors whose driving licence indicated "yes" to corneal donation had a much higher consent rate than those whose intention was "not stated" or had "no driver's licence". There was no clear pattern of consent by age of the deceased. Of the 303 records whose driving licence stated "yes" to corneal donation, 46 (15.2%) were overridden by their next of kin.

Table 2 presents the results of the multivariate analysis. The groups of "no driver's licence" and licence intention "not stated" were not significantly different ($\chi^2 = 0.01$, $p = 0.9$) and were therefore combined into "no intention" for simplicity. Next of kin was simplified into sex (male or female) and type (spouse, child, parent or sibling of the next of kin). It was not possible to assign a sex for the 15 requests where both parents were identified as the primary decision maker.

The rates of donation by next-of-kin type were not modified by the sex of next of kin ($\chi^2 = 4.10$, $p = 0.3$), indicating that the simplification into sex and next of kin

Table 1 Univariate predictors of donation (n = 837)

	Refused donation, n (%)	Consented to donation, n (%)	Odds ratio (95% CI)
Relative			
Husband	80 (45.2)	97 (54.8)	
Wife	114 (36.8)	196 (63.2)	1.4 (1.0 to 2.1)
Son	40 (41.2)	57 (58.8)	1.2 (0.7 to 1.9)
Daughter	43 (33.6)	85 (66.4)	1.6 (1.0 to 2.6)
Father	6 (17.1)	29 (82.9)	4.0 (1.6 to 10.1)
Mother	2 (6.1)	31 (93.9)	12.8 (3.0 to 55.0)
Both parents	13 (86.7)	2 (13.3)	0.1 (0.03 to 0.6)
Brother	3 (15.0)	17 (85.0)	4.7 (1.3 to 16.5)
Sister	7 (31.8)	15 (68.2)	1.8 (0.7 to 4.5)
Intent recorded on NSW licence (excluding one response of refused)			
Not stated*	148 (59.2)	102 (40.8)	—
No licence	73 (59.8)	49 (40.2)	1.0 (0.6 to 1.5)
Not checked	41 (25.5)	120 (74.5)	4.2 (2.7 to 6.6)
Yes	46 (15.2)	257 (84.8)	8.1 (5.4 to 12.1)
Age of deceased (one missing observation)			
<30*	20 (37.7)	33 (62.3)	—
30–39	12 (33.3)	24 (66.7)	1.2 (0.5 to 2.9)
40–49	31 (38.8)	49 (61.3)	1.0 (0.5 to 2.0)
50–59	59 (34.3)	113 (65.7)	1.2 (0.6 to 2.2)
60–69	78 (42.4)	106 (57.6)	0.8 (0.4 to 1.5)
70–79	88 (38.6)	140 (61.4)	1.0 (0.5 to 1.8)
≥80	19 (22.9)	64 (77.1)	2.0 (1.0 to 4.3)

*Referent category.

After excluding four observations with relative type = deceased.

Table 2 Multivariate predictors of donation (n = 835)

	Adjusted odds ratio (95% CI)	Overall test statistic, p value
Relative type		
Spouse (n = 486)*	—	$\chi^2 = 45.29$, $p < 0.001$
Child (n = 225)	1.3 (0.8 to 1.9)	
Mother or father (n = 67)	11.8 (3.8 to 36.2)	
Both parents (n = 15)	0.3 (0.04 to 1.6)	
Sibling (n = 42)	2.6 (1.2 to 5.9)	
NSW licence		
No intention (n = 372)*	—	$\chi^2 = 161.48$, $p < 0.001$
Not checked (n = 160)	5.3 (3.4 to 8.3)	
Yes (n = 303)	9.5 (6.4 to 14.3)	
Age of deceased		
<30 (n = 52)*	—	$\chi^2 = 18.31$, $p = 0.006$
30–39 (n = 36)	1.5 (0.4 to 5.3)	
40–49 (n = 80)	2.0 (0.6 to 6.9)	
50–59 (n = 172)	3.6 (1.1 to 12.0)	
60–69 (n = 184)	3.1 (0.9 to 10.4)	
70–79 (n = 228)	4.4 (1.3 to 15.0)	
80 or more (n = 83)	7.5 (2.0 to 28.0)	

*Referent category.

