

Original Article

Corneal Donation from Cancer Patients

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Abstract.

Background: Corneas from donors with systemic malignancies are usually accepted for transplantation and represent a major source of donor material for keratoplasty in many Western countries. Since, corneal donation from cancer patients has not been reported in Taiwan, and it is also rare in other Chinese societies, we report our limited experience.

Methods: From April/2004 to Dec/2007, health care professionals (HCPs) in our cancer ward tried to approach the cancer patients there about the option of corneal donation. After obtaining patient consent, we consulted our ophthalmologist to evaluate the eligibility of corneas and checked VDRL, anti-HIV, anti-HCV, HBsAg, anti-HBs and anti-HBc to exclude infectious diseases. After the consenting patients were deceased, the ophthalmologist obtained their corneas within 12 hours.

Results: During the study period, 9 terminally ill cancer patients gave their consent. However, corneal procurement succeeded in only three cases. Among the six cases of unsuccessful procurement, one case was an HBV carrier, two cases were not considered qualified by our ophthalmologist, the families of two cases refused the procurement in spite of the donors' consent, and one case withdrew consent.

Conclusions: Corneal donation from cancer patients is a complex decision, not only for donors but also for their family members. According to our limited experience, it is difficult but not impossible to encourage cancer patients for corneal donation. However, there is a long way to go in Taiwan.

Keywords : Corneal donation, Systemic malignancies, Chinese societies, Taiwan

原著論文

癌末病人捐贈眼角膜

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中文摘要

背景: 在許多西方國家，來自於癌末病患所捐贈的眼角膜已經成為眼角膜移植的重要來源。但是在台灣以及其他華人社會，癌末病患捐贈眼角膜卻很少被提及，因此吾人

提出報告。

方法: 從 2004 年 4 月至 2007 年 12 月, 本院癌症病房的醫護人員徵詢癌末病患捐贈眼角膜的意願。當病患填立同意書之後, 醫護人員便照會眼科醫師並檢測 VDRL、anti-HIV、anti-HCV、HBsAg、anti-HBs 及 anti-HBc 以排除感染性疾病的可能。當病患過世之後, 眼科醫師在十二小時內摘取其眼角膜供移植用。

結果: 在研究期間, 有九位病患填立同意書, 不過最後卻只有三位成功地捐出眼角膜。在其餘六位病患中, 一例被查出是 B 型肝炎帶原而被排除, 兩例是眼科醫師擔心癌症轉移而不願意執行手術, 兩例是家屬拒絕而無法執行, 一例是在死亡前撤除其原先填立的同意書。

結論: 癌末病患捐贈眼角膜一事, 對於病患本人、家屬和醫護人員都是一件複雜的事。根據吾人有限的經驗, 要在台灣推動此一風氣, 雖非不可能, 但卻是困難重重, 因此未來仍有極大的努力空間。

關鍵字: 眼角膜捐贈、癌症、華人社會、台灣

BACKGROUND

In the USA, UK, France and Spain, the cadaveric organ donation rates were 22.7, 13.5, 16.8 and 31.5 donors per million population (pmp) in 1998[1,2]. However, according to a report from the Taiwan Organ Registry and Sharing Center, founded in 2002, there are about 7000 patients/year waiting for donation, but the number of donors is only about 100 persons/year. The donation rate is only 6.6 pmp, far below those of the above Western countries.

The failure of the current system to procure organs, tissues, and corneas for transplantation may be attributed to a number of factors[3]. Because procurement consists of several steps, problems can occur at any point in the procurement process. First, health care professionals (HCPs) sometimes do not approach donor-eligible families to request donation. The reasons may be HCPs' lack of knowledge of donor eligibility criteria, disinterest and discomfort with the procurement process, or time constraints. Secondly, even when HCPs do properly request an organ donation,

requests are refused by families over 50% of the time.

The majority of organs are donated by families of patients who fulfill brainstem death criteria in intensive care units. Many of these patients have been well previously and then died suddenly. Their families are often reeling from the unexpected loss of a loved one, so decisions are inevitably entangled with many other emotions and stress[4,5]. The experiences of families whose relatives die in a hospice setting may be quite different[6]. Although distressed, these families have often had more time to come to terms with impending death. Such people may have discussed wishes regarding funerals or organ donation and represent an ideal population for consideration of donation, in particular of tissues such as corneas. Many difficult issues such as accepting the diagnosis of brainstem death and saying goodbye while the patient is warm, ventilated and has a heartbeat may not apply[5]. Since corneas may be removed up to 24 hours after death, corneal donation will not interfere with the family spending time with their recently deceased relative.

