**Barriers and Facilitators to Eye Donation in Hospice and Palliative Care Settings – A scoping review**

Eye Donation in Hospice and Palliative Settings

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**Key words** – End of Life Care, Eye donation, Perception, Practice, Palliative Care, Scoping Review

## **Abstract:**

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. Patients who die in Hospice and Palliative care settings could be potential donors, therefore the potential for eye donation and barriers toward it from these clinical contexts needs to be established. A scoping review following the Joanna Briggs scoping review methodology retrieved thirteen papers from the global literature. Evidence from retrieved papers indicate that 542 patients could potentially have donated their eyes. Key barriers to increasing eye donation include: the reluctance of Health Care 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. 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.

## **Introduction**

The need for eye tissue is a global issue, Gain et al (2016)1 indicate that approximately 53% of the world’s population has no access to interventions such as corneal transplantation reporting that globally, only one cornea is available for the 70 that are needed. This data highlights an ongoing disparity in supply and demand for eye tissue in most countries worldwide. Furthermore, over two million people in the UK are living with sight loss which is predicted to increase to four million by 20502. Corneal blindness is the fourth leading cause of blindness worldwide with an estimated 80% of all cases being avoidable and reversible 3,4.

**Evidenced barriers to increasing eye donation**

International empirical data report that low levels of eye donation outside of Intensive Care Units and Emergency Departments 5-8is due to: negative attitudes toward eye donation held by Health Care Providers (HCPs) 9-13, negative public views regarding eye donation 14,15, and low levels of support on the Organ Donor Register (ODR) 16. Recent data indicates that 85% of registrants on the ODR indicated a willingness to donate all organs and tissues but of those who log a restriction, 68% decline eye donation 16. Furthermore, recent data from UK Hospice Care settings 17,18 identified that the majority of staff had rarely or never raised the topic of eye donation with patients or relatives as part of end of life care planning.

Low levels of eye tissue have a direct impact on service providers such as NHS BT who aims to achieve a weekly stock of 350 eyes for use in transplant and other sight saving surgery, but current stocks are approximately 150 eyes per week (personal communication with tissue services 04.12.2020). There is a need to achieve a sustained supply of eye tissue and as patients who die in palliative and hospice care settings could be potential eye donors, 2,19 this paper presents a scoping review of the global literature that specifically looks at the barriers and facilitators to achieving eye donation from these settings.

### **Review methodology**

This scoping review followed the Joanna Briggs Institute (JBI) framework for scoping review 20 (Table 1) and used the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist to illustrate selection of the final included papers (Figure 1) 21. Scoping review methodology was deemed appropriate to: identify the scope, coverage and type of research currently available on a topic, map the available evidence and generate a synthesis of the available knowledge 22-24.

**Review question and objectives**

*Review question*: What are the evidenced barriers and facilitators to eye donation in Hospice and Palliative care settings?

*Objective 1.* To systematically map the current international evidence base relating to eye donation in hospice and palliative care settings.

*Objective 2*. To identify the factors that are evidenced as informing or influencing the option of eye donation being discussed with service users in hospice and palliative care settings.

**Inclusion criteria**

The inclusion/exclusion criteria were developed in line with the JBI framework clarifying the Population (P) Concept (C) and clinical Context (C) (PCC), type of evidence sought, and other limiters within which the search was bounded (Table 2).

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### **Evidence searching and selection**

An initial search was undertaken in the PubMed database using the terms 'Eye[MeSH] AND Tissue Donation[MeSH](Table 3)'. The search was limited to papers published during or after the establishment of the UK Corneal Transplant service 25 . However, the resulting 190 articles did not include several key articles known to the review team. Therefore, 23 papers (the development set) known to the review team and verified against the inclusion criteria were compiled and checked for indexing in PubMed. Results showed that only five (28%) could be retrieved in PubMed*.* Seventeen of the 18 excluded papers were not indexed under the term ‘Eye[MeSH] despite six of them having eye related terms in the title and/or abstract. MeSH or equivalent database-specific terms were dropped for further searchers. Screening of title, abstract and full paper of the 190 papers from the initial search resulted in 70 papers being added to the developmental set of 23 papers previously identified, producing a test set n=93 records. Finally, a two-stage process aiming to maximise the sensitivity of the search strategy and minimise the number of irrelevant records (specificity) was implemented 26. Stage one applying search terms – “(eye OR cornea\*) AND (donat\* OR donor\*)” returned 10313 records (retrieving 85 (91.4%) of the test set). Stage two involved iterative, stepwise identification and testing of exclusion terms (specified by the Boolean term ‘NOT’) to exclude irrelevant records whilst maintaining the 91.4% level of sensitivity. The team used the PubMed PubReminer tool 27 to identify potential exclusion terms (PubMed PubReminer allows users to see frequency tables of occurrences of relevant terms from articles included in a given search, and their associations with other attributes such as topics or keywords) 27. We consulted specialist subject librarians at University of Southampton throughout development of the search terms28. This strategy was repeated across five additional databases returning a total of 4322 records from all sources (Table 3).

