


BMJ Open Family refusal of eye tissue donation from potential solid organ donors: a retrospective analysis of summary and free-text data from the UK National Health Service Blood and Transplant Services (NHS-BT) National Referral Centre (1 April 2014 to 31 March 2017)

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ABSTRACT

Objectives Long-standing undersupply of eye tissue exists both in the UK and globally, and the UK National Health Service Blood and Transplant Service (NHSBT) has called for further research exploring barriers to eye donation. This study aims to: (1) describe reported reasons for non-donation of eye tissue from solid organ donors in the UK between 1 April 2014 and 31 March 2017 and (2) discuss these findings with respect to existing theories relating to non-donation of eyes by family members. **Design** Secondary analysis of a national primary data set of recorded reasons for non-donation of eyes from 2790 potential solid organ donors. Data analysis including descriptive statistics and qualitative content analysis of free-text data for 126 recorded cases of family decline of eye donation.

Setting National data set covering solid organ donation (secondary care).

Participants 2790 potential organ donors were assessed for eye donation eligibility between 1 April 2014 and 31 March 2017.

Results Reasons for non-retrieval of eyes were recorded as: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%). In >50% of recorded cases, reasons for non-donation were based on family's knowledge of the deceased wishes, their perception of the deceased wishes and specific concerns regarding processes or effects of eye donation (for the deceased body). Findings are discussed with respect to the existing theoretical perspectives.

Conclusion Eye donation involves distinct psychological and sociocultural factors for families and HCPs that have not been fully explored in research or integrated into service design. We propose areas for future research and service development including potential of only retrieving corneal discs as opposed to full eyes to reduce disfigurement concerns; public education regarding donation processes; exploration of how request processes potentially influence acceptance of eye donation;

Strengths and limitations of this study

- This secondary analysis paper is the first reporting of primary data discussing reasons for non-donation of eyes recorded by Specialist Nurses in Organ Donation (SNODs) for 2790 potential solid organ donors in the UK.
- The authors applied qualitative content analysis to free-text data and discuss findings in relation to existing theoretical perspectives to identify areas for further research and service development.
- The paper reports proxy commentary recorded as free-text data generated by SNODs when recording reasons provided by family members for declining donation of eye tissue, and, therefore, is limited in depth of detail available for reporting.
- Due to study design limitations, factors that may have influenced family decision-making (ie, potential donor demographics/regional differences, changes in legislation) cannot be addressed in this paper.
- Due to data sharing restrictions, the paper presents descriptive statistics only.

procedures for assessment of familial responses to information provided during consent conversations.

BACKGROUND

Globally, 53% of the world's population has no access to the benefits of sight saving and sight restoring transplantation surgery due to a short fall in the supply of ophthalmic tissue (cornea and sclera) that is only available via eye donation.¹ According to Pascolini and Mariotti,¹ over 10 million people worldwide have bilateral corneal blindness, which

could be restored with a corneal transplant.¹ According to the Royal National Institute of Blind (RNIB), over two million people in the UK are living with sight loss² caused by conditions such as Keratoconus and Fuchs' Corneal Dystrophy, which can be treated if eye tissue is available (eg, by corneal transplantation and reconstructive surgery). Eye tissue is also needed for research into a wide variety of eye diseases, for example, endothelial failure postcataract surgery.³ The RNIB reports that approximately 5000 corneal transplants are required annually in the UK to address disease and injury resulting in sight loss, with costs to the UK economy (unpaid carer burden and reduced employment rates) reported as £4.34 billion annually.² Critically, the organisation predicted that by 2050, the number of people with sight loss will double to nearly four million.² It is, therefore, imperative that the tissue needed to intervene in these conditions via corneal transplantation, reconstructive surgery, glaucoma surgery and research into the causes and treatment of eye disease is available.

However, there is a long-standing shortfall in supply of eye tissue in the UK and globally, with eyes being the least donated of all organs and tissues when decision-makers are offered a 'list' that they need to agree to that can be retrieved for use in transplantation (n.b. as eyes are referred to as both organs *and* tissues in different contexts, we will refer to them as organs from here on).^{4,5} The UK National Health Services Blood and Transplant (NHSBT) Eye Bank in Speke, Liverpool and Bristol (who supply most eye tissue used for surgical purposes in the UK) seeks to have 10 eye donors per day consistently to satisfy the demand for the treatment of patients. This number is not consistently met.

