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# Eye donation in Palliative and Hospice care settings: patient views and missed opportunities!

*Findings from the Eye Donation from Palliative and Hospice care contexts: investigating Potential, Practice, Preference and Perceptions (EDiPPPP) study !*

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# The EDiPPPP Project

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Project Homepage

[https://www.southampton.ac.uk/healthsciences/research/projects/e  
dipppp.page](https://www.southampton.ac.uk/healthsciences/research/projects/e<br/>dipppp.page)



# Study objectives and methods

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## **Work Package 1** (*Potential and Practice*)

**Obj1)** *Scope the size and clinical characteristics of the potential eye donation (ED) population across palliative and hospice care settings*

**(Retrospective note review)**

**Obj2)** *Identify factors (attitudinal, contextual) that enable or challenge service providers (HCPs) to consider and propose the option of ED as part of EOLC planning from a local and national perspective.*

**(National survey and interviews)**

## **Work Package 2** (*Practice, preference, perceptions*)

**Obj3)** *Identify what service users' (Patients and Carers) think about the option of ED and the propriety (acceptability) of discussing eye donation as part of EOLC planning conversations.*

**(Interviews)**

## **Work Package 3** (*Intervention design*)

**Obj4)** *Develop, pilot, and evaluate an empirically based and theoretically informed intervention aimed at facilitating ED in SPSS/HPS settings (TEC, Pilot study)*



# Further evidence

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Original Article



## A qualitative study using semi-structured interviews of palliative care patients' views on corneal donation and the timing of its discussion

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Lucy Walker<sup>1</sup>, Karen Neoh<sup>2</sup> , Hazel Gilkes<sup>3</sup>   
and Clare Rayment<sup>4</sup>

### Abstract

**Background:** Corneal transplantation can lead to sight restoration, but globally there is a donor shortage. Many palliative care patients can donate their corneas but think they are ineligible due to comorbidities. Healthcare professionals are reluctant to breach the topic, but studies have shown that relatives would be upset if they were not offered this chance. There is no existing research involving patients.

**Aim:** To understand the views and feelings of patients in palliative care settings towards corneal donation and explore their opinions regarding the timing of its discussion.

**Design:** This is an exploratory study based at one UK palliative care unit. A census sampling method was used. Nine participants took part in semi-structured interviews and thematic analysis was undertaken.

**Results:** Themes found included altruistic motivation and the value of sight. Family views were important, but the influence on final decisions varied. The timing of discussion relative to the illness trajectory was important; patients want to be able to engage fully in

discussions about corneal donation. Participants also associated discussion of corneal donation with a close rapport.

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Original Article



## Obstacles to corneal donation amongst hospice inpatients: A questionnaire survey of multi-disciplinary team member's attitudes, knowledge, practice and experience

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### Abstract

**Background:** Corneal donation is a sight restoring procedure. Internationally demand exceeds supply. It is a tissue that palliative care patients may be able to donate, yet donation rates from this group are low.

**Aim:** To explore the attitudes, knowledge, practice, and experience of corneal donation from hospice staff with direct clinical contact with patients.

**Design:** Anonymous paper questionnaire with fixed response and free text components.

**Setting/participants:** Questionnaires were delivered to 704 clinical multi-disciplinary team members in 12 hospices within the Yorkshire Palliative Medicine Regional Learning Group, UK.

**Results:** 494 completed questionnaires were received. Most respondents believed that corneal donation is a rewarding opportunity of which patients and families should be aware, but over 90% of respondents rarely or never raised the topic, and only 33% felt that it was part of their role. Key reasons for not engaging in discussions were: concerns about the impact of the discussion on patients and families, a belief held by hospice staff that they lacked essential knowledge, negative experiences of corneal donation, concern about enucleation, a perception that donation is not part of hospice culture, low levels of training and the personal significance of eyes.

**Conclusions:** Despite positive staff attitudes towards corneal donation, many barriers to discussing donation were identified, which may reduce donation rates. This could be improved by local policies encompassing further education, prompts in documentation and availability of leaflets.