In the USA, between 1965 and 1968, systemic malignancy was the most frequent diagnosis (39%) among patients donating their corneas to the New England Eye Bank[7]. In the UK in 2000, the annual number of corneal donors to Manchester and Bristol eye banks was 2000, 400 of whom (20%) died from

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Table 1. Characteristics of consented cancer corneal donors

	Age (years)/sex	Cancer diagnosis	Date of consent	Outcome
Case 1	64/male	Hepatoma	04/2004	Failure
Case 2	40/male	Lung cancer	08/2005	Success
Case 3	67/female	Melanoma	11/2005	Failure
Case 4	66/male	Multiple myeloma	03/2006	Failure
Case 5	39/male	Buccal cancer	11/2006	Failure
Case 6	20/male	Soft tissue sarcoma	02/2007	Failure
Case 7	56/male	Esophageal cancer	02/2007	Success
Case 8	64/female	Pancreatic cancer	03/2007	Failure
Case 9	53/male	Melanoma	05/2007	Success

cancer; the total annual national cancer death number was 151,200[6]. In France, corneas from donors with systemic malignancies represented 30% of donor material in the eye bank of the University of Besancon[8]. In the USA, there were 45,897 cases of corneal transplant and 12,032 cases of kidney transplants in 2000. The former outnumbered the latter, obviously. Quite differently from the USA, there were 86 cases of cadaveric corneal transplant and 82 cases of kidney transplant in Taiwan in 2003. According to the statistics, corneas were most likely to be identified and donated when the donor was also an organ donor. When this occurred, it was more a by-product of the organ donation than a deliberate act separate from the organ donation. It is clear that in Taiwan, almost all the cornea donors come from brain death patients, without other resources such as corneal donation from cancer patients.

Studies about the attitude toward corneal donation in the Chinese societies are minimal. Yew et al. reported the knowledge and beliefs on corneal donation in Singapore adults[9]. Among 544 subjects, 69.8% were Chinese. Sixty-seven percent of the subjects were willing to donate their corneas. However, talking about corneal donation to a healthy person is quite different from making a decision about corneal donation when decease is impending. In 2004, there were

about 35,000-40,000 patients who died of various malignancies in Taiwan. We consider that donor material from patients who died of systemic malignancy could provide a large source of material for keratoplasty. However, corneal donation from cancer patients has not been reported in Taiwan, and it is also rare in the other Chinese societies. Here, we report our very limited experience on this issue.

METHODS

From April/2004 to Dec/2007, 9 cancer patients consented to donate their corneas after being approached by HCPs in our cancer ward. The patients' characteristics are listed as Table 1. After obtaining the consent, we routinely consulted our ophthalmologist to evaluate the eligibility of corneas and checked VDRL, anti-HIV, anti-HCV, HBsAg, anti-HBs and anti-HBc to exclude infectious diseases. There were two kinds of cornea harvest, procedure according to the donor's preference. The first one was enucleation. The enucleated eyeball was disinfected with 5% better-iodine and the cornea was removed and preserved in optisol-GS. The second method was in situ cornea removal. After harvest, the cornea was preserved in optisol-GS. After the procurement, delicate suture of the eyelids was done so there would be no cosmetic difference before and after the harvest procedure. For

Table 2. Characteristics of cancer whole-body donors

	Age (years)/sex	Cancer diagnosis
Case A	62/male	Duodenal cancer
Case B	42/female	Breast cancer
Case C	44/male	Pancreatic cancer

the recipient, penetrating keratoplasty with or without secondary intraocular lens implantation was performed. After keratoplasty, steroid eye drops were given to prevent rejection.

