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GENERAL ETHICS

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An analysis of the identity issues involved in facial allograft transplantation is provided in this paper. The identity issues involved in organ transplantation in general, under both theoretical accounts of personal identity and subjective accounts provided by organ recipients, are examined. It is argued that the identity issues involved in facial allograft transplantation are similar to those involved in organ transplantation in general, but much stronger because the face is so closely linked with personal identity. Recipients of facial allograft transplantation have the potential to feel that their identity is a mix between their own and the donor's, and the donor's family is potentially likely to feel that their loved one "lives on". It is also argued that facial allograft transplantation allows the recipients to regain an identity, because they can now be seen in the social world. Moreover, they may regain expressivity, allowing for them to be seen even more by others, and to regain an identity to an even greater extent. Informing both recipients and donors about the role that identity plays in facial allograft transplantation could enhance the consent process for facial allograft transplantation and donation.

n the fall 2004 issue of the *American Journal of Bioethics*, several articles focused on the ethical issues involved in facial allograft transplantation. The main issues addressed were the appropriateness of offering such a high-risk procedure for a non-life-threatening condition, whether or not patients could truly consent to such a procedure, privacy issues, the ethical climate of the institution where the transplant is to be performed and the social effects of the availability of facial allograft transplantation. Several articles called for an analysis of the identity issues involved in facial allograft transplantation.^{1–3} This paper provides such an analysis.

There is a pressing need for an examination of the identity issues involved for two reasons. First, the identity issues are closely linked with the ethical issues. In fact, part of the Royal College of Surgeons of England's rejection of facial allograft transplantation was because the issues associated with facial identity present a significant ethical impediment. Concerns about the face and identity were also part of the reason for The French National Ethics Consultation Committee's opinion that facial allograft transplantation is not an ideal solution for the problem of facial disfigurement. There were two main concerns with the identity

issues. They worried that the recipient would not identify with the transplant and not view it as their own, and it would be rejected or removed, as was the case with the first hand transplant recipient. They also worried that the recipient would not regain physical expressivity from the facial graft, and so the ability of a facial allograft transplant to allow the recipient to once again express her identity through facial expression (eg, blinking, smiling and frowning) would not probably be regained. Moreover, the identity issues are important to the ethical issues because informing both recipients and donors about the role that identity plays in facial allograft transplantation may enhance the consent process. The other reason is because the first partial human facial allograft transplant occurred in France only in December 2005 and the first full human facial allograft transplant will most probably occur in the near future.

Before moving to the analysis, it will be useful to make a note of what types of facial allograft transplant I am referring to, and to make a note of the language that I am using. I use the term "facial allograft transplantation" as opposed to "facial transplantation" or "composite tissue allotransplantation". The French National Consultation Committee uses the term "composite tissue allotransplantation", arguing that the term facial transplantation is inaccurate: "The expression 'facial graft' should be discouraged. It is never a face that is grafted, but composite tissue. A tissue is not a face, but the object is to provide morphology that will again be akin to a human face" (p 20). George Agich and Maria Siemionow⁶ also discourage the term facial transplantation, preferring the more clinically accurate term "facial allograft transplantation". Additionally, facial allograft transplants involve transplanting considerable amounts of skin, muscle and sometimes bone.5 Lastly, this paper refers to both partial and full facial allograft transplants, and I argue that the closer the transplant is to a full facial allograft transplant, the deeper the identity issues will be.

PERSONAL IDENTITY AND ORGAN TRANSPLANTATION

To explore the identity issues involved in facial allograft transplantation, it is helpful to first explore the identity issues involved in organ transplantation. There are two ways to approach how organ transplantation affects personal identity. One way is to examine the issue under different theories of personal identity and the other is to examine the first-person experiences of organ recipients with regard to identity.

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The psychological account of personal identity and organ transplantation

The psychological account of personal identity holds that what makes me *me* is my psychological make-up or my "mind"—that is, I am essentially my memories, beliefs, desires and so on.⁷ On the psychological view, once my psychological life ceases to exist, so do I. My body and my organs remain, as do my house, my car and my cat. These are all things that I used to own and they will be handled in accordance with my wishes when I cease to exist.

The lived-body account of personal identity and organ transplantation

Developed by phenomenologist Maurice Merleau-Ponty, the lived-body account of personal identity seeks to remove the mind/body dualism found in the psychological account. On the lived-body view, personal identity is not just the mind. A conscious being is the integration of mind and body. We are living bodies, or embodied selves. Merleau-Ponty⁸ points to the phantom limb as evidence for the lived-body idea: if the body were just a machine for the mind, then when one loses a limb one would just go on operating the machine without that part. But this does not happen; the person who loses a limb still feels the limb and still attempts to use the limb, even though it is no longer there. Merleau-Ponty further describes the idea of the lived body by pointing out that (in normal experience) it is not that "I" observe or move my body; I am my body. Describing the experience of movement, he comments that one does not have to find one's body and figure out how to move it, one simply moves it (p 108).