Increasing supply is a key strategic aim for NHSBT Tissue and Eye Services Division⁶ and they, along with the UK Royal College of Ophthalmology,⁷ have expressed a need for research exploring barriers to eye donation. This knowledge is needed not only as a basis for developing new routes to supply but also to inform guidance underpinning donation conversations with family members who are approached to consider the option of eye donation. Increasing supply requires understanding of how patients and families relate to eye tissue donation (ie, attitudes, beliefs, information needs, etc) and how these processes shape donation outcomes, specifically family members declining eye donation.

Eye donation from solid organ donors (EPSOD) continues to prove problematic, with slow progress in increasing supply from this specific cohort of donors. For example, EPSOD generated 320 eyes between 1 April 2015 and 31 March 2016⁴ and 446 eyes between 1 April 2019 and 31 March 2020.⁸ Current evidence indicates that nationally, on average, only 40% (range 31%–64%) of next-of-kin (NoK) agree to eye donation when approached to consider solid organ donation, while 67% of NoK agree to solid organ donation,⁵ and, therefore, what contributes to this difference is an important area for investigation.

In this paper, we aim to contribute to the knowledge base around non-donation of eye tissue from solid organ donors by reporting, for the first time, national clinical data collected and provided by NHS Blood and Transplant between 2014 and 2017, aligned with key theoretical perspectives reported to explain donating behaviours. This body of work from the past 30 years will advance knowledge and understanding of the reasons why of all organs and tissues can be donated, eyes remain the least donated organ.^{4,5}

Study objectives

1. Describe the reported reasons why eye donation did not take place from potential solid organ donors in the UK between 1 April 2014 and 31 March 2017.
2. Discuss these findings in the context of existing theoretical perspectives relating to non-donation of eyes by family members.

Study design

To gain further insight into the factors leading to low numbers of eyes being secured from solid organ donation, a working party (EPSOD, 2014–2017) was convened with the remit to: plan and action an effective response to demand and supply problems and make evidence-based recommendations to NHSBT and external stakeholders regarding potential service development that would impact on the current low supply of eye tissue.

Patient and public involvement

The paper presents a secondary analysis of primary data collected by NHSBT Tissue Services as part of a service development initiative. As such, there were no patients or members of the public involved in the design or conduct of the primary service development initiative. No dissemination of the primary data has occurred until this secondary analysis. As part of secondary analysis carried out by University of Southampton (UoS) team, and in line with the team's commitment to the value of patient and public involvement input, a summary of key findings was made to members of the NHSBT Tissue Services Donor Advisory Group, which includes next of kin of donating patients and public representatives. Members were invited to ask questions as part of an update to their regular meeting in Q4 2020.

Data collection

Data for 2790 potential* donors from England, Scotland, Wales and Northern Ireland, assessed for eligibility to donate eyes between 1 April 2014 and 31 March 2017, were collected using a standardised proforma (*n.b. potential donor refers to a deceased person who could become an organ donor unless medical criteria for non-donation or consent/authorisation is withheld by next of kin). Specialist Nurses in Organ Donation (SNODs) were requested to record reasons for non-procurement of eye tissue selecting from the domains listed in [table 1](#). SNODs were also asked to add further commentary via use of a free-text box. Data were gathered by SNODs with

Table 1 Summary of recorded reasons for non-donation of eye tissue from potential solid organ donors for the period from 1 April 2014 to 31 March 2017 (focus categories for this paper are shaded grey)

Period	Family wishes		Medical reasons		Deceased wishes		Coroner refused		All other reasons		(Reasons not recorded)		Total	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(% all years)
1 April 2014 to 31 March 2015	452	0.51	242	0.27	68	0.08	51	0.06	53	0.06	26	0.03	892	0.32
1 April 2015 to 31 March 2016	420	0.48	253	0.29	68	0.08	58	0.07	50	0.06	32	0.04	881	0.32
1 April 2016 to 31 March 2017	467	0.46	346	0.34	44	0.04	51	0.05	109	0.11	0	0	1017	0.36
All years	1339	0.48	841	0.3	180	0.07	160	0.06	212	0.08	58	0.02	2790	

the requirement that they complete data collection for each potential donor following discussion with family members and other stakeholders (eg, coroner). Data for each SNOD were collated into a monthly regional team returns to the NHSBT statistical team, who generated descriptive statistical data reported in this paper. Data

were collected over 3 years, with a cessation in 2018 due to the operationalisation of eye donation moving from the Organ Donation and Transplant division of NHSBT to its Tissue and Eye Services division. The full data set for descriptive statistics relating to non-procurement of eye tissue is presented in online supplemental file 1

