Corneal donation in the hospice setting: A questionnaire survey of multi-disciplinary team members’ knowledge and experience, to inform an education programme for staff, with the aim of increasing corneal donation from this hospice population.

Aims

To determine the knowledge and practice of corneal donation in staff at St Nicholas Hospice Care (SNHC) using a questionnaire, to inform design of a staff education programme, aiming to increase patient choice and increase corneal donations. To compare staff knowledge and experience of corneal donation with the 2011 Gillon et al study.

Methods

All SNHC clinical staff (working in ward, community and day services) were invited to complete a questionnaire (Fig 1) based on Gillon et al. A box of questionnaires was placed in important clinical areas with a slot for them to be returned anonymously.

Results

St Nicholas Hospice Care is a well-established charitable foundation with ten inpatient beds, serving a population of 285,000. 37 multi-disciplinary staff responded (approx. 100 clinical staff had access to the questionnaire). 92% of respondents never or rarely raised the subject of corneal donation with patients or relatives. 76% had not received any information or training regarding corneal donation. 81% felt they did not know enough about corneal donation to discuss it with patients or relatives. And like Gillon et al, knowledge and training were identified as significant barriers to raising these discussions.

Conclusion

The results mirrored that of the previous study, suggesting the 2011 Gillon et al paper’s findings are generalisable to other hospice populations. Lack of knowledge and training were identified as significant barriers to conversations about corneal donation.

Like many conversations at the hospice, raising the subject of corneal donation could be perceived as difficult, but improving staff knowledge and awareness could enable these conversations to become more commonplace, and thus increase patient choice, and the number of corneal donations.

References


Figures

Figure 1. Questionnaire enquiring about previous experience and knowledge of corneal donation

Introduction

Corneal transplant saves sight. In the UK there is a shortage of approx. 500 corneas each year. Corneal retrieval can take place in hospices and funeral directors. 26,000 people die in hospices annually and around half could donate their corneas. The corneas are one of the few tissues that patients (most types of) cancer can donate. Each donation can be used to help up to four people.

A recent questionnaire of staff knowledge and experience of corneal donation in twelve UK hospices found that only around a third of staff had ever been involved in organising a corneal donation, that around a third of those had experienced difficulties with the process, and that 90% of respondents rarely or never discussed corneal donation with patients. Only 43% felt that corneal donation should routinely be discussed with eligible patients, and 67% either felt, or were not sure, that corneal donation was too distressing to be discussed with patients and families. There is little available evidence in the literature to support these fears. The authors' personal experience is that many patients, despite having previously registered for organ donation, were under the impression that there would not now be any body part they could donate.

How often do you personally raise the subject of corneal donation with patients and/or their relatives?

Do you feel you know enough about corneal donation to discuss it in general terms with patients and/or their relatives?

How many years have you worked in Palliative Care?

Where can corneal removal take place?

Would any of the following prevent corneal donation from a patient?

How to arrange a corneal donation

Arranging a corneal donation is very simple. After death, a staff member or relative contacts Tissue Services on their 24hr pager on 0800 432 0559. The Specialist Nurse in tissue donation will call the healthcare provider for the medical history to assess eligibility, and then contact the next of kin to gain consent for donation. They will then arrange a convenient time to retrieve the corneas at the hospice, hospital or funeral home within 24 hours of the patient’s death.

References


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