Improving Eye Bank Tissue Donations in a Hospice Population

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Terri S, a patient on the Palliative Care Unit at the University of Rochester Medical Center, passed away in May of 2011. It was her and her husband's hope to donate her eyes for corneal transplantation; unfortunately the possibility of sepsis at the time of death prevented her from becoming a donor. This was an obstacle that had been encountered before on the hospice unit, but Terri's strong wish to donate proved to provide the inspiration for DF, a nurse on the hospice unit, to develop a program to facilitate the process of corneal donation for those patients and families with that desire.

As a brief background, the number of domestic surgeries (keratoplasty or non-keratoplasty) utilizing preserved corneas or corneal segments and supplied by a US eye bank source increased in 2013 to 48,229 as did US donated corneas utilized internationally to 20,213 in 2013 (both reflecting a 3% rise from 2012 statistics).[1] Based on US Eye Banking Statistics, 738,404 death referrals were made to all U.S. eye banks in 2013 and of these, 168,977 (22.9%) were determined to be eligible for donation. Amongst those deemed to be eligible, 62,274 went on to become donors (36.9% of all those eligible).[1]

The Growth of Hospice Care

The National Hospice and Palliative Care Organization estimates that 1,113,000 deaths occurred in the U.S. while under the care of hospice in 2012 (44% of all deaths)[2]; approximately one-third of those were located in a hospice inpatient facility or acute care hospital at the time of death. The number of patients and families served by hospice has steadily increased year after year with a growth of 22.7% from 2008 to 2012 (as measured by total number of hospice patients served per year).[2] Corneal donation is one of the few tissues that those with active cancer can potentially donate; the incidence of ocular metastases in corneal donors with active malignancy is very low (0.6-3.7% in a study by Lopez-Navidad)[3] and tumor transmission to corneal tissue recipients has not been observed. We propose that the hospice population is an under-represented and potentially under-utilized source of eye tissue donation.

Corneal Donation Among Hospice Patients

The donation rate amongst hospice individuals seems to be exceedingly low though this statement is based on limited data. At the time of this writing, rates reflecting corneal donation practices among those enrolled in palliative care in the United States were not available. In studies conducted in Australia, 50 patients became eye donors out of over 2000 (2.5%) total donors, in a one-year period in a Sydney metropolitan area.[4] A retrospective chart review of 100 consecutive hospice inpatient deaths in the UK revealed 52% of patients had no documented contraindication to corneal donation; no individuals had been approached or went on to tissue donation.[5] Fortunately, there is evidence that donation rates can be affected by educational intervention. Stiel et al, from Germany, have shown that rates of potential corneal donors (those with no obvious contraindications), and subsequently actual corneal donation rates, (in which palliative staff members raised the possibility of corneal donation) can be similar in a palliative care unit to

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rates among other patients in the hospital.[6] In their analysis 32.5% of all palliative care deaths were potential corneal donors and 48.9% of those went on to donation once the eye bank and the palliative care unit began working in conjunction, comparable to 24.6% and 44.9% in a university hospital setting.[6]

Barriers to Hospice Corneal Donation

It has been suggested that the main barriers to corneal donation amongst hospice inpatients are institutional barriers leading to lack or failure of the hospital staff to identify potential donors and to offer the opportunity to donate.[7, 8] Gillon et al surveyed multi-disciplinary hospice staff with direct patient contact in the UK (434 returned/704 questionnaires distributed). Greater than 90% of respondents rarely or never raised the topic of corneal donation with only a small minority feeling that it was their duty. Health care worker reluctance to bring up the topic with patient and/or family may be due to fear of causing distress or sense of burden amongst family members or from lack of knowledge or training to discuss donation.[9] Other health care workers may not believe that discussions of donation are a part of the hospice culture or they have not had exposure to that aspect of donation.[9]

Other major obstacles to corneal donation in a palliative care/hospice care setting include donor and/or family perception of ineligibility. In Carey and Forbes' study from 2003 over 80% of hospice donor families (out of 12 altogether) were surprised their relative was eligible to donate.[7] Patients or families may be unable to make an informed decision due to a lack of necessary information.

