

## Testing knowledge of eye donation: a survey of intensive care nurses

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### ABSTRACT

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**Introduction:** Corneal transplantation is a sight restoring procedure that enhances the recipient's quality of life. Most deceased patients in Intensive Care Units (ICU) are potential eye donors, but the number of referrals from this group remains low. Understanding how nurses view eye donation and identifying their educational needs is vital in order to increase donation rates while offering choice to patients and families.

**Purpose:** To assess nurses' knowledge about the identification and referral of potential eye donors.

**Materials and methods:** An online, 18-item, questionnaire survey assessing the knowledge, training and views towards eye donation was emailed to 100 ICU nurses working in a tertiary NHS Trust. Fifty-eight percent (n=58/100) of nurses completed the questionnaire.

**Results:** The majority of nurses (n=50/58) could not identify the medical contraindications to eye donation, just one was aware of the referral process

and only two reported that they received previous training on eye donation. Overall, participants were in agreement that corneal transplants improve the recipients' quality of life (n= 50/58) and that offering eye donation should be considered as part of end-of-life care (n=43/58). However, only seven felt confident raising the subject with relatives.

**Conclusion:** ICU nurses play a pivotal role identifying and discussing the potential for donation. However, the results of this survey showed that the majority of responding nurses lacked knowledge, training and confidence to effectively undertake this role. Therefore there is a need for educational programmes that focus on eye donation and communication skills to be able to offer the choice to patients and families. There is also a scope for research to evaluate the efficacy of educational programmes and their impact on donation rates.

**Key words:** Corneal donation, tissue donation, attitudes, views, knowledge, intensive care, nurses

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## **INTRODUCTION**

The aim of this survey was to assess the ICU nurses' knowledge and views towards eye donation. The objectives of the project were to evaluate nurses' understanding about the identification and referral of potential eye donors as well as explore their perceptions towards eye donation.

Corneal transplantation is a sight restoring procedure that enhances the recipient's quality of life [1]. Among all transplantable human tissues, corneas have the largest potential donor pool as they are the only tissues that a patient with metastatic cancer can donate [2]. Corneas can be retrieved up to 24 hours after death, and therefore their potential for transplantation is greater than that of solid organs [1]. Each year more than 3500 people in the UK [1] benefit from corneal transplantation. Despite this, there is a shortage of corneas [3].

While requests for organ donation are an established practice in intensive care units (ICUs), tissue donation is less commonly considered [4]. A baseline audit conducted previously showed that 25 out of 36 eligible eye donors were not considered for donation [5]. Although 59% of the population are in favour of donation [6], not all inpatients and relatives know about the opportunity to donate and may not raise the subject [7]. Failure by healthcare professionals to offer this option denies patients and families their option to donate [8] and it is an important barrier to corneal procurement [9].

Nurses looking after patients towards the end of their lives are ideally placed to identify potential donors and initiate discussions about donation [10]. However, nurses must be appropriately educated and trained in this area, as their contribution to the donation process might depend on their knowledge, experience and attitudes [10]. Understanding how nurses view eye donation and exploring how best to address their educational needs is paramount if the number of corneas available for transplants are to be maximised and the wishes of many individuals fulfilled.

Corneas can be retrieved from tissue-only donors or organ-tissue donors [1]. For tissue-only donors, local Trust policy advocates that nurses initiate discussions with eligible families and make the referral to the Eye Bank. Upon referral, tissue donation coordinators (TDCs) from the Eye Bank assess the patient's suitability for donation [11]. In the absence of both medical contraindications and coronial objection, the TDC contacts the family to discuss the option of donation [1]. The Human Tissue Act (HTA) [12], states that legal consent needs to be obtained for the retrieval, storage and transplantation of human tissue. If the deceased had expressed the wish to donate, via the Organ Donor Register (ODR) or written will, this consent should not be disrespected except in extraordinary

circumstances [12]. When the wishes of the deceased are unknown, consent might be sought from the next of kin [12].