### Keywords

Corneal transplantation, hospice care, hospices, palliative care, tissue and organ procurement

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REVIEW

Open Access

## Barriers and Facilitators to Eye Donation in Hospice and Palliative Care Settings: A Scoping Review

Banyana Cecilia Madi-Segwagwe, PhD,<sup>\*\*\*</sup> Mike Bracher, PhD, Michelle Myall, PhD, and Tracy Long-Sutehall, PhD

### Abstract

**Background:** The need for eye tissue for use in sight saving and sight restoring surgery is a global issue. Approximately 53% of the world's population has no access to interventions such as corneal transplantation. Low levels of eye tissue impact on service providers such as National Health Service Blood and Transplant who aim to achieve a weekly stock of 350 eyes but do not meet this target.

**Aim:** Patients who die in hospice and palliative care settings could be potential donors; therefore the aim of this systematic scoping review was to identify the potential for eye donation and barriers toward it from these clinical contexts.

**Design:** A scoping review following the Joanna Briggs scoping review methodology was applied to search the global literature.

**Results:** 13 articles from the global literature were retrieved. Evidence indicate that 542 patients could potentially have donated their eyes. Key barriers to increasing eye donation include the reluctance of healthcare professionals to raise the option of eye donation and the evidenced lack of awareness of patients and family members about donation options and eligibility. This review also indicates a lack of clinical guidance drawn from high-quality evidence proposing interventions that could inform clinical practice and service development.

**Conclusion:** The scoping review presented here provides an up-to-date view of the current potential for, perceptions toward, and practice underpinning offering the option of eye donation to dying patients and their family members in hospice and palliative care context.

**Keywords:** end-of-life care; eye donation; palliative care; perception; practice; scoping review

## Corneal Donation within a hospice setting: hospice patients' experience of the routine discussion of corneal donation options on admission to the inpatient ward at St Nicholas Hospice Care.

Authors: Emma Tregenna and Sarah Mollart

Participants	Patients	Carers
<b>Gender</b>	<b>F = 21</b>	F = 17
	<b>M = 18</b>	M = 6
<b>Age</b>		
30-39	<b>1</b>	0
40-49	<b>2</b>	1
50-59	<b>9</b>	5
60-69	<b>11</b>	5
70-79	<b>6</b>	8
80-89	<b>5</b>	2
90+	<b>1</b>	0
MD	<b>4</b>	2
<b>Total</b>	<b>39</b>	23
<b>Ethnicity</b>		
(self selected)		
White British	<b>33</b>	21
Indian	<b>1</b>	
White and Asian	<b>1</b>	
MD	<b>4</b>	2

HCP participants	Strategic	Front line	Survey
Hospice	20	30	98
Palliative Care	18	37	58
<b>Total</b>	<b>38</b>	<b>67</b>	<b>156</b>



## Background

- **Global shortage of donated eye tissue** for sight saving and sight restoring operations (e.g. corneal transplantation) *(Madi-Segwagwe et al., 2021)*
- **Two Million people in UK** are living with some level of sight loss and this figure is predicted to increase to **Four Million by 2040** *(RNIB & Specsavers, 2016)*.
- **Majority** of patients with **Cancer** are **unable to donate Organs or Tissues** despite what their wishes about being a donor are or have been through their life.
- There is very **limited knowledge** about the **propriety of discussing ED** as part of End of Life care planning discussions or Advanced Care Plans from the patient perspective.



# Missed opportunities

● **Lack of identification of potential donors and low levels of approach regarding the option of ED (MO1)**

● **Lack of inclusion of discussions re Eye Donation in care planning discussions with patients (MO2)**

● **Lack of awareness raising, informatics for patient and carer access (MO)**

## Lack of identification and approach to ED in HC and SPCS (MO1)

- *Retrospective note review of 1200 deceased patients notes over past two years by CI's indicated that 46% (n = 553) patients met the eligibility criteria for ED.*
- *However only 14 patients and 13 family members were recorded to have been approached about the option of ED.*
- *Almost all HCPs interviewed and 48% of national survey HCP participants had **not been involved in a discussion with either patients or families in the past year.***





# Missed opportunities

Lack of identification of potential donors and low levels of approach regarding the option of ED (MO1)



Lack of inclusion of discussions re Eye Donation in care planning discussions with patients (MO2)



Lack of awareness raising, informatics for patient and carer access (MO3)



