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Understanding Selective Refusal of Eye Donation Identity, Beauty, and Interpersonal Relationships

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Abstract

Corneal transplantation is the most common form of organ transplantation performed globally. However, of all organs, eyes have the highest rate of refusal of donation. This study explored the reasons why individuals decide whether or not to donate corneas. Twenty-one individuals were interviewed who had made a donation decision (13 refused corneal donation and 8 consented). Analysis was performed using Grounded Theory. Refusal of corneal donation was related to concerns about disfigurement and the role of eyes in memory and communication. The request for donation therefore raised concerns about a potential adverse change in the ongoing relationship with the deceased, even in death. For those who refused donation, these concerns overshadowed awareness of need or benefit of transplantation. Adjusting the donation message to be more congruent with the real, lived experience of corneal donation may to some extent “prepare” individuals when the donation question is raised.

Keywords Organ and tissue procurement; Tissue donors; Corneal transplantation

Introduction

Corneal transplantation is the most common form of organ transplantation performed globally; each year sight is restored by transplantation to more than 3,500 people in the United Kingdom (Gaum et al. 2012) and more than 50,000 people in the United States (Li and Mannis 2010). Despite this, in Australia, the United Kingdom, and the United States, the number of corneas available does not meet demand. While the relative influence of various factors affecting this mismatch have been debated (Murnane et al. 2002), the rate of families refusing to donate is significant.

A number of studies of families who refuse organ donation have identified important demographic and contextual associations, including the type of health care professional who made the request, the time elapsed between a declaration of death and a request for donation, and the amount of information provided at the time of request (Gallup Organization and United States Health Resources and Services Administration Division of Transplantation 2005; Lawlor et al. 2006; DeJong et al. 1998; Siminoff, Arnold, and Hewlett 2001; Siminoff et al. 2001; Siminoff and Lawrence 2002). The majority of this research has been conducted in the context of multi-organ donation; much less is known about factors that families take into account when making decisions specifically about corneal donation. This is important as studies of organ donation consistently find that the consent rate for donation of corneas is significantly lower than for that of other organs. One U.S. survey of adolescents found that a third of individuals indicated a specific reluctance to donate corneas (Baughn, Rodrigue, and Cornell 2006) and other studies suggest that when individuals do specifically indicate unwillingness to donate particular organs this restriction invariably includes the eyes (Lawlor et al. 2010; Manninen and Evans 1985; Sanner 1994; Wilms et al. 1987). For families who have actually made a decision about organ donation after a family member's death, there is also evidence of selective reluctance to donate eyes. In Australia, approximately 30 percent of families agreeing to multi-organ donation specifically refuse corneal donation (Excell, Hee, and Russ 2009), and a similar disparity is noted in large U.S. studies (Siminoff, Arnold, and Hewlett 2001).

The Study

Aim

This study explored the reasons why individuals decide whether or not to donate corneas. More specifically it also examined why individuals are more likely to refuse corneal donation in comparison with solid organ donation.

Qualitative Approach

Decisions about donation are likely to involve complex psychosocial phenomena for which quantitative methods of investigation are not necessarily appropriate; while quantitative methods are able to generate externally generalisable results, in a relatively under-researched field such as corneal donation, they also have the danger of forcing responses into preconceived categories and thereby generating results with limited validity.

In contrast, qualitative research allows a nuanced examination of the circumstances surrounding a donation request and focuses on diversity rather than on standardisation. This diversity is crucial in an under-researched area such as corneal donation, as it may provide a broad overview of the area under examination. Qualitative methods also allow exploration of a phenomenon or action—for example, low rates of donation—without specifically examining one particular question or hypothesis, and they enable open-ended and exploratory questioning without preconceived ideas as to what will emerge, thereby allowing respondents to express the things they believe to be of importance.