Despite the high number of potential corneal donors and the prime position of ICU nurses facilitating donation, there is limited literature regarding nurses' practice in this area. One of the main reasons behind the deficit of corneas is the high refusal rate [3]. Corneal donation does not seem to have the same level of support as organ donation amongst the public. In the UK, 10.6% of the 20.2 million of people registered on the ODR are unwilling to donate their corneas [13]. In the UK, the main reasons given by people, who object to eye donation, are based on concerns of mutilation and personal significance of the eyes [14]. Lawlor and Kerridge [3] explain that unlike solid organs, eyes are external and visible and that this might explain the fears of disfiguration by people when imagining their absence.

In addition to low consent rates, large-scale audits demonstrate that the potential for donation remains significantly under-exploited mainly due to lack of identification and referral of potential donors [15,16]. A cohort study conducted in three Dutch hospitals found that, despite the absence of medical contraindications, physicians failed to identify 25% (n=123/484) of eligible tissue donors [16]. Education and reminders in documentation have been suggested to maximise the number of referrals [17]. Local Eye Banks also advise health care practitioners to refer all deceased inpatients irrespective of their potential for donation [11]. This is thought to decrease the number of missed potentials as a result of an incorrect assessment by healthcare staff, who may be unfamiliar with the donor suitability criteria [18].

Offering the option of organ and tissue donation should be an integrated part of end-of-life care [19]. ICU patients are often unable to be involved in end-of-life care decisions, therefore, the role of ICU nurses is to provide an informed choice about donation and empower families to make a decision based on what the deceased would have wanted [4].

Approaching patients and families for donation has been reported by ICU nurses as one of the most stressful tasks for which they received little training [20]. The European Hospital Education Program (EDHEP) is one of the most successful training initiatives addressing the educational needs and communication skills of critical care staff on how to approach families for donation consent [21]. After the implementation of EDHEP, several countries have reported increased donation rates [22].

An international survey of almost 20 thousand critical care professionals from 11 countries found a strong positive correlation between the levels of education, attitudes and confidence in

the organ and tissue donation process and optimal rates of donation [15]. From the reported interventions designed to increase donation rates, behavioural change through the provision of instruction is the most used [23]. Practical and theoretical instruction can be delivered in the form of seminars, workshops, meetings, conferences, simulation presentations and written documents. A systematic review assessing the efficacy of interventions aimed at health professionals to maximise organ and tissue donation concluded that the efficacy of the available educational programmes had not been rigorously evaluated [23]. In the systematic review, none of the 15 evaluated studies selected a randomized sample or justified their sample size. In addition, the validity and reliability of the assessment methods were not specified.

An English survey exploring the barriers to corneal donation found that, despite positive views, less than 10% of the hospice staff routinely discussed eye donation with their patients and relatives [9]. The main reasons for not initiating these discussions included lack of education, fear to add distress to patients and families and concerns of disfigurement. The authors suggest further training, policy development, reminders in documentation and informative leaflets [9]. The use of informative leaflets is advocated as an impersonal vehicle to inform families about eye donation [24]. However, leaflets are more effective when used to complement, rather than replace, face-to-face discussions [24]. Reluctance of health professionals to initiate donation discussions as a way to protect patients and families from further distress has been reported by many studies [8,9]. Whether donation has an impact on the grieving process is contentious. Whilst some studies suggest that donation has a positive impact on the grief [25], others conclude that the bereavement process remains unchanged by donation [26]. Nonetheless, it is widely agreed that the majority of families consenting to donation view this as a positive outcome and that some individuals would have felt offended if they had not been given this option [26].

## **MATERIALS AND METHODS**

Data was collected from December 2014 to February 2015. The online questionnaire designed for this project was distributed to 100 nurses in a neurosurgical 18-bedded adult ICU in a large NHS transplant centre in South England, using the tool 'Survey Monkey' ([www.surveymonkey.com](http://www.surveymonkey.com)). To assess its internal validity, the questionnaire was piloted by 10 nurses and reviewed by the Trust Clinical Lead in Organ Donation. The final 18-item questionnaire contained 8 multiple-choice questions with fixed answer, 1 dichotomous item, 9 attitudinal statements using 5-item Likert scales and 1 open-ended question. Likert scales rated from strongly

agree to strongly disagree and included a neutral point. The questionnaire can be found in Appendix 1.