Patient and/or family beliefs may also contribute to considerations about tissue donation. Lawlor and Kerridge suggest concerns surrounding disfigurement or the personal significance the eyes hold may contribute to lower donation rates.[10,11]

An additional obstacle that is not commonly mentioned in the literature is the potential difficulty on the part of the eye bank facility in converting a palliative care referral into transplantable tissue. Contraindications for transplantation include those with risk factors for HIV and Hepatitis infection, persons who are deceased and have a documented medical diagnosis of sepsis or documented clinical evidence consistent with a diagnosis of sepsis that is not explained by other medical conditions, people with a history of rapid progressive dementia or degenerative neurological disease, leukemia or active disseminated lymphoma, or intrinsic eye disease such as active intraocular inflammation or malignant intraocular tumor.[12] From the perspective of eye banking facilities, donors from hospice facilities may be an under-utilized population based on concerns inherent to those patients enrolled through a palliative care or hospice care setting and the stringent criteria applied to suitable donors. Dementia as the primary diagnosis accounts for 12.8% of hospice admissions and those patients aged 75 or older account for 68.2% of hospice admissions.[2] Medical record or autopsy findings, i.e. evidence of sepsis, dementia, unknown cause of death, are responsible for 22.0% of all discarded corneas based on EBAA statistics from 2013.[1] Sepsis accounts for about half of the tissue not released within this subset. It may be the assumption or direct experience of an eye banking facility that the quality of tissue or the utilization of tissue from a palliative care donor is problematic and may be avoided.

Benefits to Hospice Corneal Donation

Motivations to corneal donation can be varied.[7, 13] Relatives or patients may feel a societal duty to donate. Others may derive satisfaction from the idea of "living on" through the donation or at the thought of bringing happiness to the recipient. Donations originating from a hospice setting share a unique characteristic in that patients and their family members may have more time to consider end-of-life wishes, including organ and tissue donation. This is an opportunity that lends itself to family and patient education regarding the utility of corneal donation, not only for transplant purposes but also for research and training, time to answer questions, the ability to prescreen appropriately, and to institute eye care for the comfort of the patient and the preservation of the cornea.

Terri's Eyes Project, a special program launched in November 2011 and continuing presently, is an effort at the University of Rochester Medical Center-Strong Memorial Hospital, and created through the dedicated efforts of a hospice nurse (DF) and the former Clinical Director (TS) of the Rochester Eye and Tissue Bank (RETB) to address the barriers that prevent corneal tissue donation among a hospice inpatient hospital unit. This is accomplished through a multi-pronged approach, namely by addressing 1) institutional barriers, by training nurses to become skilled in educating patients and families about eye and tissue donation, 2) knowledge barriers, by educating patients and families so they are able to make an informed decision, and 3) quality assurance, by improving sepsis screening tools before recovery by monitoring body temperature and drawing a blood sample for a white blood cell count blood test prior to death with patient or family's permission.

Once a patient is admitted to the hospice unit, a Gift of Life referral form is completed for those patients less than 80 years of age, and the Rochester Eye & Tissue Bank is contacted for an initial donor screening. If the patient is preliminarily deemed to be eligible based on current admission and medical history, contact information is supplied to RETB and a hospital staff member who has been certified to educate patients and families about eye and tissue donation, termed a Gift of Life Advocate, approaches the patient and family to educate and advocate for patients' and families' rights to make an informed decision about organ donation. The patients and/or families are approached prior to death so they have the time to ask questions and to consider the impact a donation could make on their family as well as the recipients. One major barrier to accepted corneal donation from hospice inpatients in Rochester, NY had been difficulty in ruling out sepsis. By educating patients and families prior to death, the patients are given the opportunity to have a blood sample drawn for a white blood cell count prior to the patient's death, which provides important information regarding donor eligibility.

Our future interests for this project include collecting data on the donation patterns within this hospice population as well as quality and utilization of the tissue recovered from our hospice patients. Patients enrolled in palliative care may have higher rates of corneal dryness from exposure, medication use, or oxygen supplementation and may not be able to voice their discomfort if minimally responsive or with altered mental status. This may also impact the epithelial integrity and therefore the quality of the recovered tissue. Per the EBAA, the number of corneas intended for transplantation, but not used, numbered 32,456 in 2013, mostly secondary to poor tissue suitability based on slit lamp examination (responsible for 38.2% of all discarded corneas).[1] To address the issues of patient comfort, with the possible additional benefit of improving corneal surface, a quality improvement initiative has already been implemented in the hospice unit to improve the quality of eye care with the addition of ocular lubrication, the frequency determined by the level of patient responsiveness.

Based on early results, the program has been a success in many ways. To date, six nurses on the hospice unit have been trained as Gift of Life Advocates. The number of corneal donations received from this hospice inpatient unit has increased exponentially from 3 donors over the entire year of 2010 to 48 donors over a 2 year period after the program was officially launched (2011- 2013), representing an 8-fold increase in annual donations from this unit.

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