### **Selecting the evidence**

The final screening process following the PRISMA-ScR framework for reporting scoping reviews 21 is illustrated in Figure 1. After removing duplicates (n=206) from the 4,322 hits, 4,116 records were exported to Microsoft Excel for title and abstract review by authors (BMS, MJB, TLS). Following title and abstract review 3,984 papers were excluded resulting in 132 papers for full review. The reference lists of the 132 papers were searched resulting in eight additional papers being included. Full review of the 140 papers was undertaken by two authors (BMS, MJB) with any disagreements resolved by TLS. One hundred and twenty-seven papers (of 140) were excluded: 14 records did not relate to eye donation (i.e. these contained only incidental references to eye donation, or did not include a significant focus on it); 28 did not relate to ‘perceptions, preferences, views, attitudes, beliefs, experience, knowledge’ elements of our PCC), while 85 were not in the context of hospice and palliative care (as relevant papers often did not clarify this context in the title, abstract, or keywords). Thirteen records met the inclusion criteria and were included in the final review.

## **Extracting the evidence**

Authors, aims/ purpose; study design/methodology, participants/sample size, method of data collection and analysis, finding and limitations were extracted from the final 13 records and reported in Table 4. Studies listed in Table 4 are referenced in the text by numerals in square brackets [].

**Charting the evidence:**

Thirteen records that met the inclusion criteria were exported to Atlas.ti 8 29 for management and analysis. Papers were analysed in line with the review objectives.

***Objective 1: To systematically map the current evidence base relating to eye donation in Hospice and Palliative care settings***

***Year of publication****:*The search date range was set as 1983 – 2020 . This date range commenced from the date of set up of the first UK corneal transplant unit 25 until March 2020. No publications were retrieved between the date range of 1983 – 2000. Eight publications were retrieved between 2001-2011 [1,2,3,7,9,10,11,12]. Five publications were retrieved between 2012-2020 [4,5,6,8,13]. Search results indicated that there has been an evidenced increase in publications linked to eye donation from palliative and hospice care settings since 2001. This may be in response to increasing awareness of the shortage of eye tissue for use in transplantation and medical research and the recognition of the potential for donation from these settings.

***Countries and contexts****:* Retrieved publications included papers from five countries, including: UK (n=9) (four were in palliative care context [1,5,12,13] and five in hospice care contexts [2,3,6,8,10] and four countries generated one publication each in: USA (in a hospice setting) [7] Taiwan [4], Australia [9], and Germany [11] (all in palliative care contexts).

***Methodology/Design****:*Of the 13 retrieved publications, six reported empirical research [1-6], four of the empirical studies were qualitative studies [1,2,4,5], one was a survey [3] and one a mixed method study combining a survey and retrospective patient note review [6]. There was one service evaluation [7] and four letters to the editor reporting retrospective note reviews [8,9,10,11]. Two literature reviews [12,13] were retrieved (both appear to be scoping reviews although the review methodology was not stated).

***Participants*:** Sample sizes in the retrieved empirical studies ranged from 8 – 25 participants involved in semi-structured interviews [1,2,4,5] and 11 to 704 respondents in surveys [3,6,8]. Publications reporting retrospective note reviews included between 84 and 2000 records [6,8,9,10,11]. Ten publications reported participant characteristics: five studies included health care providers [1,3,6,7, 8], three included patients [4,5,6] and two studies included carers or family members [2,8]. Five publications reported the outcome of retrospective reviews of deceased patients’ records [6,8,9,10,11]. None of the retrieved evidence reported participant characteristics such as: gender ethnicity or religion. Of the two literature reviews, one focused on how health care professionals could impact on the number of eye donations from their clinical areas, outlining the potential benefits and considerations when involving patients in eye donation discussions [12]. The second focused on involvement of patients and family members in eye donation discussions [13].