### **Sample**

A purposive sample of all (n=100) nurses working in this particular ICU were invited to participate in the study. This unit was selected due to its large number of potential organ and tissue donors. Nurses in this study ranged from 21 to more than 50 years of age, with 40 (70%) participants falling into the 21-30 age group. Of the respondents, 33 % (n=19) had worked in ICU for less than a year, 22% (n=13) for 1-2 years, 10% (n=6) for 2-3 years and 34% (n=20) for more than 3 years.

### **Ethical considerations**

Permission to conduct this study was obtained from the ICU Lead in Research and Development, on behalf of the Ethical Committee. Participants were informed that participation in this study was voluntary and that consent was implied by completing the questionnaire. The questionnaire included a cover letter explaining the aim of the study and the participants' rights. The participants' anonymity and confidentiality was respected as the questionnaire did not ask for any personal data that could reveal the participant's identity.

## **RESULTS**

Fifty-eight of the 100 questionnaires were completed, giving a response rate of 58%. With the assistance of 'Survey Monkey', dichotomous, nominal and ordinal data were analysed as means of numbers and percentage values. Grouping of positive statements (strongly agree and agree) and negative statements (strongly disagree and disagree) were made to facilitate the presentation of the results. Qualitative data from the participants' comments were analysed for emerging themes and grouped accordingly. Some of the nurses' comments were presented in script forms with appropriate quotations. Emerging themes are listed below:

### **Knowledge and training**

Of the 58 participants, only two had received some formal training over a year ago. Although 36 nurses correctly stated that all deceased inpatients should be considered for eye donation, only 1 knew how to make the referral to the Eye Bank. With regards to eligibility criteria, just 12 respondents rightly selected 90 as the age limit for eye donation and only 8 were able to identify the true medical contraindications to eye donation. Only 4 knew that eyes can be retrieved up to 24 hours post-mortem. Of the 14 nurses, who provided qualitative responses, 6 stated that their knowledge about eye donation was poor and 7 expressed their wish to

receive more information and regular training in regard to this topic:

Participant 7: *‘‘I have very poor knowledge in this area. Therefore I don’t have evidence base for any of these answers’’.*

Participant 10: *‘‘I have never had training about eye donation before and I know very little about it... It would be useful to know if patients who are unsuitable for organ donation are able to donate their eyes’’.*

Participant 18: *‘‘I do not know much about eye donation in particular... Training is needed for staff*

*members to provide accurate information to promote this’’.*

### Willingness

Of the 58 respondents, 37 (64%) strongly agreed/agreed with the statement ‘I would be happy to donate my eyes after death’ and 15 (26%) strongly disagreed/disagreed. Of the 58 participants, feeling ‘squeamish’ or uncomfortable with eye donation was reported by 17 (29%) who strongly agreed/agreed. Table 1 shows that the majority of the sample held positive views towards eye donation. However, only 7 (12%) participants felt confident to refer a potential eye donor.

**Table 1.** Positive statements towards eye donation

Statement	Strongly Agree/Agree	Strongly disagree/disagree	Neither Agree or Disagree
<b>Having a corneal transplant greatly improves the recipient’s quality of life</b>	n=50 (86%)	0	n=8 (14%)
<b>Ocular tissue donors set a good example for others to follow</b>	n=42 (72%)	n=1 (2%)	n=15 (26%)
<b>Offering families the option of eye donation should be an usual part of end-of-life care</b>	n=43 (74%)	n=2 (4%)	n=13 (22%)
<b>I feel confident referring a potential eye donor</b>	n=7 (12%)	n=38 (66%)	n=13 (22%)

Positive views towards donation were also reported by some participants:

Participant 18: *‘‘. I do believe strongly in organ donation...’’*

Participant 43: *‘‘...I am supportive of it...’’*

Participant 50: *‘‘My dad received a corneal graft, which greatly improved his quality of life!’’.*

Participants were more evenly divided in their answers to the statements presented in Table 2.