Sample

Twenty-one individuals who had made a decision about donation were interviewed. These individuals were recruited through two different methods. Eight interviews were with a family member of individuals who had been declared brain dead, were approached for multi-organ donation, and gave consent for kidney, heart, and lung donation but refused corneal donation. These individuals were approached between 18 and 24 months after the date of donation. The remaining 13 interviewees were with family members of individuals from whom corneal-only donation was requested; of these 13, five individuals had refused corneal donation and eight individuals had consented to cornea-only donation. These individuals were approached between six and 12 months after the donation request. The age range of all interviewees was 26 to 78 with a

mean of 56. There were 11 males and 10 females, and the relationship with the deceased included husband, wife, brother, and daughter. All interviewee names and names mentioned by interviewees have been changed to maintain anonymity.

The Interview

The interviews were carried out by a single interviewer (ML). Interviews were conducted face-to-face, except for four that were telephone-based due to either physical distance or difficult logistics of organising a time for a face-to-face meeting. The interviewer used a basic prompt sheet, as needed, but interviews were deliberately open-ended in order to allow the emergence of themes. All interviews were recorded and transcribed. The interviewer kept a journal in conjunction with undertaking the interviews, which generated further questions, aided reflexivity, and provided a credible audit trail of the investigation and data analysis.

Analysis

This project assumed a critical realist perspective and used Grounded Theory for the analysis. Grounded Theory was chosen because of its focus on the emergence of themes (in contrast with classifying research into predefined concepts) and its explicit goal of using data to generate theory—a coherent framework of concepts that has some explanatory power. The analysis involved an iterative process. First, themes were identified within the interview transcripts and coded (or labelled). This was followed by synthesis of themes into categories and focused coding for categories, and finally abstraction of categories to concepts and focused coding for concepts. While spontaneous and intuitive responses were recognised as part of the analytic process, coding involved continual comparison and dialectical engagement with the data. This strategy was the basis of developing a Grounded Theory that did not only rely on intuitive “emergence.” A number of sessions to build consensus on coding and thematic analysis were then undertaken with three colleagues who had independently analysed the transcripts.

Results

Our analysis revealed three main concerns that contributed to refusal of corneal donation: visibility and disfigurement, identity, and beauty.

Visibility

When considering donation, interviewees distinguished between organs that are part of the external, visible body and those that are invisible or internal. The discomfort associated with removing the external organs related in part to concerns about the physical act of looking at a person without eyes; the familiarity of the external organs made their potential absence readily conceivable.

This physical alteration or disfigurement was clearly articulated as a potent source of distress. For some this was grounded purely in physical concerns about the appearance of the body at a viewing. For others there was a symbolic component to the disfigurement that manifested as concerns about the consequences of the “perception” of disfigurement or a more tangible feeling that the “essence” of the person is in some way altered by physically disfiguring the body. The symbolism associated with eyes also appeared to feed concerns that removing them diminished the human aspect of the deceased. In a number of instances, interviewees appeared to be drifting between these two forms of disfigurement, and the boundary between the two was quite blurred.

William, who did not consent to corneal donation, was explicit about the role of the visibility of the eyes in his decision: “You can see someone’s eyes, everything else you can’t, they are all within the body: hearts, lungs ...” He also extends this idea to note that concerns about appearance and disfigurement extend to more than just surface change, using an analogy of a car that has been repaired after an accident:

WILLIAM [No to corneas]: The car is back to you 100 percent but you know that that car's been repaired, so therefore you've got it in the back of your mind that you know the car is not new anymore, or it's not the same car it was. I think that's possibly the same way that you perceive the removal of the eyes, that that body, the body's not the same, it's not the same body that it was prior.

Luke also found it relevant that he would be unable to see whether some of his wife's internal organs have been removed.

LUKE [Yes to kidneys, no to corneas]: I can't see the fact that she doesn't have a heart, I can't see the fact that she's got her kidneys, her liver, any of those things, I can't see that all of that's gone. What I can see is on the outside.

Again, however, donation of the eyes for him would be more than just surface disfigurement; his concern relates to the thought that the eyes would no longer be present.

LUKE [Yes to kidneys, no to corneas]: It's easy to say yes to anything on the inside because you can't see what's going on there anymore, you can't see it, but I didn't want to be looking at skin that had been peeled back, away, taken off, and to think that her eyes weren't there.