***Potential for eye donation***

*F*indings from retrieved retrospective note reviews were conducted in one palliative care and four hospice care settings . Data from the hospice settings reported between 52/100 (52%) and 164/174 (94%) of deceased patients could potentially have been eye donors [6,8,9,10] and in the palliative care setting the potential was 229/704 (35.2%) [11]. In aggregating data from these retrospective reviews, the potential for eye donation from hospice care settings was 313 and from palliative care settings 229. This suggests a potential donor population of 542, however, these figures relate to patients who were assessed as medically suitable to be eye donors, but we cannot extrapolate how many patients would have agreed to eye donation if asked. However, limited evidence suggests that discussions about eye donation can increase donation rates [6,7,8]

***Summary: Objective 1 :*** Mapping of the global literature retrieved little evidence exploring barriers and facilitators to eye donation from palliative and hospice care settings was available prior to 2001 and that a limited range of study designs/evidence synthesis methodologies had been adopted in the reported empirical work. Nine of the thirteen publications were conducted in the United Kingdom with a dearth of literature from other countries and cultures. With the USA and India reportedly supplying 55% of all corneas available globally 1, it is surprising that there is no literature from these countries. Whist the evidence available includes representation from relevant participant groups: patients, family members and health care providers, the sample sizes are frequently small, however the themes generated by the retrieved publications speak to recurring barriers and facilitators. To date the available literature base is very slim with a lack of high-quality primary research adopting mixed methods of investigation/exploration which would support practice and policy development.

**Objective 2: To identify the factors that are evidenced as informing or influencing the discussion of eye donation in hospice and palliative care settings.**

Analysis for Objective 2 focussed on identifying factors that were evidenced as informing or influencing the end of life option of eye donation in hospice and palliative care settings applying qualitative content analysis 30. Coding of papers was performed by BMS and reviewed by TLS following development of a coding handbook. Coding focused on identifying barriers and facilitators to the option of eye donation being discussed with patients and family members. Codes were grouped under two category headings: I) Attitudes toward eye donation (with subcategories beliefs and perceptions), II) Knowledge (with subcategories assets and deficits).

***Evidenced Attitudes toward eye donation (including beliefs and perceptions):***

Attitudes is defined as a learned tendency to evaluate things people, issues, objects, or events in a certain way 31. Evaluations are often positive or negative and informed by a person’s beliefs and perceptions 31,32. Findings in this section have been synthesised from four studies reporting the attitudes of health care providers [1,3,6,8 ], three reporting the attitudes of patients [4,5,6] and three reporting the attitudes of carers or family members [2,7,8].

Health care providers are reported to be generally favourable toward eye donation, perceiving it as worthwhile [1,3,6,8]. Authors report that while participants felt uncomfortable discussing eye donation, the majority felt it was their professional responsibility to do so [1]. Similarly, Gillon et al 2011 [3] exploring attitudes, knowledge, practice and experience of corneal donation across a sample of 410 HCPs respondents report that 70% (291/410) perceived corneal donation as a rewarding opportunity for patients and/or their families and 82% (345/410) reported that corneal donation was compatible with their personal beliefs [3].

Furthermore, survey findings [8] report that 42% (8/14) of doctors raised the issue of eye donation based on their experience that the option was perceived by patients and family members as a way of giving something back to society. Of note is that while HCPs acknowledge that eye donation is worthwhile, evidence indicates that discussing eye donation is not common practice [3,6,8,12]. Specifically, two surveys including HCPs found that 92% (92/100) and 93% (399/431) never or rarely raised the subject of corneal donation with patients or relatives [3,6].

Authors suggest that HCPs’ perception that discussing eye donation will cause distress to patients and family members is a barrier to eye donation [1,3,8,12]. For example, retrieved publications reported that: health care professionals believed that discussing eye donation would detract from the tranquil environment of a hospice and that donation requests could cause patients and their families physical and psychological harm[1, 3]. However, service evaluation data reports that 86% (12/14) of doctors reported that conversations did not cause additional distress with 57% (8/14) reporting that the conversations about eye donation were perceived by patients and families as a positive outcome from the death [8].

Of note is that HCPs perception that discussing eye donation would cause distress was not supported, in the retrieved records [4,5,6,7,8] . Three studies reported the attitudes, beliefs or perceptions of patients [4,5,6], indicating that patients were willing to participate in discussions about the option of eye donation [5,6] but that patients were unaware of the option of eye donation or assumed that they were ineligible,. Furthermore, participating patients were motivated to be eye donors and felt positive about the possibility of helping others [5, 6].

A survey of inpatients [6] found that the majority of participants 73% (8/11) reported that they did not find it upsetting to discuss eye donation and that asking about donation enabled them to make an informed decision about donation. A further potentially important finding is that participants reported their preference to talk about eye donation while they were still well rather than when deteriorating [5] .

Comments from nursing logs [7] following the introduction of an admission script which included questions about eye donation confirmed that patients (n = 121) and families were not aware of their eligibility to donate their eyes, but they were not concerned about the topic of eye donation being mentioned during admission . Nurses were positive about introducing the option of donation at admission [7].

Only one study mentioned cultural and religious beliefs as a barrier to eye donation[4]., the study explored the views of 25 terminally ill cancer patients towards eye donation. The majority of patients (14/25 (56%) were unwilling to donate their eyes based on their Buddhist beliefs that: the body must remain untouched for eight hours after death to allow the spirit to depart and remain intact as the spirit should be able to see in the afterlife. [4].