Table 2 Reasons for non-donation of eye tissue from potential solid organ donors by category and major sub-category for the period from 1 April 2014 to 31 March 2017

Domain	Subdomain	1 April 2014 to 31 March 2015		1 April 2015 to 31 March 2016		1 April 2016 to 31 March 2017		All years	
		N	% of category	N	% of category	N	% of category	N	% of category
Family wishes	Decision made on personal views	195	0.43	154	0.37	129	0.28	478	0.36
	Decision made on disfigurement concerns	186	0.41	180	0.43	222	0.48	588	0.44
	Decision made on current physical/emotional state	13	0.03	12	0.03	27	0.06	52	0.04
	Decision made on religious/cultural/spiritual grounds	4	0.01	12	0.03	5	0.01	21	0.02
	Decision made on lack of knowledge	N/A*	N/A*	2	0	1	0	3	0
	Other/not specified family reasons**	54	0.12	60	0.14	83	0.18	197	0.15
Deceased wishes	Decision based on deceased prior registered wishes	54	0.79	50	0.74	24	0.55	128	0.71
	Decision based on deceased inferred wishes	14	0.21	18	0.26	20	0.45	52	0.29

*Category was not included in data collection for this period.

†Includes subdomains inviting free-text comment (ie, 'please specify').

Table 3 Summary of free-text comments relating to family reasons for decline of eye tissue donation from potential solid organ donors

Family reason categories	Cases (n)*	Cases (% of n=126 cases with free-text comment relating to family reasons)
No additional information	65	0.52
Family uncomfortable with eye donation	22	0.17
Family reasons indicated but case not classified as either '88-Family, not specified' or '87-Family other reasons, please specify'	17	0.13
Consent for solid organ donation but not eyes	10	0.08
Nothing 'visible' to be removed	7	0.06
Family withdrew initial consent	6	0.05
Family infer patient wishes (eg, NoK recorded as indicating deceased 'would not have wanted' eye donation)	3	0.02
Family refuse moving of body for retrieval	3	0.02
No ODR restrictions but family refuse eye donation	2	0.02
Family reasons due to religious reasons	2	0.02
Tendons only	1	0.01
Family wish to donate to scientific research	1	0.01
Family believed patient ineligible due to medical contraindication	1	0.01
Family member worried that they may inadvertently work with tissues in professional role in donated but not transplanted	1	0.01

Cases do not equal 126 as some can belong to more than one category (eg, a comment could relate to both 'Consent for Solid organ donation but not eyes' and 'no ODR (Organ Donor Register) restrictions but family refuse eye donation').
NoK, next-of-kin.

([tables 1–3](#))—however, this paper focuses on data relating specifically to *family decline of eye donation*.

Analysis

Secondary analysis⁹ included generation of descriptive statistics on reasons for non-donation of eyes recorded by SNODs for 2790 potential donors ([table 1](#)) and application of qualitative content analysis¹⁰ to free-text data for 126 recorded reasons for family decline of eye donation. Analysis of free-text data was undertaken using Nvivo computer-assisted qualitative data analysis software (V.12).¹¹

As international empirical evidence from the past 30 years indicate, eye donation involves reactions that do not impact other forms of donation including: discomfort reactions,^{12 13} disfigurement,³ the belief that eyes will be needed in the afterlife, eyes being viewed as the 'windows to the soul'^{6 14} as well as disgust-related aversion ('yuk'/'ick factor') (findings from this national data set have been grouped under these headings).

The aim of the analytic process was to generate a descriptive analysis of data recording reasons for non-donation of eye tissue as reported by SNODs (objective 1) and to underpin a theoretically informed discussion aimed at unpacking the key reasons why family members decline the option of eye donation when this is a possibility (ie, no medical reasons for non-donation are evident) (objective 2). By engaging with existing theory

regarding donation decision-making, this paper also aims to inform interventions that can lead to an increase in donation of eye tissue for use in transplant operations.

Descriptive statistics

Reasons for non-donation of eye tissue (overview)

The data related to 2790 potential donors from England, Scotland, Wales and Northern Ireland assessed for eligibility to donate eyes between 1 April 2014 and 31 March 2017, but from whom eye tissue was not retrieved (reporting periods cover UK financial year, see [table 1](#)). The most common reasons for non-retrieval of eyes were: family wishes (n=1339, 48% of total cases); medical reasons (n=841, 30%); deceased wishes (n=180, 7%) and coroner refusal (n=160, 6%), with 'All other reasons' accounting for n=212 (8%) of cases (reasons were not recorded in n=58 (2%) cases—see [table 1](#)). The reporting in this paper will focus on data related to *family and deceased wishes* only as these contribute to over 50% of recorded reasons why eye donation did not proceed when donation discussions took place.