Sarah corroborates the importance of the physical visibility of eyes and skin and the relevance of this to her decision not to donate them.

SARAH [Yes to kidneys, no to corneas]: I've felt her when she would hug me, I've felt her skin on my skin, I've looked into her eyes, I haven't seen her heart, I haven't felt her internal organs. I guess the things that you've seen and you've felt are different to the things that you don't.

When Doug is discussing the reasons his sons did not feel comfortable donating their mother's eyes, he suggests that a part of it was the potential physical space where the eyes once were.

DOUG [Yes to kidneys, no to corneas]: I think that they thought that they would see their mother, as a person with no eyes. Like just a vacant space there; we had an open casket, we had a viewing, and I thought that's what they would feel.

However, as with other interviewees, Doug elaborates on the reason why it is that this situation would be confronting.

DOUG [Yes to kidneys, no to corneas]: When you talk to someone you look right at their eyes and I mean, you see a lot of things in your eyes, what they are feeling and how they are reacting and things like that. ... Let's face it if you take your eyes away from a person, what have you got? I mean you've just got holes there, I couldn't look at you and talk to you.

Similarly Matthew articulates uncertainty about potential visible disfigurement if he agreed to allow his wife's eyes to be removed for corneal donation.

MATTHEW [Yes to kidneys, no to corneas]: I don't know what sort of, with the eyes, whether they actually put plastic balls in the back so that it would give the impression that there are still eyes are there, I don't know, but I didn't want them to have that, you think when they remove the eyes there would be nothing there.

Matthew also elaborates on his perception that removing the eyes is more than just physical disfigurement—there is also a symbolic aspect to the removal.

MATTHEW [Yes to kidneys, no to corneas]: At the funeral parlour ... you look at a body that is fully dressed, you don't see what they've taken out, but it's just that perception that the eyes, if you remove the eyes it removes the soul, so to speak, and you just don't want to lose that perception.

But while many participants were concerned about physical disfigurement, this was not ubiquitous. Sally, who did not consent to corneal donation, is quite clear that she does not have any discomfort about donation when thinking of it purely from a physical perspective: "I mean the eyes are shut, even if they put something there, you couldn't tell." Kichu likewise had no concerns beyond ensuring the body wasn't altered in appearance.

KICHU [Yes to kidneys, no to corneas]: If somebody said “can we take the eye and we just want the cornea or whatever it was and we leave everything as is and there will be something in the eye socket” at the end of the day we would have said “no problems.”

The relative anonymity and lack of physical experience of the internal organs appear, therefore, to mitigate the psychological discomfort associated with their removal. In contrast, the thought of donation of the external organs conjures immediate concerns about the aftermath of the removal of something that is visible and well known.

Identity

An individual’s physical appearance is intrinsically associated with his or her identity. The face is the primary feature that enables recognition of a person, and the eyes are a distinctive component of the face. The eyes also convey expression, mediate social interaction, and are the “site” of sentience. Unsurprisingly then, many of the interviewees were concerned that removing the eyes interfered with the identity of the deceased.

As someone who made the decision not to donate his wife’s eyes, Luke made a clear link between the importance of eyes to identity and his unwillingness to donate them. His concern was that by agreeing to the removal of his wife’s eyes he may in some way remove many of her personal qualities. His grammar suggests this concern was still present a year after his decision about donation.

LUKE [Yes to kidneys, no to corneas]: When I look at a person, I mean what attracts me to other women or to other people, I guess in general is that sort of quality that you can see. And you can see mischief, and you can see life, and you can see love, and you can see friendliness and all those things in people’s eyes in the same way as you can see negative horrible things in people’s eyes, and I guess maybe a part of me does think that if you take those out then you remove, in Greta’s case, all those wonderful good qualities that she had.

For Luke, removing Greta’s eyes was an ontological threat because it stripped away Greta’s identity—leaving behind an entity that retained none of the characteristics that he associated with her.