**Table 2.** Negative statements towards eye donation

Statement	Strongly Agree/Agree	Strongly disagree/disagree	Neither Agree or Disagree
<b>Offering the option of eye donation can add distress to the already grieving families</b>	n=13 (22%)	n=19 (33%)	n=26 (45%)
<b>Eye retrieval badly affects the appearance of the deceased</b>	n=10 (18%)	N=27 (46%)	n=21 (36%)
<b>I rarely have the time to refer a patient for eye donation</b>	n=9 (16%)	n=24 (41%)	n=25 (43%)

## DISCUSSION

The authors believe this is the first study assessing the knowledge and views of ICU nurses towards corneal donation and supports the findings of previous studies conducted in ICU that focus on organ and tissue donation. The results of this survey highlight that the majority of nurses had a limited knowledge regarding donor suitability criteria and referral process. The perceived lack of knowledge was reported by some participants, suggesting the

need for training. It was also revealed that only a minority of nurses felt confident approaching eligible families for donation. Due to the lack of training received by nurses with regards to eye donation, these results are not surprising and might explain the failure to identify and discuss the potential for donation. Many studies have shown that ICU nurses [27] and other healthcare professionals have a limited knowledge about donor suitability criteria, and this has been linked with a failure to identify potential donors [16]. Educating nurses and other healthcare professionals about the donor suitability criteria and highlighting their role in

approaching families for donation have led to increased donation rates [28]. There is evidence that healthcare professionals with appropriate levels of education are more confident in approaching families and are more likely to be involved in the donation process [15]. In a Scottish service evaluation, nurses attended a two-day workshop focusing on the communication skills around consent request. Post-training, the number of families approached for corneal donation increased from 0 to 77% in one of the units [18].

Lawlor and Kerridge [29] suggest that healthcare professionals, who object to corneal donation, are more reluctant to approach families with this option. Healthcare professionals have been shown to share the same concerns as the public in relation to eye donation [29]. Some authors argue that an increased knowledge of eye donation and the retrieval process can dispel misunderstandings and myths often reported by nurses [4]. However, it is unclear whether educational programmes are effective in changing behaviours related to the personal significance of the eyes and whether other socio-cultural and religious factors also need to be considered [3].

The results from this survey support previous findings that most nurses recognise the positive impact of ocular tissue transplant on the recipient's quality of life and that offering the option of eye donation should be a part of end-of-life care. However, some of the respondents believed that eye donation could negatively affect the appearance of the deceased and that donation discussions could add distress to bereaved families. Increased knowledge and a culture that promotes donation might facilitate nurses to have better understanding and skills to offer choice to their patients and families [4].

### **Limitations**

The use of a purposive sample from a single ICU means that the results of this survey cannot be generalised to all ICU nurses and that ideally, a larger sample from a number of randomised institutions should have been selected. The use of a questionnaire as a data collection method might have forced the nurses' responses into preconceived categories; thus limiting the validity of the results. It should be acknowledged that the questionnaire did not include items assessing socio-cultural, religious and psychological factors that could also affect the actual behaviour of nurses relating eye donation.

### **Implications for practice**

Educational programmes that focus on eye donation might enhance the nurses' knowledge, views and confidence to be involved in the donation process and ultimately improve the donation rates [15]. Discussion groups, simulation training and clinical supervision could be helpful to dispel some myths and misunderstandings associated with eye donation and increase awareness of the tissue

donation process and local policies. A group of link nurses specially trained in eye donation could act as 'Champions' raising the culture of eye donation and establishing routine practice within the unit. Stronger links between nurses and the Eye bank need to be developed. A flowchart and reminders in documentation might help increasing the number of referrals. A culture that promotes donation is recommended to further improve the nurses' views [4]. Paternalistic approaches that fail to consider the patient's choice should be challenged [30]. It might be useful to consider including organ and tissue donation in the undergraduate nursing curricula.