After excluding four observations where the deceased consented to donation before death, one observation where the deceased had refused donation on their licence, and one observation where data on age were missing.

type was valid. Sex was not significantly associated with consent after adjusting for next of kin type, intention recorded on the driving licence and the age of the deceased ($\chi^2 = 2.11$, $p = 0.1$) and was not included from the multivariate model. Next of kin type ($\chi^2 = 45.29$, $p < 0.001$), intention recorded on the driving licence ($\chi^2 = 161.48$, $p < 0.001$) and the age of the deceased ($\chi^2 = 18.31$, $p = 0.006$) were all highly significantly associated with donation in the multivariable analysis (table 2).

After adjustment for intention as recorded on the driving licence and the age of the deceased, the rate of consent for children was similar to that of spouses, whereas siblings or a mother or a father were more likely to donate than spouses. Approaches that included both parents were much less likely to result in donation. Potential donors whose licence indicated willingness were considerably more likely to donate than those for whom intention was not stated, as were those whose licence intention was not checked. Rates of consent increased as the age of the deceased increased, after adjustment for next of kin type and intention recorded on driving licence.

DISCUSSION

Published consent rates to corneal donation vary depending on the method by which they are determined. Although the consent rate of 63% within this study is consistent with previously published data, as previously indicated, this is likely to be an overestimate. The Lions NSW Eye Bank routinely checks the indication about donation on the driving licence of all potential donors, and does not investigate further whether the deceased had indicated that he or she did not want to become a corneal donor. During the study period 8% of referrals were not investigated further, as the deceased had refused corneal donation on his or her licence.

The decision not to investigate potential donors who had refused donation on their licence can be justified on the grounds that it respects the wishes of the deceased and that it ensures efficient use of limited Eye Bank resources. It has been shown that 95.5% of families will refuse donation if the deceased had explicitly stated he or she did not want to donate.⁸ The issue of family refusal for organ donation when the deceased had indicated a wish to become an organ donor has been discussed in the context of potential policy responses.⁸⁻¹¹ In our series, 36.2% of people indicated on their driving licence that they wished to become corneal donors, and in 15.2% of these instances the next of kin overrode this indication and refused donation. This rate of override is higher than the equivalent rate determined for organ donation, at 10.2%.⁸

This study shows an overall increasing trend towards consent with an increase in the age of the deceased; potential donors >80 years of age were much more likely to have given consent for donation than potential donors <30 years. Whereas non-randomised retrospective studies have shown that the endothelial count of corneas from older donors is lower,¹³ and that for particular indications of graft survival may be worse,¹⁴ there is also evidence that cell counts at the end of storage in organ culture are not considerably different from those of younger donors.¹⁵ The considerably higher rate of consent must be balanced with the findings from prospective randomised trials of corneal quality from older donors that are currently under way.

This study also shows that the relationship with the deceased of the person asked for consent to donation is an independent predictor of consent. After adjustment for all other factors, mothers or fathers were more likely to donate than siblings, and siblings were more likely to donate than children and spouses. To our knowledge, this is a new association in the literature. We believe this is important as it is strong evidence that attitudes and feelings about corneal donation are at least partly determined by social

relationships. In the 15 instances when the person requesting consent thought that both parents were equally involved in the discussion of donation, consent was considerably lower. It is difficult to draw conclusions from this incidental finding, although it may suggest that consent rates are lower in situations of shared decision making.

One limitation of this study was that demographic information was not collected from people who refused corneal donation. We were therefore unable to assess the influence of ethnic background or family income on the decision of whether to donate.

CONCLUSIONS

When considering efficient procurement strategies, Eye Banks and Organ Procurement Organisations should account for the observation that consent to corneal donation is markedly higher for older potential donors. Consent to corneal donation also appears to be at least partly influenced by the social relationship between family members. Further research should investigate reasons underlying the different consent rates between family members, thereby allowing specific strategies to be considered that may overcome any barriers to consent and maximise the number of corneas available for transplantation.

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