LUKE [Yes to kidneys, no to corneas]: Does it mean that the last time I see her, that last opportunity I get to say goodbye basically, to kiss her on the cheek, does that mean that I am going to be looking at this defaced creature that’s had its skin removed and had its eyes taken out?

Sarah indicates that while not all people will feel that their loved one’s eyes are integral to their identity, for her mother they were. Further, she is explicit that it was this link to identity that played an important role in her decision not to donate her mother’s eyes.

SARAH [Yes to kidneys, no to corneas]: Everyone sort of says your eyes are the windows to your soul and you have probably heard that from other people, but I just think you, some people’s eyes you look into and you don’t, they don’t show feeling through their eyes. But her eyes you could always tell what she was thinking from her eyes because they were very expressive, and they were really nice blue and you could just, you could see love in her eyes when she looked at someone in the family, in our family, or when she used to talk to me and tell me she was proud of things I was doing and, you could just, she could never any hide anything in her eyes, you always knew if she was angry or happy or anything, and I just thought they are too personal, they were too much a big part of her. Spent too many years looking into them.

Cheryl, who consented to kidney but not corneal donation, similarly acknowledges that eyes play an important role in an individual’s identity and identifies this as a barrier to allowing corneal donation: “People’s eyes are so much connected to how people identify them, that it’s something that people, I would expect most likely to say, to want to retain them because they are so symbolic of that person.”

A number of interviewees who agreed to donate corneas also touched on the fact that they understood that for some people agreeing to corneal donation might be difficult. As typified by Nancy, this was often thought to relate to the integral association between eyes and identity.

NANCY [Yes to corneas]: The eyes, they give expression to your face. And I guess, I'd always donate them, I always would and I want mine donated. But I can understand where people might say no, it's taking away from the, from the person that you knew.

Beauty

Our participants also identified the aesthetic importance of the eyes and frequently raised concerns about donation on the grounds that it threatened to disturb that beauty. Luke epitomised this position—raising concerns that removing the eyes may disrupt a person's spiritual and physical beauty.

LUKE [Yes to kidneys, no to corneas]: That's where you really see true beauty in a person is in their eyes, because that's where you can see what's really going on inside their heads. And I guess me personally, I didn't want those beautiful things that had looked at me so many times, and these things you'd seen so much life in, I didn't want to think that they were being, taken out, removed from her.

Cheryl talks about the role that her husband's eyes played in the development of their relationship, noting that his eyes both reflected his passions and were a source of beauty.

CHERYL [Yes to kidneys, no to corneas]: He could be silly and have fun without a drop of alcohol, so it all reflected in his eyes, he loved his dancing, he loved, and that's where we met dancing, and that always reflected in his eyes, and so it was, and so he did really have really, really beautiful, beautiful blue eyes.

These observations appear to have been particularly relevant at the time of the request for corneal donation. Cheryl recalls that it was her husband's son who stated that he did not want to donate his father's eyes; he memorably, and uncharacteristically, made some comments about the beauty of his father's eyes in the context of his unwillingness for donation to proceed.

CHERYL [Yes to kidneys, no to corneas]: He said "he had such beautiful sparkling eyes," and for a son, a pretty sort of, he's a builder, he's a footballer, not a very articulate man, for him to feel as strong, and he really has felt the loss of his dad, it was a very strong statement about how he felt about his dad.

As noted in the section above, Sarah, who consented to kidney but not corneal donation, cited identity as relevant in her decision, but it is clear that the beauty of the eyes was also a related association: "Her eyes ... were very expressive, and they were really nice blue and you could just, you could see love in her eyes when she looked at someone in the family."