RESULTS

During study period, 9 terminally ill cancer patients gave their consent (Table 1). However, corneal procurement succeeded in only three cases. For Case 2, cornea harvest was done by in situ removal at a special room (House of Peace) in our cancer ward. For the first recipient, graft rejection was noted on 08/01/2007, and his vision was HM/20 cm on 08/20/2008. For the second recipient, no complication was noted during transplantation. No post-operative vision was recorded, and she was lost to follow-up on 04/26/2006. For Case 7, cornea harvest was done by enucleation at the House of Peace. However, the donor cornea was edematous, so transplantation was cancelled due to poor donor cornea quality. For Case 9, cornea harvest was done by enucleation at operative room. For the first recipient, no complication was noted during transplantation. His vision was 0.02 on 05/08/2008. The cornea was clear, without rejection. For the second recipient, no complication was noted during transplantation. Her vision was 0.06 on 05/06/2008. The cornea was clear, and no rejection was noted.

In Cases 2 and 9, the corneal procurement was done immediately after the donor died. In Case 7, the families performed some religious rituals for 8 hours and then corneal procurement was done.

Among the six cases of unsuccessful procurement,

one case (Case 1) was an HBV carrier, two cases were not considered qualified by our ophthalmologist, the families of two cases refused the procurement in spite of the donors' consent, and one case withdrew consent.

DISCUSSION

Since the cornea is part of the human body, there are strong intervolving relationships between corneal donation and donation of other organs. In accordance with current legislation in practically all Western countries[10], the process of organ donation depends ultimately on the decision of the deceased's family to give permission for extraction. Family refusal to give consent for the extraction of the deceased's organs and being unable to identify potential donors represent the most important factors limiting donation success[11]. Terminally ill cancer patients always have a period of time to think about the decision on organ (corneas) donation and have some discussion with their families. It means that the donation decision could be made by patient himself, instead of by his family. However, in our limited experience, the donor's wish was ignored by their families most of the time. In Taiwan, the decision-making authority of family members is often superior to that of the donor, although talking with family members about the donation decision is very important in Western countries[12] and the decisions are much easier if the deceased's wish are already known[6]. For case 5, although his spouse supported the donation decision made by her husband, his mother declared that she would commit suicide if someone dared to remove the corneas from her son

and she would never change her mind. After several discussion with our social worker, she still insisted on her decision. Therefore, the donation failed in spite of the patient's and his spouse's consent. In case 8, the patient gave her consent with full consciousness, but her elder son declined and stated that he would like to keep his mother's body intact. In Chinese society, the family is considered as the core structure. To maintain a family's power, influence, and capital, it is necessary for the Chinese to follow a large family system, and the Taiwanese family is characterized by reciprocal relationships reinforced by hierarchical authority[13]. Based on this cultural framework, agreement from the important family members is a crucial factor influencing their donation decision. The important persons in a Taiwanese family are usually the grandparents, parents (father in particular), spouse (husband in particular), the oldest sibling (when adult children are not available), and the oldest child. Nevertheless, the priority of identifying the key persons involved in this decision-making process may not have been identical to their legal position. For example, the donor's parents, elder siblings, children, and spouse, in that order, often play important roles in decision-making, rather than the donor's spouse who, if present, may sit in the last position for decision-making, just like our case 5. To overcome the above problem, we discussed the corneal donation with all our 9 patients when they were able to make a decision before their death. Otherwise, it would be almost impossible to obtain consent from the family members after the patient's death.

Since corneal donation from cancer patients has not been reported in Taiwan, HCPs here including ophthalmologists are not familiar with it. The ophthalmologist in our hospital had too many concerns and refused to perform corneal procurement for case 3 and case 4 even though the Eye Bank Association of America and the European Eye Bank Association did not exclude the donors with melanoma or multiple myeloma[7]. During our study period, there were 3 cancerous patients who consented to donate their

whole-body for medical research. Their characteristics are listed in Table 2. Theoretically, they could donate both their corneas and whole body at the same time. However, this was not planned, and we never approached these 3 potential donors and their families for the corneal donation. In the USA, the organ/tissue procurement procedures are regulated under the Conditions of Participation (COP) rules, which stipulate that all deaths in hospitals must be reported to the local organ procurement organization (OPO). The OPO or its designee then tries to obtain consent for donation. Since there is no such legislation in Taiwan, HCPs are not obligated to approach the potential donors.