### **Implications for future research**

A larger scale survey investigating the nurses' barriers towards eye donation in critical care settings is needed to gain better understanding of why donation is not offered to patients and families more often. There is also scope for future interventional studies evaluating the efficacy of educational interventions aimed at increasing the donation rates.

## **CONCLUSIONS**

Nearly all patients who die in ICU are potential eye donors, but the number of referrals from this group remains low. ICU nurses play a pivotal role identifying and discussing the potential for donation. However, the results of this survey showed that the majority of nurses lacked knowledge, training and confidence to effectively undertake this role. These results support the findings of previous research conducted in hospice settings, emergency departments and general wards. There is a need for educational programmes that focus on eye donation and communication skills needed to offer the choice to patients and families. Adequate levels of education and training among nurses have been associated with positive attitudes and predisposition to be involved in the donation process [15]. However, further research evidence is needed to evaluate the efficacy of educational programmes aimed to increase the donation rates.

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### **Conflicts of interest**

The first author has an honorary contract in the hospital where this survey was conducted. The

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## APPENDIX 1: QUESTIONNAIRE

### Nurses' knowledge and views towards eye donation

We are conducting this baseline survey to assess your knowledge and views towards eye donation. Your participation would help us identifying any educational gaps or areas in practice that would need to be improved. The questions are not perfect but we want you to give your most honest answer. The questionnaire is entirely anonymous and voluntary. Consent will be assumed if you complete this questionnaire

#### 1. Age group

- 21-30                       31-40                       41-50                       >50

#### 2. How long have you been working as a qualified nurse in ICU?

- <1 year                       1-2 years                       2-3 years                       >3 years

#### 3. Have you ever received any formal training with regards to eye donation?

- Yes                                       No

#### 4. If yes, how long ago?

- <6 months                       <1 year                       >1 year

#### 5. Which patients should be considered for eye donation?

- All hospital inpatients who have died  
 Only intubated patients who have died in ICU  
 I do not know

#### 6. How can I refer a deceased patient for eye donation?

- Page the SN-OD  
 Call/fax the referral form to the Eye Bank or Tissue Services  
 Contact/fax the referral form to the bereavement office  
 I do not know

#### 7. Please select any contraindication/s to eye donation

- Cancer  
 Sepsis  
 Hepatitis B  
 All the above  
 None of the above  
 I do not know



## Nurses' knowledge and views towards eye donation

### 8. For how long after death can eyes be retrieved for transplantation?

- 4 hours       72 hours       24 hours       I do not know

### 9. What is the age limit for eye donation?

- 75 years       85 years       90 years       I do not know

### 10. Do you feel comfortable initiating discussions about corneal donation with bereaved families?

- Yes       No

### 11. To what extent do you agree with the following statements?

#### Having ocular tissue transplant improves the recipient's quality of life

- Strongly agree       Agree       Neither agree or disagree       Disagree       Strongly disagree

#### 12. Offering the option of eye donation can add distress to grieving families

- Strongly agree       Agree       Neither agree or disagree       Disagree       Strongly disagree

#### 13. Offering families the option of eye donation should be an usual part of end of life care

- Strongly agree       Agree       Neither agree or disagree       Disagree       Strongly disagree

#### 14. Eye retrieval negatively affects the appearance of the deceased

- Strongly agree       Agree       Neither agree or disagree       Disagree       Strongly disagree

#### 15. Ocular tissue donors set a good example to others to follow

- Strongly agree       Agree       Disagree       Strongly disagree       Neither agree or disagree

#### 16. I feel 'squeamish' or uncomfortable about eye donation

- Strongly agree       Agree       Neither agree or disagree       Disagree       Strongly disagree

#### 17. I would be happy to donate my eyes after death

- Strongly agree       Agree       Disagree       Strongly disagree       Neither agree or disagree

#### 18. Please use the space provided below to add any further comments