Publications which reported family/carer attitudes towards donation [2,8,12,13] found a lack of awareness of their dying family member’s eligibility to be a potential eye donor. Findings indicated a range of beliefs including that donation was right, is a social duty to donate, and that it would be ‘wasteful’ not to [2]. Family members’ decision to decline eye donation was based on the prior stated wishes of the patient not to donate or the family’s uncertainty about the patient’s wishes [2,8].

Findings from across the retrieved dataset indicate that HCPs are a key barrier to the option of eye donation being raised [1,3,6,8] usually avoiding discussions about eye donation unless the issue is raised by the patient or the patient’s family [1,3,6,12]. While HCPs were cautious about discussing eye donation, patients [5,6] and carers [2,7,8] wanted to be informed and were not averse to holding discussions about eye donation. This points to a clear disconnect between the perceptions and beliefs of service providers and the perceptions of services users as reported in the existing literature.

## **Knowledge - Assets and Deficits:**

Five publications included HCPs reports of their knowledge about eye donation [1,3,6,7, 8]. In all studies HCPs reported knowledge deficits including not having sufficient knowledge about the process of eye donation [1] and lacking confidence to initiate eye donation discussions [3,6,7,8]. However, training is not a guarantee that eye donation would be discussed [3] A study in UK reported that 115/433 (27%) of HCPs had received some information, education and training on eye donation, but 399/431 (93%) rarely or never raised the option of eye donation, with 357/433 (83%) of HCPs reporting that they did not know enough about eye donation in general terms to discuss it with patients and their families [3].

Furthermore, reviews of the literature including HCPs confirm the facilitative impact of education and training and that willingness to discuss donation is positively correlated to knowledge about the process of eye donation (referral, retrieval) and being aware of local policy and guidance [12,13].

Key knowledge deficits synthesised from the retrieved publications indicate that: hospice and palliative care patients are generally unaware about eye donation and eligibility criteria[4,5,6,]. For example, in two studies, patients thought they could transmit their cancer to recipients [4,5] or that their eyes would not be good enough for use in transplantation [4], furthermore, next of kin are unaware that their dying family member with cancer could donate their eyes [2]. ,Retrieved evidence further indicates that not knowing the beliefs/wishes of the deceased regarding eye donation is a key barrier to increasing eye donation [2,8].

**Discussion**

Current literature in the donation and behaviour change contexts continue to link attitudes toward a topic leading to a specific behaviour taking place. For example, if people have a positive attitude toward donation generally, they will be willing to donate, however authors report that attitudes alone are a poor indicator of behaviour as the context within which an action takes place will cancel out favourable attitudes (Bracher et al, in press). Early, research reports no linear causal relationship between knowledge, values, attitudes, willingness, and action related to donation behaviours 33 with further modelling supporting the general finding that behavioural intention (or willingness) does not predict action34. Therefore, relying on changes in attitudes toward eye donation alone, is not the route to increasing eye donation as the context within which discussions about eye donation need to take place is key.

This context within which discussions around eye donation need to take place is that of death. Apart from living donation, all donation options cannot proceed until someone has died, therefore, raising a topic that so profoundly signals impending death may be why HCPs are reluctant to raise the option of eye donation. A further consideration in the reluctance to raise the issue with family members is that death not only denies the next-of-kin of a significant relationship, but also robs them of many of their usual coping mechanisms, imposing a sequence of events that leave family members feeling dispossessed of physical and psychological equilibrium 35 therefore HCPs may avoid what they perceive to be ‘distressing topics’ due to concerns about the reactions of family members [7].

The retrieved evidence indicates that patients and family members are not averse to, nor distressed by, discussions around the option of eye donation, however, as with all end of life discussions timing is key. Evidence supports the benefits in ‘introducing’ this issue at admission with this discussion being merely to assess donation status [7]. For example, a general discussion around being on the donor register and carrying a donor card. Adding eye donation to admission protocols would offer the opportunity to clarify potentially long held plans to be a donor, which with the onset of a cancer diagnosis, would be limited to tissue and eye donation.

Furthermore, in raising this issue as part of ‘the usual’ admission process, patients and family members are then able to discuss this option if they wish to and seek further information and guidance. As reported by the Organ Donation Taskforce 36 making donation ‘usual’ as opposed to ‘unusual’ is essential if donation rates are to increase36. However, early indications from a national study into the potential of eye donation from hospice and palliative care settings [*(EDiPPPP)*](https://www.southampton.ac.uk/healthsciences/research/projects/edipppp.page?) is that both clinicians and the public are poorly informed about the need for eye donation, potential donor eligibility criteria and the process of eye donation. It is essential that empirically informed interventions are developed that successfully raise public awareness and clinical confidence and competent in operationalising the end of life option of eye donation.