The follow-up periods of our recipients were short, and the public may worry about the safety of corneas from cancer patients. There was a long-term retrospective analysis of 73 patients who received 86 grafts from donors with various systemic malignancies including 5 hematological malignancies. These patients were followed for a mean of 127 months. There was no increased incidence of malignancy or higher mortality in the studied patient population when compared with a reference population. There was no evidence of transferring the same malignancy to any of the recipients[7]. Salame et al. made a study related to the incidence of cancer transmission through corneal transplantation in France. Using data from a cancer registry, the authors compared the incidence of cancer in recipients of corneas coming from donors with malignancies (40 patients) with that in recipients of corneas coming from donors without malignancies (103 patients). They found no statistical or clinical evidence to suggest the transmission of cancer from donors with malignancies via corneal transplantation[8].

Currently, most cancer patients in Taiwan spend their last days in the hospital, even though they always wish to be at home. Therefore, it is natural that HCPs will be the closest to the family members of the deceased. However, most HCPs show negative attitude to the term "death". They do not want to discuss the

truth about cancer and death with patients. If telling the truth about cancer is unavoidable, they try not to mention the severity or prognosis of the cancer. If the discussion about the severity or prognosis of the cancer is unavoidable, they will try not to mention “death”. It is obvious that without talking about “death”, HCPs can not touch the topic of organ or tissue donation. Without the discussion of corneal donation from HCPs, cancer patients and their families hardly know that they could donate their corneas to help blind people[7].

Case 6 gave his consent for corneal donation but declined a few days later during the pre-donation transition. He declared that he would like to see heaven with both his eyes intact. For a cancer patient who agrees to be a corneal donor, the pre-donation stage refers to the period of time from when the donor signs the donation consent to the time the donor is deceased. During this stage, the donor and donor’s family may suffer from intense physical, psychosocial, and spiritual difficulties. We could not find any study of the needs, worries and expectations of cancer patients being potential corneal donors during this stage. Therefore, further study is warranted.

In Taiwan, one of the special cultural beliefs about corneal donation is that without eyes or corneas, the deceased can not find the way home. The concept of a homeless soul is a nightmare for Taiwanese. In Western countries, studies on donation of the eyes with multiorgan donors were made. To our surprise, aesthetics or the concern that the deceased would need the eyes in an afterlife were the most common reasons cited for refusal[6]. It is considered in popular culture that the fear of mutilation of the body extends to the mutilation of the of deceased’s beauty, identity or personhood by removal of the eyes[5]. Similarly in Taiwan, there is another very common belief in Buddhist idea, i.e. “To keep the body whole is necessary to move to the Western happy land”. Corneal donation will destroy the wholeness of body.

There are few studies focusing on the topic of

corneal donation from cancer patients. Carey and Forbes in the UK tried to explore the experiences, attitudes and feelings of relatives who consented to corneal donation of a loved one who had died of cancer. Almost all were glad they had agreed to donation[6]. We would like to emphasize that for the majority of donor families, organ donation was a positive end to the otherwise senseless death of a loved one[4,14,15]. In Taiwan, people always consider cancer as a bad fate; therefore, HCPs could emphasize that cornea donation is a positive outcome from what is otherwise a tragedy.

Most Taiwanese share cultural roots with the Chinese. We consider that while taking care of Taiwanese and Chinese corneal donors with cancer and their families, HCPs should learn the cultural, ethical, and religious backgrounds, which often frame their client’s decision-making regarding donation and their need for help. In fact, we also need to do some study to understand the needs and expectations of cancer patients who are corneal donors during the transition of getting through the stressful time. HCPs should also know that the persons who legally sign the donation consent form may not be the key persons in a Chinese donor family. Chinese donor families like to be led by the key decision-makers to meet together and discuss such a sophisticated ethical issue as organ/corneal donation. Therefore, HCPs are encouraged to find out the key decision-makers in a Chinese donor family and ask them to call a family meeting[16].

HCPs must recognize that organ or tissue donation is not just a surgical procedure, but a complex decision for donors and also for their family members. In this report, we have tried to emphasize that most cancer patient could donate their corneas to help others, not only in Western countries but also in Taiwan. According to our very limited experience, it is difficult, but not impossible, to encourage cancer patients for corneal donation. However, there is a long way to go in Taiwan.

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