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Anything but the Eyes: Culture, Identity, and the Selective Refusal of Corneal Donation

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Abstract

At the time that a patient is diagnosed as brain dead, a substantial proportion of families who give consent to heart and kidney donation specifically refuse eye donation. This in part may relate to the failure of those involved in transplantation medicine and public education to fully appreciate the different meanings attached to the body of a recently deceased person. Medicine and science have long understood the body as a "machine." This view has fitted with medical notions of transplantation, with donors being a source of biologic "goods." However, even a cursory glance at the rituals surrounding death makes it apparent that there is more to a dead body than simply its biologic parts; in death, bodies continue as the physical substrate of relationships. Of all the organs, it is the eyes that are identified as the site of sentience, and there is a long tradition of visual primacy and visual symbolism in virtually all aspects of culture. It therefore seems likely that of all the body parts, it is the eyes that are most central to social relationships. A request to donate the eyes therefore is unlikely to be heard simply in medical terms as a request to donate a "superfluous" body part for the benefit of another. That the eyes are not simply biologic provides one explanation for both the lower rates of corneal donation, compared with that of other organs, and the lack of adequate corneal donation to meet demand.

The eye mediates conversations, imparts information, and expresses, or conceals, thoughts and emotions. The eye glances and glares and stares, softens and hardens, winks at a friend and blinks in amazement, and finally closes in ecstasy or horror, sleep or death (1).

At the time that a patient is diagnosed as brain dead, family members are not only asked to consider whether they are willing to donate their loved ones' organs but also the more specific question of which particular organs may be used. One relatively common refusal is that of the cornea: large data sets from the United States and Australia demonstrate that 30% of families who agree to donate their loved one's heart, lung, and kidney, specifically refuse corneal or whole eye donation (2, 3). Studies of donor families from the United Kingdom (4) and surveys of the general public from

Australia (5), Europe (6), and the United States (7, 8) find that when individuals indicate unwillingness to donate particular organs, this restriction invariably includes the eyes.

This selective reluctance to donate eyes exists despite the fact that the general public are both supportive of transplantation and aware of the need for donated organs and corneas (7, 9, 10). One explanation for this is the failure of those involved in transplantation medicine and public education to fully appreciate the different meanings attached to the body of a recently deceased person.

Medicine and science have long understood the body as a “machine.” Viewing the body in this way allowed generalizations that permitted the scientific identification, classification, and treatment of disease, and enabled the physician to treat the body (and the patient), with detachment. With the development of transplantation throughout the mid-20th century, the possibility that pathologic organs from one person could be effectively replaced with healthy organs from another fitted perfectly with this mechanistic idea of the body. Bodies were seen as having collective medical utility, and donors, more specifically, were a source of biologic “goods.”

However, even a cursory glance at the rituals surrounding death and the social aspects of dying makes it apparent that there is more to a dead body than simply its biologic parts. The moment of death does not immediately sever the complex web of relationships between the recently deceased and their surviving family members. These ongoing relationships are evident in the care and respect with which a dead body is treated and also in the myriad behaviors and rituals associated with death and bereavement. The process of grieving thus can be seen as a social process that allows family members and friends to come to terms, with the gradual loss of their relationships with the deceased, and a way for the deceased to become less “present” in the lives of others.

If we accept that bodies form the physical substrate of relationships, then it seems highly likely that of all the body parts, it is the face and most particularly the eyes that are most central to social relationships. In contrast with relative anonymity of the internal organs, we look into each other's eyes when we talk, we attach meaning to particular “looks” or gazes, and we locate intelligence, thought, identity, and sentience within the eyes. The role that eyes play in social relationships is further evidenced by the extent of visual symbolism that exists in virtually all aspects of culture.

Vision is the most dominant of all the senses, and as noted by Freud (11), there can be little doubt that ours is a “visual world.” Our language, cultural narratives, literature, philosophy, and faith traditions are all strongly infused with references to eyes and vision. In King Lear, Shakespeare (12) explores wisdom and reflective understanding by juxtaposing literal and metaphorical references to sight. Lear fails to “see better” in his assessment of his daughters' motivations, and it is only when Gloucester's eyes are physically destroyed that he is able to “see” the true nature of the situation he is in. Similarly, Sophocles' tale of Oedipus Rex makes literal and metaphorical references to vision. Oedipus has normal physical sight but remains blind to the reality of his heritage, while the blind prophet Tiresias can “see” the truth of the situation. Furthermore, after the truth is revealed and Oedipus realizes that he has fulfilled the prophecy, Sophocles has him respond by blinding himself, plunging two pins from his mother's dress into his eyes.

The linkage between truth and sight is also evident in philosophy; Plato wrote of reason as the eye of the soul, and Aristotle maintained that a desire for knowledge stems from pleasure in perception,

particularly the visual (1). Voltaire maintained that an idea is “an image that paints itself in my brain,” believing that abstract thought must have a basis in perception, and that in fact “I've ideas only because I've images in my head” (13). More generally, the ancient Greeks equated truth with the idea of being uncovered; the Greek word for knowledge (eidenai) is the state of having seen (14). Similarly, the French verb “to see” (voir) is etymologically linked to power (pouvoir) and knowledge (savoir). This association continues in modern English, with seeing being synonymous for understanding.