Decline of eye donation based on family and deceased wishes

Where non-procurement of eye tissue was recorded under *Family wishes* (n=1339), the most common reasons related to disfigurement concerns (n=588, 44% of family decline), or 'personal views' about eye donation held by Next of Kin (NoK) (n=478, 36%—see [table 2](#)).

For cases where non-procurement of eye tissue was recorded under *Deceased's wishes* (n=180 cases, 7% of total), 128 (71% of deceased wishes cases) were due to the fact that the deceased had registered (on the organ donor register, which is always checked by SNODs in preparation for discussing donation options) that they did not want to donate eye tissue. A further 52 (29%) cases of non-procurement of eye tissue resulted from discussions with NoK where they stated that the deceased's wish not to donate eyes was known to them—see [table 2](#).

Findings from analysis of free-text data (family decline)

[Table 3](#) lists results of content analysis, showing all resulting categories of recorded reasons for family decline (n=126). Of note is that in 65 cases (10%) of SNODs reporting 'family refused', '*No additional information*' was recorded in the free-text comment box. For these cases, we, therefore, have no information on which to base any commentary regarding family decline. The findings and discussion are, therefore, related to the italicised categories in [table 3](#) (n=61 cases within this group).

Findings from analysis of free-text comments

Cases are reported as a percentage of the 126 free-text comments available relating to family refusal (% of n=126).

Discomfort reactions

For 22 cases (17%), free-text responses recorded by SNODs indicated family discomfort with eye donation. In addition to general expressions of discomfort with eye donation comments also referred to personal attachment to the eyes of the deceased, which influenced family decision-making (eg, [box 1](#)).

Disfigurement concerns

Linked to discomfort reactions, concerns about disfiguring the body of the deceased were raised by seven family members (6%) with SNODs recording that family members only wanted solid organs to be retrieved. It is notable that comments include words and phrases such as '*nothing visible, external and outside*' underlining that family members are concerned about how the body will look postdonation ([box 2](#)).

Box 1 Recorded family comments relating to discomfort reactions to eye tissue donation

[B]rothers who had had discussion and all felt 'funny' about eyes. Family did not like the idea of eye donation. Family reported they didn't like the idea of someone else seeing through their loved ones eyes'...

'Family did not want eyes removing as they felt they were part of her'
Family were very much against eye donation as they said they were 'windows to the soul'
... eyes refused as wife couldn't bear the thought of him without them.
Partner believed the eyes were the window to the soul

Box 2 Recorded family comments relating to disfigurement concerns

This is how we saw him
Family did not like the thought of external surgery to the body other than through the initial operation site.
Family did not want anything 'external' donated
Family did not want eye donation as not wanting anything visible
Family not wanting the face touching
Only wanted internal organs donated, nothing from the 'outside'

Solid organ only—not eye tissue!

As well as concerns about disfigurement and the reported wish that '*nothing visible be removed*' in a further 10 cases (8%), family consent was recorded as being given for solid organs but declined for eyes. In [box 3](#), we see examples of differing decisions recorded for tissues (eyes are also referred to as tissues) and solid organs. Some comments record SNOD-perceived strength of feeling as a factor restricting further discussion about eye donation. Of note, here is that we do not have evidence indicating on what basis the assessment about 'appropriateness' is based (eg, '*Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation*') or how much time was taken in this approach for donation. Higher consent/authorisation rates are reported when parents perceive that they have had adequate time to discuss donation within the family and with the health-care team.^{15 16} In one case, we see a priority invoked as the reason for decline, '*life saving organs only*' suggesting that a *value* was being associated with different organ or tissues.