**Conclusion**

This scoping review has provided an up to date appraisal of the current potential, perceptions and practice underpinning offering the option of eye donation to dying patients and their family members in palliative and hospice care context.

Studies included in this review from one palliative care [6] and four hospice care [8,9,10,11] settings report that a total of 542 patients could potentially have donated their eyes. This equates to over 1000 eyes from just these settings which could make a significant contribution to sight saving and sight restoring treatment and surgery.

The review outlines the key barriers to increasing eye donation from these settings include the reluctance of HCPs to raise this issue to avoid causing perceived distress to patients and their next of kin, and the evidenced lack of awareness of patients and family members about their own or their relatives donation options and eligibility. This review also indicates a lack of clinical guidance drawn from high quality evidence proposing interventions that could inform HCPs’ practice. The absence of this guidance is a barrier to change.

**Limitations:**

* *Search strategy:* in many papers, ‘eye donation’ was subsumed under a wider term such as ‘tissue donation’ or ‘organ donation’. This has implications for search strategies in future reviews focusing on eye donation, as relevant terms many not be directly visible to searches with a resulting risk of excluding papers that include eye donation as a sub-set of wider investigations.
* MeSH headings did not reliably include all relevant studies relating to the focus of this search. Those developing search strategies to underpin reviews may find it helpful to use a test set of familiar papers, as we have done here.
* None of the retrieved records included a diverse cultural participant group nor specifically looked at variables such as age, sex and religious views, despite religious/cultural factors being evidenced as factors that influence organ and tissue donation decision making 37 38, 39

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**Figure 1:** Process followed in the selection of included studies using the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) Tricco et al (2018)

Duplicates removed

(N=206)

Records identified through database searching (n=4322)



Records screened at title and abstract level (n=4116)



Records excluded (n =3984)



Full text articles assessed for eligibility (n=132)

Additional records identified through searching reference lists of full text articles n=(8)

Final full text assessed for eligibility

(n140)=

Full text articles excluded with reasons (n=127)

Not eye donation (n=14)

Not person based (n=28)

Not in hospice or palliative care (n=85)

Final selected studies

(n=13)

**Tables**

**Table 1: JBI Framework for scoping review (20)**

|  |  |
| --- | --- |
| 1 | Defining and aligning the objectives and questions |
| 2 | Developing and aligning the inclusion criteria with the objectives and questions |
| 3 | Describing the planned approach to evidence searching and selection |
| 4 | Searching for the evidence |
| 5 | Selecting the evidence |
| 6 | Extracting the evidence |
| 7 | Charting the evidence |
| 8 | Summarizing the evidence in relation to the objectives and questions |
| 9 | Consultation of information scientists, librarians and/or experts throughout |

**Table 2: inclusion/exclusion criteria**

|  |  |  |
| --- | --- | --- |
|  | **Inclusion** | **Exclusion** |
| **Population** | Patients (*Donor, deceased donor, potential dono*r)  Carers (*Relative, next of kin, family member, Informal carer)*  Members of the public  Health Care professionals *(Physician, Doctor, Nurse)* | Children, Young people, Adolescents, |
| **Concept** | Barriers and facilitators to eye tissue donation (*perceptions, preferences, practice, potential, views, attitudes, beliefs, experience, knowledge)* | Organ, body, egg, sperm donation, surgery to the eye. |
| **Context** | Hospice and Palliative care settings | Acute care areas, e.g. Intensive Care Units, Critical Care Units, Emergency Departments, Eye Banks, process of retrieval, storage, treatment of eye tissue. |
| **Type of study** | Empirical research, clinical guidelines, expert opinion, letters to editors, initial reporting of findings, literature reviews |  |
| **Language** | Full paper in English language | Non-English language |
| **Year of publication** | 1983 – 2020 |  |

**Table 3 – Final search strategy and results by database (all searches conducted 27/01/2020)**

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| **Search terms** | | |
| (Eye OR cornea\* OR ocular) AND (donat\* OR donor\*) NOT “eye drop\*” NOT acqueous NOT genetics NOT histology\* NOT membrane NOT microscopy NOT MRI NOT oculoplast\* NOT oocyte NOT endotheli\* NOT keratoplat\* | | |
| **Database** | **Results** | **Limits applied** |
| PubMed | 3602 | Species: Humans |
| CINAHL | 141 | Exclude MEDLINE records |
| Embase Classic+Embase | 288 | Exclude MEDLINE records |
| PsychInfo | 186 | None |
| Epistemonikos | 34 | No PMC (PubMed) |
| Cochrane Reviews | 71 | None |
| Total retrieved | 4322 |  |
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Table 4: Data extraction summary