## Lack of inclusion of ED in care planning discussions with patients (MO2)

- *48% (n=63) of survey participants indicated that their service did not actively encourage the option of eye donation being discussed with patients and/or their family members*
- *76% (n=115) of total national survey participants reported that eye donation is not 'embedded' as a routine part of end of life care clinical practice'*
- *61% (n=23) of interview participants with front line roles and 83% (n=109) of survey participants indicated that eye donation conversations are not currently part of regular conversations (e.g. MDT meetings) within their service.*



# Why?

- *66% (n=99) of total participants rated Health care provider reluctance to discuss the option of eye donation due to concerns that they will cause distress as a key barrier to ED being integrated into usual care.*
- *Current literature supports this finding with evidence reporting that many HCPs believe that discussing ED would detract from the tranquil environment of a hospice and that donation requests could cause patients and their families physical and psychological harm (Madi-Segwagwe et al, 2021; Gillon et al., 2010; Walker et al., 2018).*



# But?

- *Majority of patients interviewed (94%) indicated that they were in favour of eye donation being raised with patients receiving EoLC*
- *Current evidence supports the view that patients and carers are not distressed by having these discussions (Madi-Segwagwe et al, 2021; Gillon et al., 2010; Walker et al., 2018; Mollart).*



## Who should raise the question of ED?

- *All but one patient indicated that HCPs (rather than patients or families) should raise the option of ED and not rely on the patient or family bringing this up.*

*“I think it is their [HCP] job, to inform you, put it down on paper what, if you want to donate, then, yes, if you don’t want to donate. It’s like when, when people are coming along and they’re saying do you want a DNR notice writing on that patient, it would be the same thing in my opinion”.*



## When should the topic of ED be raised?

- *97% (n=37) of patients interviewed indicated a preference for conversations to take place early in the EoLC pathway; with many (SPCS, 58%; HPC, 39%) identifying EoLC/ACP conversations as an appropriate point at which to raise the issue.*

*“I thought like the health profession that would be part of their job to inform, I know they inform patients of everything that’s going on, but for people like myself that are terminal, I’m not deluded, I know what’s coming, you know, although I haven’t got a time, I know what’s coming and I would prefer my nurse or somebody in that profession to approach me to ask me whether I want to donate or not, because then that could be written up on your paperwork without the doctor having to go and ask distressed family members at the time of when they need to go and ask the question. But I don’t, I don’t understand why they’re reluctant to bring it up ..... but in my opinion if that is part of their job then they should be raising the question”(P00603)*



## Who should decide about ED?

*91% (n=32) of patients interviewed indicated that patients should make the decision about becoming an eye donor, and that their views should take priority (as opposed to family) (SPCS – 81% (n=13 participants) and HPC – 100% (n=19)*

*“I think, it’s something that we really need to do and I don’t see there’s any point in just wasting things that we could use in research or use to give somebody else a better quality of life”  
(P00704)*



# Missed opportunities

Lack of identification of potential donors and low levels of approach regarding the option of ED

Lack of inclusion of discussions re Eye Donation in care planning discussions with patients

Lack of awareness raising, informatics for patient and carer access (MO3)





## Lack of awareness raising, information for patients and carer access (MO3)

- *94% (n=33) of 39 patients interviewed indicated that they were in favour of eye donation being raised with patients receiving EoLC*
- *95% (37 of 39) of patients interviewed were not aware that ED was a potential option and/or that ED had not been raised with them during their current care programme*

*“Absolutely not, nobody at all, up until N\* coming in yesterday to arrange this interview, nobody’s said a single word to me, no. And I’ve been, I’m not. I’m not very often in hospital, but when I’ve been in and obviously this time we are talking, I am heading towards the end, I’m not, I’ve not got five years left anymore, you know, so, but no, nothing has been said at all, maybe it’s not near enough the time yet, I don’t know how close do you need to get. I might have six months, you know, I don’t know” (P00803).*



## Conclusion

- There is a national and global shortage of donated eye tissue for use in sight saving and sight restoring operations such as corneal transplantation
- Patients who die in palliative and hospice care settings could potentially donate eye tissue.

### However:

- Potential donors are not identified!
- Potential donors are not approached!
- The option of eye donation is not routinely raised in end of life planning discussions!
- Awareness raising initiatives are lacking!



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