Change in decision-making

Six cases (5%) described initial consent for eye donation being provided by families that was later withdrawn (see [box 4](#)). Comments suggest the potential influence of postdecision dissonance (see the Discussion section)¹⁷

Box 3 Recorded family comments relating to reasons for eye tissue accompanying consent for solid organs

[Family] did not want any tissue donation organs are enough.
Family did not want any tissue donation only solid organs.
Family only wanted kidneys donated, no other reason given.
Family very uncomfortable with tissue donation and only wanted organs as they cannot be seen.
Kidneys only would not discuss anything else.
Life-saving organs only.
On ODR (Organ Donor Register) no restrictions, partner consented to kidney only, nothing else.
Parents did not wish to donate anything other than liver and kidneys not appropriate to ask as risking loss of donation.
Wife wanted solid organs only.
Son certain he did not want to donate eyes, or any tissue. Was a very strong no to tissue and did not elaborate too much despite open questioning.

**Box 4 Recorded family comments relating to a change in decision to donate eyes**

[Father] changed his mind after consent provided. Even though partner consented initially, family wanted patient embalmed and wanted body home ASAP (As soon as possible). Family withdrew consent as needed quick release. Family withdrew eye consent, reason not specified. Initial consent provided for eyes and skin but then changed their mind, no reason given. Parents consented for all tissues but withdrew consent whilst visiting him in Chapel of rest saying he had 'given enough' and they did not want him to be touched anymore.

and the impact of wider family views stimulating a reversal of the decision to agree to eye donation.

DISCUSSION

The data presented in this study indicate that the main reason for non-procurement of eye tissue from potential solid organ donors in the UK is the decline of this option by bereaved family members. One thousand, three hundred and thirty-nine approaches for eye donation resulted in family decline, despite this being a valid donation option over the time period of data collection. Therefore, potentially, over 2000 eyes did not become available for use in transplant operations and research into eye diseases, resulting in loss of sight due to family decline.

This picture of potential donor eyes not becoming available in the context of solid organ donation is reflected in the global literature, with authors in the USA reporting that of 10 000 potential solid organ donors, where a consent rate of 47% for organ donation was achieved, only 24% eye donation consent rate was achieved.¹⁸ Reporting data from a survey carried out with 371 individuals renewing their driving licence in Sydney Australia, authors indicated that of 369 participants who responded to questions related to willingness to donate corneas, 153 (41%) indicated that they would not.¹⁹ This reluctance for eye donation is not just reflected in Western contexts (eg, Europe, North America, Australasia): for example, Acharya *et al*²⁰ surveyed 407 bereaved NoK of potential eye donors in Delhi (India), reporting that the majority 239 (59%) of NoK would decline eye donation.²⁰ Commentary from all three papers highlight concerns regarding disfigurement, discomfort with the thought of eye removal and spiritual/atheistic links to the eyes.

The comments illustrated in boxes 1–4 support the findings from international literature, that personal attitudes to and beliefs about the propriety of eye donation are influential in shaping negative orientations toward this option and, thus, to decline of donation when it is raised with NoK.

How can we understand these reactions?

Concerns with, and negative reactions to the option of eye donation, as well as the critical shortage of eye tissue for use in transplant operations and research, are persistent and pervasive in the UK and across many other parts of the world. Therefore, we will now discuss these factors in light of theoretical work aimed at illuminating factors underpinning these outcomes. The discussion will look at theories developed from social cognitive psychology, which outline general concepts influencing behaviour, and more specific theories/models focused on psychological concepts that propose explanations for the reactions reported both in these data and the wider global literature. While an exhaustive review of relevant theory is not possible in this paper, we focus on application of key findings and thinking to the national recorded data analysed here with the aim of: (1) making recommendations to guide communication with patients, carers or other NoK when making an approach regarding the option of eye donation and (2) stimulating thinking on communications strategy (eg, future publicity and campaigns) by organisations responsible for securing a reliable and sufficient supply of eye tissue.

Social cognitive models

Most early studies exploring factors influencing individual donation decision-making applied concepts laid out in social-cognitive models such as the Theory of Reasoned Action (TRA)²¹ and the Theory of Planned Behaviour (TPB).^{22–23} Horton and Horton²⁴ developed one of the earliest models proposing that the action of signing or requesting an organ donor card and willingness to donate own, or a deceased loved one's organs after death was a product of: *values, knowledge, attitudes (toward donation), willingness and action*.²⁴ Their path analysis and causal modelling study included two cohorts of participants: University students (N=295), and members of the public (N=465). While establishing that the tested concepts were related to donation decision-making, it was also clear from results that there was no linear causal relationship between knowledge, values, attitudes, willingness and action related to donation behaviours.²⁴ Further modelling by Radecki and Jaccard²⁵ identifying barriers to sharing donation intentions with legal next of kin supported the general finding that behavioural intention (or willingness) does not predict action.