Discussion

The participants in this study identified that refusal of corneal donation was based in concerns about disfigurement (superficial, symbolic, or often both), the disruption of beauty, and the loss of identity. While donor coordinators suggest that it is relatively easy to reassure families that corneal donation will not interrupt funeral plans, that a viewing is still possible, and that physical disfigurement is not evident after donation (Verble and Worth 2000), our research suggests that concerns about disfigurement are nonetheless still evident. However, instead of these concerns being physical, they were often more symbolic—the eyes in one sense personified the person who was. For example, even though William did not think that he could notice a change in appearance after eye donation, it was simply the perception that the eyes are not there that was a concern: "Removing of the eye changes the appearance of the person ... even although visibly it's exactly the same." This potential symbolic change after corneal donation appears to relate to a change in the ongoing relationship with the deceased in death. While most interviewees recognised the potential good that could come from corneal donation, many still maintained that removing the eyes was something that would potentially have a significant adverse effect on their ongoing relationship with the

deceased. John, for instance, was explicit that he knew of the benefits of corneal transplantation, but for him the more important factor was that his wife was still “complete” and not made less “whole” by the act of donation. Similarly, while Luke acknowledged the potential benefit of corneal transplantation in improving sight for two other people, this was not his most important consideration at the time. Of much more importance to him was the fact that his wife’s eyes were reflective of their relationship; he looked into her eyes and he loved her “looks,” her beauty, and her eyes themselves. As he said: “The decision to say no we don’t want to donate the eyes or her skin, part of it is due to the fact that this is a living person that you have loved, and every time you have looked at her she has been looking at you with those things and they are like the windows to what goes on inside the person.”

Likewise, the role of eyes relating to identity and beauty meant that the eyes were a conduit for memories, intimacy, and communication. For Matthew, the last shared memory—the final interaction between him and his wife—occurred when they looked into each other’s eyes. “So if that’s the last thing you see of each other is through your eyes, so I just didn’t want to lose her eyes, I wanted to keep her eyes.” And for Sarah: “I’ve felt her when she would hug me, I’ve felt her skin on my skin, I’ve looked into her eyes, I haven’t seen her heart, I haven’t felt her internal organs.”

These characteristics of the eyes relate in part to the fact that, while the internal organs are known only to the world by their function or by metaphor, the eyes are there for all to see and are thereby a central feature of social contact and interaction. During conversation we make and maintain eye contact because we know that this is, in itself, a means of communication, because it recognises the dignity and moral status of “the other,” and because the eyes are a manifestation and source of intelligence, identity, and sentience. All manner of emotions, including virtue, integrity, and authenticity, are thought to be elucidated by looking into someone’s eyes—a concept captured by the popular notion that the eyes are the “windows to the soul.” Similarly, the absence of eyes presents a powerful and persistent image; it is strongly associated with cruelty and torture and symbolically linked with an absence of insight or wisdom (Lawlor and Kerridge 2011).

The results of this research—that the symbolic and cultural meanings of eyes may influence decisions about corneal donation—are consistent with other research that decisions about organ donation are influenced by the value and meaning that people attach to the body and body parts, most especially the eyes (Kesselring, Kainz, and Kiss 2007; Sanner 2001).

Implications for Corneal Donation

The findings of this research lead to three implications for corneal donation. First, the particular cultural status given to vision and to eyes means that the removal of the eyes—even from the newly dead—will for some individuals have negative associations. A request for corneal donation from a recently deceased family member is unlikely to be understood as simply a utilitarian decision about potential benefit to those awaiting transplantation. In discussions at the bedside, corneal donation coordinators are invariably attuned to the social considerations that are intrinsic to a discussion about potential donation, and this research should help to inform these bedside (or telephone) discussions about corneal donation.

Second, policy responses to improve donation have maintained a special silence concerning the role of social factors in the donation decision. Ongoing policy aimed at increasing corneal donation may be more effective if it attempts to influence consent by engaging with some of the social perspectives of the eyes and body identified in this research. Adjusting the donation message to be more congruent with the real, lived experience of corneal donation may to some extent “prepare” individuals when the donation question is raised.

Finally, while the inclusion criteria of this research only identified individuals who selectively refused corneal donation, the possibility exists that the strong sociocultural importance associated with eyes may also make certain individuals in the community more likely to want to donate eyes. One such person in our cohort suggested that he was happy to donate eyes yet retained some reluctance about donating other organs, a finding consistent with other empirical reports published in the

transplant literature (Verble and Worth 1997). Further research should investigate this possibility as it may provide an avenue through which to further engage the public about the complexities of corneal (and organ) donation.

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