The association between visual perception and truth is reflected in the scientific empiricism of Francis Bacon, John Locke, Isaac Newton, and Robert Boyle, each of whom asserted that ideas only come from the perception of external objects, not from innate intuitions or deductions (15). Bacon maintained “I admit nothing but on the faith of the eyes” (16), while Boyle emphasized intersubjective visual witnessing as the basis of scientific legitimation (15). These philosopher scientists maintained in common a belief in the association between lucidity and rationality and distrusted evidence from other senses, notably the ear, which absorbed only unreliable “hearsay” (15). The significance of the visual during the Enlightenment is summarized by Starobinski, who has noted “such was the century of the Enlightenment which looked at things in the sharp clear light of the reasoning mind whose processes appear to have been closely akin to those of the seeing eye” (17).

Given the desire to “see” and to “know,” it is unsurprising that successive technological developments have sought to extend human gaze. The remote became accessible by the telescope, the small with the microscope, and the self through the mirror. By the end of the 16th century, the Venetians had perfected the art of making mirrors, profoundly influencing ideas about civility, grooming, modesty, sexuality, and self-consciousness (18).

In many ways then, eyes have come to be associated with beauty, both as beautiful in themselves, but also as the sense or organ that gives access to the beauty of the world. As Leonardo noted “The eye is the window of the human body through which it feels its way and enjoys the beauty of the world. Owing to the eye the soul is content to stay in its bodily prison, for without it such bodily prison is torture” (19).

While eyes may give access to beauty, they are similarly entwined with wisdom, insight, and God. In Ancient Greece, the goddess of wisdom, Athena Glaukopis (the epithet meaning gleaming eyes) is frequently represented in association with an owl—an animal with prominent eyes and superior vision. In Buddhism and Hinduism, the “third eye” plays a role in enlightenment and is alternately known as the “eye of wisdom.” And in ancient Egypt, the eye of Horus was a powerful symbol of protection and royal power, and the Egyptian gods were created by Ptah the Opener, who brought them forth from his eyes (20). Metaphors of vision and eyes are evident throughout Christian texts; not only does Jesus restore sight in numerous miracles within the Gospels but also throughout the text God and light are depicted as synonymous.

Conversely, belief in the power of the “evil eye” to cause injury and death dates from the Stone Age and appears throughout ancient Egyptian, Greek, and Roman writings, as well as in the folklore of Africa, India, and China (21). The evil eye was also present during the black death of England, when a glance from a sick man was believed to transmit the infection (20), and the belief is even present in the Christian Bible, with Proverbs 23 insisting: “Eat thou not the bread of him that hath an evil eye.”

The importance of vision and sight within the western tradition reinforces that eyes are integral to social interaction and therefore central to our social lives. For many the eyes are the “windows to the soul,” and perhaps more than any other body part, personify an individual. The fact that there are multiple layers of meaning attached to the eyes means that their removal is likely to have negative associations. In part, this may relate to their physical visibility and hence the ease (and horror) in imagining their absence. However, their close association with truth, beauty, identity, and most importantly with social relationships means that a request to donate the eyes of a loved one is unlikely to be heard simply in medical or mechanistic terms as a request to donate a “superfluous” body part for the benefit of another. That the eyes are not simply biologic provides one explanation for both the lower rates of corneal donation, compared with that of other organs, and the lack of adequate corneal donation to meet demand.

In bedside discussions, organ and corneal donation coordinators are invariably attuned to the social considerations that permeate a discussion about potential donation. In contrast, however, public education concerning organ donation has remained silent on these factors and instead maintained a focus on the instrumental medical body; this is unsurprising as such a view of the body is intuitively the most conducive to donation. Although this perspective may have been an important part of successful efforts to increase public support for organ donation, ongoing policy involving public education or donation registries may be more effective if attempts to influence consent engage with both social and medical perspectives of the body. Rather than continuing as parallel fields of enquiry, insights from sociology, anthropology, and “death studies” could all contribute to more informed donation policy approaches to seeking consent to corneal and organ donation.

Nonetheless, there is no guarantee that these measures will actually raise donation rates. First, although sociocultural considerations are likely to be an important determinant in relatively lower eye donation rates, there are other factors that may also play a role. Insufficient corneal procurement to meet transplantation needs may relate to insufficient resource allocation or to practical difficulties associated with the fact that potential corneal donors die in many and varied environments. In addition, donation coordinators themselves feel some disquiet about eye donation (22) and so may be more reluctant to pursue donor families consent to eye, as opposed to solid organ donation. Second, although harmonizing the donation message to be more congruent with the real lived experience of organ donation may persuade individuals that the benefits of transplantation override the social importance of eyes, it is also possible that it may make individuals more uncomfortable about eye donation and hence lower donation rates. Finally, it may have no effect, as there remains an irreducible tension between corneas as a public good that can reverse blindness, and eyes at the moment of death as an integral part of the ongoing relationship with a wife, brother, mother, or lover.

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