This brief review reminds us that while prior attitudes towards a behaviour are influential, that they do not 'ensure' action will follow intention. Models such as TRA²¹ and TPB^{22–23} are fundamental models that presume a process of rational decision-making that is not evidenced in studies where donating and non-donating family decision-makers have been included and interviewed.

For example, research by Kopfman and Smith²⁶ aimed at informing donation campaigns introduced new thinking by looking both at concepts such as 'knowledge, attitudes and intention to donate' and identifying that those who measured low in intent to donate were more

likely to ‘have inaccurate knowledge about donation and gain lower scores on a measure for altruism’—and also highlighting that *‘those low in intention felt that signing a donor card would be frightening’*. We see here one of the first instances of what have been referred to as *non-rational*²⁶ or later *non-cognitive* factors^{27 28} (anxiety/fear) being reported. Further work by authors carrying out qualitative research increasingly identified deeply held beliefs and feelings that were reported as influencing the decision to donate organs of self and others or register an intent to become an organ donor on death, including anxiety, mistrust, superstition-based fear and views about what should or should not be done to a body post death.^{12–14 17 18 27 29–32}

Sanner’s discomfort reactions

We gain some important insights if we revisit Sanner’s work exploring public views of post-death procedures on the body.^{12 13} Although this work was carried out in the 1990s with 400 members of the public aged from 18 to 75 years, Sanner identified particular ‘discomfort reactions’ in relation to post-death procedures that are both relevant and of value in moving forward our understanding of reactions to requests for eye donation. Interviews with three subgroups selected from the original 400 who represented negative, positive and undecided views regarding donating their own organs identified that people with ‘intense discomfort reactions tended

to ignore or suppress positive motives (*eg, attitudes, intentions*) towards donating organs”.¹²

Sanner identified 600 statements that referred to what may or may not be done to the body after death, and after content analysis of these statements, she constructed 20 ‘motive’ categories. These categories were analysed to ‘discern psychologically meaningful reaction patterns’ by applying a frame of reference based on psychodynamic defence theory and resulted in six central motive complexes¹³ (table 4).

Not only can we see these discomfort reactions articulated in the free-text comments recorded during data collection by SNODs in our own findings (boxes 1–4), we can also see that non-rational reactions have been evidenced by other authors and include: *fear that doctors would hasten the death of declared donors in order to procure transplantable organs*,¹⁸ *belief that donation would negatively impact rebirth or reincarnation (deceased would be reborn blind)*³³ and later work identifying the impact of *emotional beliefs including the ‘ick’ factor and the role of ‘Body Integrity’*²⁹ (for a detailed view of all variables tested in development of the organ donor model, see Morgan and Miller²⁷ and Morgan *et al*^{29 34}). The ‘ick’ factor and concerns about body integrity are of particular relevance to eye donation and will, therefore, be discussed in more detail.

Table 4 Motive complexes and categories relating to discomfort reactions to post-death procedures (Sanner¹³)

Motive complexes	Sanner’s motive categories (for details see Sanner ¹³)
The illusion of lingering life	1. Uneasiness at the thought of cutting the dead body 2. Anxiety about not keeping the dead body intact 3. Discomfort with donation of certain organs 4. Difficulty with cutting children 5. Fear of destruction (of the body) 6. Uneasiness with exposure (via autopsy or dissection) 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 11. Apprehension about the funeral 13. Discomfort at giving useless organs
Protection of the value of the individual	5. Fear of destruction 7. Fear of disrespect for the dead person 9. Discomfort with changes in appearance 10. Apprehension about the funeral 13. Discomfort of giving useless organs 15. Distrust of the doctors
Distress, anxiety and alienation	14. Problems with the concept of death 15. Distrust of the doctors 16. Anxiety about biomedical and social development
Respecting the limits set by nature/God	12. Dislike of having one’s organ surviving in another body or having another organ living on in one’s own body 17. Anxiety about offending God/nature
Altruism	18. Helpfulness and solidarity 19. Contribution to medical research
Rationality	20. Organs from the deceased can be used in the treatment of the living

The ick factor and bodily integrity

According to Morgan *et al.*,²⁹ *ick factors* are those related to a basic disgust response to the idea of eye donation, as it involves what may be perceived by family members as interventions that are disfiguring and even disrespectful. Fear of body disfigurement is proposed as triggering defensive emotions that according to Parisi and Katz, ‘*seem to be deeply rooted in the unconscious and to have relatively little cognitive content*’ (1986: 576).³⁵ These defensive emotions are influenced by sociocultural and psychological factors developed early in childhood, strongly influenced by one’s particular culture and ethnicity, which are reported by Sherman *et al.*³⁶ to be resistant to modification.³⁶ Furthermore, defensive emotions and reactions are reported to underpin donation-negative attitudes and carry more weight in the decision-making process than donation-favourable ones. These findings potentially provide insight into why persuasive attempts that focus on rational messages fail or are less successful than expected by organisations that oversee donation and transplantation services.

