Eye donation in Palliative and Hospice care settings: patient views and experiences.

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Introduction: In the UK over two million people are currently living with sight loss with this figure predicted to rise to approx. four million by 2050. Patients who die in palliative and hospice care settings could potentially donate eye tissue, however, the option of eye donation is not routinely raised in end-of-life planning discussions. Research evidence suggests that health care professionals (HCP) are reluctant to discuss eye donation as they perceive it as something that will distress patients and their carers [1–3].

Aim: To gain the views of **patients** and carers about the option of eye donation being raised with them as part of end-of-life care planning. Only findings from patients are presented. For more information and carer responses please see the final report for the study [4].

Methods: Due to COVID-19 restrictions all interviews were undertaken via Microsoft Teams**.**

Participants: Thirty-nine patients (21 HC, 18 HPC) and Twenty-three carers (13 HC, 10 HPC).

Key findings:

1. Patients support the option of eye donation being raised with them.
2. Findings indicate low levels of patient awareness and low levels of approach to patients and family members about the option of eye donation (ED).
3. Patients expect HCPs to raise the option of ED and patients expect to make the decision regarding ED.

1) 94% (n=33/39) of patients interviewed indicated that they were in favour of eye donation being raised with patients receiving EoLC

"Yes, yes, I think it perhaps should be part of the end of life questionnaire, but maybe people should be asked earlier rather than later what they feel" (P00101, HPC).

"Yes, I think, everybody should be asked if they want to do it because sometimes…it's not something you think about. Even when you know you're…not going to be here for much longer …It…might be the one thing that they want to--- to donate and they don't want to donate anything else. So, if you ask them it's--- it's up to them, isn't it? It's their choice". (P00404, HPC Patient).

2) 95% (37/39) of patients interviewed were not aware that ED was a potential option they said ED had not been raised with them during their current care programme.

"Absolutely not, nobody at all, up until N coming in yesterday to arrange this interview, nobody's said a single word to me, no. And I've been, I'm not. I'm not very often in hospital, but when I've been in and obviously this time we are talking, I am heading towards the end, I'm not, I've not got five years left anymore, you know, so, but no, nothing has been said at all" (P00803, HPC).*

3) 97% (38/39) indicated that HCPs (rather than patients or families) should raise the option of ED and not rely on the patient or family bringing this up.

"I think it is their [HCP] job, to inform you, put it down on paper what, if you want to donate, then, yes, if you don't want to donate. It's like when, when people are coming along and they're saying do you want a DNR notice writing on that patient, it would be the same thing in my opinion". (P00308, SPCS)

Conclusion: It is imperative that patients who would want to be a donor are identified and assessed for eligibility as part of high-quality end of life care. Evidence from the past 10 years indicates that little has changed regarding the identification, approach, and referral of potential donors from palliative and hospice care settings. Lack of action may be due to perceptions held by HCPs that patients would be unwilling to engage in discussions regarding the option of eye donation pre their death. This perception is not substantiated by empirical research.
Impact: To ensure that eye donation is facilitated for those patients who meet the eligibility criteria and state their wish to be a donor.

Refs: 1.Edwards P. Corneal donation within palliative care: a review of the literature. Vol. 11, International journal of palliative nursing. 2005. p. 481–6; 2. Wells J, Sque M. 'Living choice': the commitment to tissue donation in palliative care. Int J Palliat Nurs. 2002 Jan;8(1):22–7. 3. Kent BC. Protection behaviour: A phenomenon affecting organ and tissue donation in the 21st century? Vol. 41, International Journal of Nursing Studies. 2004. p. 273–84; 4.Long-Sutehall T, Bracher M, Mollart S, Wale J. Eye donation from palliative and hospice care contexts: the EDiPPPP mixed-methods study. *Health Soc Care Deliv Res* 2023;**11**(20).
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