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| **Study ID** | **Study reference country and context** | **Aims/ purpose** | **Study design, participants** | **Data collection and analysis methods** | **Findings** |
| 1 | Wells J, Sque M, 2002, Living Choice: the commitment to tissue donation in palliative care *International Journal of Palliative Nursing* 8 (1):22-27***United Kingdom, Palliative care setting*** | To explore how nurses and doctors feel about tissue donation in palliative care. | Grounded theory study  Health Care Professionals (HCP) (n=8) | Data collection: Semi-structured interviews  Data analysis: Grounded theory analysis | * Patients in palliative care should have the opportunity to be consulted about their wishes and expect to be informed and consulted about tissue donation. However, in units where donation was routinely discussed, participants generally consulted relatives rather than patients resulting in concerns that patients were not involved in decision making. * Patients or family members ‘openness’ to discussing end of life planning led to   HCPs being more comfortable raising the option of donation.   * Discussing donation should be a multi-professional role. * Timing of the discussion is crucial to the outcome. * *A* main concern was whether the request for donation and the donation process would cause the patients and families any physical or psychological harm. |
| 2 | Carey and Forbes K, 2003 The experience of donor families in the hospice *Palliative Medicine 17: 241-247* ***United Kingdom, Hospice care setting.*** | To evaluate the experiences, attitudes and feelings of relatives who had consented to the donation of corneas of a loved one within a palliative setting. | Semi-structured interviews with 12 family members (Carers/ relatives) | Data collection: Semi structured interviews.  Data analysis: Framework analysis | * *Awareness of eligibility* Almost all participants were not aware that their deceased relative was eligible for donation and reported that they would not have reached the decision to donate on their own. * Participants stated that they would have been distressed if they had not been given the option to donate and later realized, they could. * *Raising the topic of eye donation:* discussions were initiated by nurses generally after the death of the patient. The timing and approach were acceptable to families although they felt it would have been easier if they had known beforehand. * *Participants views of eye donation:* Most participants felt that donation was right and had a positive experience with the process and felt they had done something worthwhile. * Social policy: Ten participants stated that the patient should make the decision about donation. |

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|  |  |  |  |  | * All participants felt that there should be publicity and discussion about organ donation preferably before the person was faced with incurable disease or imminent death. |
| 3 | Gillon S, Hurlow A, Rayment C et al, 2011,Obstacles to corneal donation amongst hospice inpatients: A questionnaire survey of multi-disciplinary team member’s attitudes, knowledge, practice and experience *Palliative Medicine 26(7): 939-*  *946* ***United Kingdom, Hospice care setting.*** | To explore the attitudes, knowledge, practice, and experience of corneal donation from hospice staff with direct clinical contact with patients. | Survey shared with 704 clinical multi-disciplinary team members in 12 hospices | Data collection: paper questionnaire with fixed response and free text option.  Data analysis: descriptive statistics and thematic analysis of free text comments. | * 70% (n = 291/418) of respondents perceived corneal donation to be a rewarding opportunity for patients and/or their families. * 88% (n = 375/425) stated it was important that patients knew that they could donate. * 43% (n = 118/427) (43%) indicated that corneal donation should be discussed routinely with eligible patients. * 17% (n = 72/418) felt that discussing corneal donation would be too distressing for a patient and/or their family. * 37% (n = 156/422) were not sure whether they were comfortable enough to start a conversation about corneal donation with a patient or a family member. * 34% felt that it was part of their role and 39% (n = 161/421) felt that it was someone else’s role to raise the issue of corneal donation with patients and/or their family members. * 93% (n = 399/431) rarely or never raised the option of eye donation Key reasons for not engaging in discussions were: * Concerns about the impact of the discussion on patients and families, * A belief HCPs lacked essential knowledge, about the process of eye donation. * A perception that donation is not part of hospice culture, |
| 4 | Kuo S, Chou P, Liao Y et al, 2018, Perspectives of decision-making for corneal donation: A qualitative research among cancer patients OMEGA - *Journal of death and dying 0(0): 1-8* ***Taiwan, Palliative care setting.*** | To identify the views of terminal cancer patients toward corneal donation. | Exploratory Qualitative study with 25 cancer patients | Data collection: Semi-structured interviews  Data analysis: content analysis | *Key findings were that:*   * Participants felt that the issue required family members to indicate their preferences * Participants preferred to maintain their bodies intact because of the deeply held beliefs that the body must remain intact after death. * Participants believed that corneal donation was against their Buddhist religious beliefs as they believe that the body should be untouched for eight hours after death. * Participants also believe that spirit should be able to see and therefore eyes   should not be removed. “ |