A final comment here is the reference in **box 1** to ‘*eyes being the windows to the soul*’. This perception has been reported in a number of studies exploring eye donation and links to both the belief in the need to maintain the integrity of the body after death³⁷ and a concern about the deceased not being able to see in the afterlife.^{14 37 38} For some ‘*eyes, more than any other body part, personify an individual*’ (17, p1190) and, therefore, have greater potential to stimulate ‘dissonance’ for individuals approached to consider the option of eye donation.

Cognitive dissonance and the context of death

Cognitive dissonance is described as an emotional state set up when two simultaneously held cognitions are inconsistent or when there is a conflict between beliefs and overt behaviour.³⁹ Therefore, relating this to eye donation, dissonance arises when family members approached to consider eye donation are aware (eg, by media campaigns such as ‘Give the gift of sight’)⁴⁰ or are made aware (eg, by SNODS or other family members) that eye donation can reverse blindness and have to rationalise their aversion/disgust/discomfort of eye removal, which they perceive as an integral part of the person they love (as indicated in **box 1**). Lawlor and Kerridge¹⁴ go so far as to suggest that despite participants in their study ‘*recognising the potential good that could come from corneal donation, many still maintained that removing the eyes would potentially have a significant adverse effect on their ongoing relationship with the deceased*’ (Lawlor and Kerridge (p62)).

We propose that non-cognitive factors including: discomfort reactions, disfigurement concerns, the ick factor and the importance of body integrity are key areas of emotional and psychological conflict for family members approached to consider eye donation. In their secondary analysis of primary data from donating and non-donating family members in the UK, Long *et al.*¹⁷ proposed that family members engage in a series of

practical and psychological activities aimed at rationalising real or potential emotional and cognitive conflict when faced with the option of donation post death of a family member. If family members are not able to rationalise *conflict* (eg, *sacrifice of an intact body to a perceived disfiguring operation even if it is for the benefit of others*), NoK will decline donation.

A key context missing from social cognitive models and also much qualitative research into barriers to donation is the context of death. Apart from living donation, solid organ donation cannot proceed until someone has died, in the case of solid organ a death that is sudden and unexpected. Death not only robs the NoK of a significant relationship but also robs them of many of their usual coping mechanisms, imposing a sequence of events that Sque *et al.*³⁰ describe as leaving family members feeling dispossessed of physical and psychological equilibrium.³⁰

Furthermore, from a sociological perspective, Kellehear⁴¹ remarks that an understanding of ‘*“dying as a social relationship” (is) vital to understanding the levels of disagreement with organ donation due to the social basis of attachment, meaning-making and identity*’ (41, p1541). Responses indicating attachment to the deceased (eg, ‘*family reported they didn’t like the idea of someone else seeing through their loved ones eyes, box 1*’) as well as the need for an intact body (eg, ‘*only wanted internal organs donated, nothing from the outside, box 2*’) are evidenced in the national data set analysed in this paper, alongside the importance of the identity of the deceased (eg, ‘*eyes refused as wife couldn’t bear the thought of him without them, box 1*’). It is in this emotional landscape that the topic of eye donation is raised, a context that appears unique to eye donation. It is, therefore, essential that those making the approach to request eye donation understand the non-rational, emotional and sociological factors underpinning NoK decision-making if an increase in the donation of eyes is to be achieved.

While messages to support positive attitudes towards donation are now embedded in social and other media campaigns in the UK (eg, Giving the ‘Gift of Sight’,⁴² ‘Yes I Donate’ etc⁴³), messages employed to reduce negative attitudes have not taken sufficient account of the psychological, emotional and sociological factors that are specifically relevant to the donation of eye tissue. As stated in the introduction, eyes are the least donated organ and this, we argue, is because the thought of removing the eyes may stimulate intense discomfort reactions, such as disgust, concerns of visible disfigurement and dissonance that suppress positive motives (eg, attitudes) towards donating eyes.