On the lived-body account of personal identity, the body is a central part of identity. The body is not some object or house for the mind; it is part of the self. Hence, giving away an organ is like giving away a part of the self. In fact, organ recipients often describe the feeling of having someone else inside of them. The subjective experiences of organ recipients relate more closely to the lived-body account of identity than the psychological account. Organ recipients do not just feel that they have something that once belonged to someone else, they feel that they have part of someone else inside of them.

First-person experience, personal identity and organ transplantation

With regard to personal identity, looking at the subjective experiences of transplant recipients is important because selfexperience is an important ingredient of self-identity. Margaret Lock9, an anthropologist, has recounted some of the experiences of organ recipients. She argues, "It is abundantly clear that donated organs very often represent much more than mere biological body parts; the life with which they are animated is experienced by recipients as personified, an agency that manifests itself in some surprising ways, and profoundly influences subjectivity". Lock cites the finding that recipients often worry about the gender, ethnicity, skin colour, personality and social status of the donor. Many recipients believe that their mode of being in the world will be radically changed (p 1410). One liver and kidney recipient had the following to say: "I still think of it as a different person inside of me—yes I do, still. It's not all of me, and it's not all this person either You know, I never liked cheese and stuff like that, and some people think I'm joking, but all of a sudden I couldn't stop eating Kraft slices—that was after the first kidney. This time around, the first thing I did was to eat chocolate. I have a craving for chocolate now and I eat some every day. It's driving me crazy because I'm not a chocolate fanatic. So maybe this person who gave me the liver was a chocoholic?" (p 1411). This recipient also said, "You know, sometimes I feel as if I'm pregnant, as if I'm giving birth to somebody. I don't know what it is really, but there's another life inside of me, and I'm actually storing this life ..." (p 1411).

Consistent with this recipient's experience, Lock reports, "... many recipients undergo a profound change in subjectivity and report that they experience embodiment in a radically different way after a transplant" (p 1411). Lock describes an interesting conversation that she had with a transplant surgeon who was against allowing prisoners to donate organs. When asked why, he replied, "I wouldn't like to have a murderer's heart put into my body, I might find myself starting to change" (p 1410).

Another person who has produced interesting work on the first-person experiences of organ recipients is anthropologist Lesley Sharp. Sharp¹⁰ found that most recipients she interviewed expressed a sense of having been reborn. She also found that recipients often feel that they have acquired the donor's emotional, moral or physical characteristics (p 372). Interestingly, the symbolic weight of the organ had a profound effect on the transformation of identity (p 372). For example, heart recipients experienced a greater transformation of identity than kidney recipients (p 372).

Reporting on the first-person experience of donor families, Sharp found that relatives often think that their loved one can "live on" in another body and that the recipient is an extension of the donor's biography (pp 364, 380). This finding relates closely to a view of identity in which the donor is not just giving the recipient a body part, he is also giving the recipient part of his identity. Sharp argues, "In the realm of transplantation, selfhood is similarly and intensely corporeal" (p 377).

PERSONAL IDENTITY AND FACIAL ALLOGRAFT TRANSPLANTATION

One may be tempted to say that the identity issues involved in facial allograft transplantation are no different from the identity issues involved in organ transplantation in general. Arguing against this, I pose that there are unique identity issues involved in facial allograft transplantation, beginning with the significance of the face for personal identity.

The face and personal identity

The face is enormously important in defining personal identity.11 The team of transplant surgeons at University of Louisville who have been considering performing a facial allograft transplant acknowledged this when they said, "... the appearance of our face is the predominant anatomical feature by which we identify and differentiate ourselves from others".12 The face not only expresses appearance, it also expresses feeling. John Robertson, a commentator on the Louisville team's article on the ethics of facial transplantation, remarked, "Faces are the external manifestation of our persons (our souls?). They provide information about age, gender, ethnicity, and emotional states, and help form the image that others have of us. Indeed, our face often provides the image that we have of ourselves".2 "... the face is a window to our inner selves—it represents the entire personality and is the focus of attention in every social interaction".13

Nichola Rumsey, ¹⁴ another commentator on the ethics of facial transplantation, remarked, "Our faces help us understand who we are and where we come from, with indicators of our genetic inheritance, ancestry, and racial identity. Wrinkles and marks serve as reminders of each individual life history". Radana Konigova and Ivo Pondelicek, ¹⁵ who studied the psychological aspects of facial burns, remark, "To quote Mortimer: 'without their faces, humans would hardly be human at all'. In this connection, we are interested in whether people suffering from facial deformation, 'loss of face' due to burns, can also lose their personalities … It is well known that the face is the representative of the entire personality for three reasons: it is the most complex area of the whole body schema

and has its own social principle, aesthetic representation is concentrated in the face, and the face makes the absolutely essential inter-personal communication possible".

Facial allograft transplantation and personal identity

Because of its close association with personal identity, the face is different from other transplantable organs. The Royal College's report on facial transplantation claims that "The face is central to our understanding of our own identity. Faces help us understand who we are and where we come from." ⁴ Francoise Baylis¹ notes that, "For these reasons, the face is not fungible in the way that other human organs and tissues used for transplant might be".