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| 5 | Walker L, Neoh K, Gilkes H & Rayment C, 2018, A qualitative study using semi- structured interviews of palliative care patients’ views on corneal donation and the timing of its discussion *Palliative Medicine 32(8): 1428*  *– 1437.*  ***United Kingdom, Palliative care setting*** | To understand views and feelings of patients in palliative care settings towards corneal donation. | Exploratory qualitative study with 9 Patients | Data collection: Semi-structured interviews  Data analysis: Thematic analysis | * Patients baseline knowledge was very limited and most did not know anything about corneal donation prior to the study. * Altruism was a key influence, patients felt positive about being able to help someone else. * Eyes were not perceived as being different to other organs and participants valued sight and felt it would be important to help someone see again. * All participants acknowledged the role played by their family in decision-making and were keen to involve them. * Participants felt they would prefer to talk about donation when they were well rather than when vulnerable and close to death. * Participants felt discussions about donation was a covert way to tell someone that they were dying. * Participants were open to discussing donation with health care professionals and felt it would be easier with someone they already had relationship with. * While participants said they did not know anything about donation, they however felt they would not be eligible to donate. Some thought they could pass on their cancer if they donated. |
| 6 | Ng I, Astle J, Tregenna E et al, 2019,  *Health Services and Policy : Future Healthcare Journal 2019, 6 (1)s38.*  ***United Kingdom, Hospice care setting.*** | To assess factors that influence corneal donation within the palliative care service. | Survey of 37 HCPs and 11 Patients  Retrospective note review of 84 deceased patient records 2016 | Data collection:  Retrospective note review  Questionnaire (developed by Gillon et al, 2012)  distributed to healthcare providers in 2014. | *Results of retrospective note review:*   * Eighty-five deceased patients’ notes were reviewed against eye donation criteria. Of these 35% ( n = 30) were judged to be eligible for corneal donation with a further 11% (n = 10 patients) potentially eligible.   *Results of survey healthcare professionals:*   * 92% (n = 92) of respondents never or rarely raised the subject of corneal donation with patients or relatives. * 76% (n = 76) of respondents had not received any information or training regarding corneal donation. * 81% (n = 81) of respondents felt they did not know enough about corneal donation to discuss it with patients or relatives. * Knowledge and training were identified as significant barriers to raising these discussions.   *Results of questionnaire with inpatients*:   * 6/11(54.5%) participants had not heard of corneal donation and all were either glad or neutral about being informed about corneal donation. |

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|  |  |  |  | Questionnaire to patients admitted to the service between June and August 2015.  Data analysis: descriptive statistics. | * 8/11(73%) participants did not find it upsetting to discuss corneal donation and the remaining 3/11(27%) indicated although they found it upsetting, they would rather have a conversation than not. * Patients decisions about donation changed following discussions of eye donation. Before discussion none of the patients were planning to donate their corneas while after the discussion 7/11 (64%) were planning to donate. |
| 7 | Niday P, Painter C, Peak J et al, 2007 Family and staff responses to a scripted introduction to tissue donation for hospice inpatients on admission *Progress in Transplantation 17(4): 289 – 294.*  ***USA, Hospice care setting.*** | To implement and evaluate a change in practice to offer information about tissue donation as part of admission process. | Service evaluation  -Written logs of 12 health care providers. | Data collection Review of nurses’ logs | * Comments on nurses’ logs indicated no concerns from patients and families to receiving information about donation at admission. There was less frustration from families at the time of death and introduction of donation * Nurses were more positive about introducing the option of donation at admission compared to when donation was introduced at the time of death. * Nurses logs confirmed that patients and families were not aware that they could donate. * Corneal donation increased by 250% during a six-month period from two out of 32 eligible corneal donors to seven out of 34 eligible donors. |
| 8 | Tredget K and Ward- Davis L, 2017, Responding to the public’s voice: changing cornea donation practice in a hospice *BMJ Supportive and Palliative care 0:1-2* | Service evaluation of the introduction of personalised plan of care for dying patients which included the option for tissue and organ donation. | Service evaluation reporting outcome of retrospective note review,  staff survey of 14 HCPs. | Data collection: questionnaire with HCPs  Retrospective note review.  Telephone interviews with | Findings from questionnaire with HCPs   * 12/14(86%) of doctors felt that discussing eye donation did not cause additional distress to patients. * 8/14 (57%) of doctors reported that the discussions had been helpful to patients and families as donation provided an opportunity to give something back and enabled a positive outcome from the death.   *Note review:* |