Limitations

Data were generated by SNODs who recorded reasons shared with them by family members, and, therefore, the data reflect proxy comments. Feedback received by the working group indicates that SNODs were likely not to probe family responses, just recording ‘*family refused*’, ‘*no additional information*’ if in their view, the discussion may lead to the family declining organ donation. The detail

provided in the comments is constrained by the response format (ie, a hand-written box), limiting the amount of information that SNODs could insert leading to wide variation in length of entries ranging between 1 and 187 words (median=6, IQR=7). Thus, both the frequency and content (ie, type and level of detail) of recorded comments were variable.

We did not have access to the demographic data of potential donors included in primary data collection under the data sharing agreement, and, therefore, have not been able to include any related commentary. We are also unable to provide any commentary regarding the impact of legislative changes that took place in Wales (as of 1 December 2015)⁴⁴ during primary data collection for the service development initiative, as practice responses to these changes were still being developed and implemented.

CONCLUSION AND RECOMMENDATIONS

In view of the reported 53% of the world's population not having access to the benefits of sight-saving and sight-restoring transplantation surgery¹ and over two million people in the UK living with sight loss,² this paper presents important data that could help organisations and HCPs involved in approaching bereaved family member for eye donation redesign modes of approach and the structure of consent conversations. In view of the data reported that potentially, over 2000 eyes did not become available for use in transplant operations and research due to family members declining this donation option, further research is needed on the construction, delivery and content of the donation conversation. We, therefore, propose the following recommendations for future service and communication strategy development.

- ▶ *Communicate propriety of the donation operation*—the 'sacrifice' of an unscathed body could be an important barrier to actualising donation even in populations where there is a high level of awareness of the benefits of transplantation.⁴⁵ The propriety of the donation operation needs to be stressed in public education and in discussions with the bereaved family approached about organ donation as discovering what worries people about organ donation is the first step towards crafting more effective organ donation campaigns.³⁴
- ▶ *Explore the potential of a disc-only corneal retrieval procedure to increase acceptance of donation*—enucleation (removal) of the entire eye (as usual in the UK) has been reported as being a potential barrier to donation of eye tissue by relatives in view of disfigurement concerns. Removal of the corneoscleral disc only has been aligned with higher consent rates,⁴⁶ however, current robust data about whether this would be a more acceptable intervention with decision makers are missing. Research comparing consent rates for these two options would be a valuable addition to the knowledge base on which to base future service planning.

- ▶ *Improve public education regarding the donation process*—public awareness campaigns as well as consent conversations with families currently focus on the benefits of transplantation. In contrast, little public education has centred on the donation process itself, which could prepare individuals for this potential life event. According to Siminoff *et al*, 'Since it is not reasonable to expect that family decision-makers can or even should relinquish strongly held beliefs about organ donation when experiencing the severe stress of a loved one's death, prior education is the best mechanism we may have to inform the public and prepare families for an organ donation request' (18, p76).
- ▶ *Explore how the request process affects acceptance of donation*—there remains significant room for improvement in the request process, as to date this pivotal aspect of the donation process has received little attention. Of note, there has been no research looking into the impact of the hierarchy of organs outlined in the consent conversation. For example, if a patient is suitable to donate all organs and tissues, the first organ mentioned is usually kidneys, followed by other abdominal organs and tissues, thoracic organs and tissues, then tissues (within which eyes are listed). It has been proposed that the order in which organs are requested may affect donation rates for eyes due to what has been referred to as 'list shock'—the idea that family members may be overwhelmed by the 'list' of organ and tissue that can be donated (this term was first coined by Margaret Verble and Judy Worth (personal communication, 21 August 2020)).
- ▶ *Explore processes for assessment of familial responses to information provided during the consent conversation*—future research should explore processes for assessing familial responses to information shared in consent conversation, and how HCPs conducting conversations may appropriately and sensitively explore areas that provoke a reaction (instead of avoiding them). Investigations of the latter type are of particular need in light of evidence indicating that many HCPs are poor *prima facie* judges of who may or may not be willing to donate.¹⁸
- ▶ *Future research topics*—topics for further research include investigation of potential demographic and/or regional differences in reasons for decline of eye tissue; the impact of legislation changes (ie, from 'opt-in' to 'opt-out' (deemed consent) on eye donation in each of the UK nations and construction, delivery and content of donation consent conversations (eg, exploring if and how systematic aspects of conversations related to seeking agreement to organ/tissue/eye donation may be related to outcomes (ie, acceptance or refusal)).⁴⁷

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