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|  | *(****Letter to the editor)* United Kingdom, Hospice care setting.** |  | Telephone interviews with five family members. | family members of deceased hospice in- patients  Data analysis: Descriptive statistics | * On average 240 deaths occurred each year at this Hospice. Prior to 2015 no patients had been referred for eye donation. * 67/77 (87%) were eligible to donate * 34/67 (51%) of eligible patients’ relatives were approached about donation prior to the patient’s death. * 15/34 (44%) of those invited to consider donation subsequently donated their corneas   *Reasons for non-discussion of eye donation*   * speed of deterioration, concern about exacerbating already significant distress and lack of clinician clarity on eligibility criteria were common reasons.   *Reasons for declining donation*   * Previously expressed wish by patient not to donate or family’s uncertainties about the patient’s wishes were reasons for decline.   Findings from telephone interviews:   * Interviews with deceased relatives indicated that relatives felt it was acceptable to raise the option of donation and felt that it did not add to their distress. |
| 9 | Roach R, Broadbent AM, 2009 Eye  donation in Sydney Metropolitan palliative care *Journal of Palliative Medicine 13(2):121-123.*  *(****Letter to the editor****)* ***Australia, Palliative care setting*** | To identify factors contributing to low rate of eye donation from palliative care unit in Sydney metropolitan area. | Retrospective Audit of 2000 deceased patient records | Data collection: Retrospective note review  Data analysis: Descriptive statistics | 2000 deceased patients’ notes were reviewed over a one-year period.   * 50 (2.5%) patients became eye donors. * Donors came from only four out of the nine palliative care units (44%) * two (22%) of units provided 90% (n=45) of the eye donations.   Palliative care units do not appear to discuss or promote eye donation with patients or their families |
| 10 | Gillon S, Hurlow A, Rayment C et al, 2010 Eligibility for corneal donation within the hospice | To quantify percentage of inpatients eligible to donate corneas and number with whom | Observational retrospective note review of 100 deceased patient records | Data collection: patient note review | 100 deceased patients’ notes were reviewed.   * There were no contraindications to eye donation for 52 patients (52%) whilst 15(15%) had definite contraindications. * No documentation regarding discussion of corneal donation was was recorded. |

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|  | population *Palliative Medicine 24(5): 551-*  *552.* ***(Letter to the editor) United Kingdom, Hospice care setting.*** | donation is discussed. | (September to December 2008). | Date analysis: Descriptive statistics |  |
| 11 | Stiel S, Hermel M & Radbruch L, 2010, Cornea donation from patients deceased at a palliative care unit *Palliative Medicine 25(2): 183-184.*  *(****Letter to the editor) Germany, Palliative care setting.*** | To assess the potential for corneal donation and the relative rate of actual donation. | Observational Retrospective note review of 704 Deceased patient records | Data collection: Review of patient electronic records  Data analysis: Descriptive statistics | 704 deceased patients’ notes were reviewed between 2003 and 2009.   * 229/704 (32.5%) patients were potential donors * 112/704 (49%) patients gave consent for cornea donation |
| 12 | Edwards, P 2005 Corneal donation within palliative care: a review of the literature *International Journal of palliative nursing 11 (9): 481-486.*  ***United Kingdom, Palliative care setting.*** | To examine whether the option of donation is being offered in a systematic manner.  To explore the moral dilemmas involved in corneal donation and the implications for nursing practice and research | Literature review in Medline and Cinhal databases | Data collection: Review of studies covering period 1995-  2005  Data analysis Thematic analysis | Findings from literature review   * *Corneal donation is rarely offered* * Cumulative findings indicated that: family members were surprised that their relative could donate * Family members would have been distressed if they had not been offered the option to donate and found out later that this could have been an option; low numbers of family members raise the issue of eye donation. * Families felt that donation did not have any effect on their bereavement * Family members desire to fulfil deceased wishes, give meaning to the death and the families’ own views about donation influenced donation decisions. * Health Care Professionals often do not raise the issue of corneal donation, often they just respond to requests by patients or family members. |
| 13 | Spencer, M 2012 The barriers to organ and tissue donation in palliative care *End of life journal 2 (2):1-11* | To explore the involvement of palliative care patients in decisions about donating their tissues. | Literature review in British nursing index, CIHAHL, MEDLINE, Embase and PsycINFO | Data collection:  Review of the literature with no date limits | Findings from literature review   * There is no consensus among palliative health care professionals about whether and/or when patients should be involved in discussions about donation. * Patients often spontaneously discuss end of life matters such as their funeral arrangements, their will and expectations for the time they have left, but they rarely spontaneously discuss organ or tissue donation. |

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|  | ***United Kingdom, Palliative care setting.*** | To explore why families may be reluctant to consent to donating organs/tissues of deceased loved ones.  To explore why nurses are wary of discussing the possibility of donation with patients and/or their next of kin. |  | Data analysis Thematic analysis | * Introducing donation discussions increased donation rates * Patients should be given appropriate information to enable them to make choices about donation * Knowing the wishes of the deceased regarding donation influences next of kin donation decision-making. * Health Care Professionals find it challenging to talk about donation even though they frequently have difficult discussions about death and dying. HCPs are fearful of the reaction of patients and families to the request for donation. * The attitudes of health care professionals influence their practice, those with negative views and less knowledge about donation are less likely to discuss it compared to those who are positive and have more knowledge. |