With regard to facial allograft transplantation, the identity issues involved are both stronger and more unique than the identity issues involved in general organ transplantation. For example, in organ transplantation the donor's family often feels as if their loved one lives on in the recipient. I pose that this feeling would be much stronger in the case of facial allograft transplantation. This is because a facial allograft transplant is externally visible and implicates continuation of the deceased person in a way that internal organs do not.2 The first-person experiences of recipients taking on part of the donor's identity will probably be even stronger in the case of facial allograft transplantation. Nichola Rumsey³ noted that in common forms of organ transplantation there is difficulty integrating the transplant into the existing body image and identity. Further, she predicts that these difficulties will be exacerbated in the case of facial allograft transplantation. If patients cannot accept the facial allograft as their own, this will negatively impact the success of the procedure as they might be less inclined to participate in physical therapy, for example.

Like externally visible allografts, hand transplants can be reflected upon to support the prediction that the identity issues involved in facial allograft transplantation are much stronger than those involved in general organ transplantation. The first hand transplant was performed in France in 1998.16 Two hand transplants were performed simultaneously in China in 1999. The doctors involved in the 1999 operation studied the psychological consequences of the transplant. They report that after the surgery the two recipients were "... horrified over seeing the long expected hand graft".17 The patients were unwilling to accept the hand immediately. They seldom looked at it, seemed indifferent to it and even turned their head to the other side while sleeping (p 1661). The doctors report that after about 1 month, there was recovery of active movement of the hand and at this point the recipients fully accepted the hand (p 1661). After 4-5 months, sensation was regained and the recipients regarded the hand as their own (p 1661).

The experiences of hand transplants are much different from those of other organ transplantations because, as Lijun et al¹⁷ state, "Unlike other organ transplantations the recipients of limb transplants must look upon and direct the transplanted hand to exert its function" (p 1660). The hand represents personal identity in a way that other organs do not. "It is indeed unsettling to think that the hand with which one has once been intimate may now stroke another body". 18 Like the hand, the face is a uniquely external structure that is visible to the recipient. This said, the psychological consequences of facial allograft transplantation will be different from those of other organ transplants, as will the effects on personal identity. Because the face is external and so closely related to identity, the effects of facial allograft transplantation on personal identity will be much stronger than those of solid organ transplants. More specifically, the recipient's experiences of taking on part of the donor's identity will probably be stronger, as will the donor families' experiences that their loved one lives on.

DIFFERENCE BETWEEN FACIAL ALLOGRAFT TRANSPLANTATION AND FACIAL DISFIGUREMENT

One might grant that the face plays a significant role in personal identity, but argue that the identity issues experienced by a recipient of a face transplant are no different from those experienced when that person initially underwent facial disfigurement. Although many identity issues are the same between becoming disfigured and receiving a facial allograft transplant, there are significant differences. One significant difference is that in the case of facial allograft transplantation, change in identity is desired, but in the case of severe facial disfigurement, changes in identity are often unanticipated and always unwanted. This is not to say that in the case of facial disfigurement the person could not accept his or her change in identity. But certainly the change in identity is not a wanted one.

Another significant difference is that in the case of facial allograft transplantation, the person is gaining an identity, whereas in the case of severe facial disfigurement, the person is losing an identity. The patient seeking a facial allograft transplant has been described as gaining a face, or an identity. Joe Demarco¹⁹, a bioethics professor at Cleveland State University said, "We need to keep in mind that this is a terrible thing not to have a face, so the benefits are potentially great—not only to medical science, but also to the individual patient." Dr John Barker, 20 a surgeon at University of Louisville, Louisville, Kentucky, USA, who has been preparing for the procedure remarked, "The human face is you. Take that away could it benefit you to give you a face back?". Even those who are hesitant about the procedure describe it in terms of gaining a face. Noting the rejection risks, they conclude "... we welcome further analysis and debate not least so that, in the drive to gain face, we do not overlook the risks of losing face".21

Dr Maria Siemionow,²² a Cleveland Clinic plastic surgeon, has also spoken of the severely disfigured recipient as "having no face" and "having no identity". In this sense, the transplant would give the recipient a face, and give her an identity. But, Siemionow is quick to point out that the procedure is not an identity transfer. The procedure is not transferring one person's identity to another because what is really being transferred is just a "skin fold". Siemionow's view, then, regards the recipient as gaining a face and even gaining an identity, but it is a new face and a new identity; not the face and identity of the donor.

A quote by John Robertson, ²³ a commentator on the ethics of facial allograft transplantation, expresses a similar view. Robertson argues, "The previously disfigured recipient is likely to welcome the new physical identity that the transplanted face brings . It is precisely the new face and associated physical identity that the recipient craves, even if internally he or she remains the same individual". Again, this view poses that the recipient is gaining a (physical) identity.

The point about the transplant recipient gaining an identity is an interesting one that deserves further development. The recipient is now granted an identity that he or she was previously denied, and this is important because one's identity is very much constructed by others. Two important ways in which the recipient gains an identity are that the recipient (1) is now recognised by others and gains an identity in the social world and (2) may gain the ability of expressivity, which allows the recipient to express himself or herself and receive identity-constructing responses from others, and also expressivity itself allows one to fully feel emotions and develop a more robust sense of self.

Philosopher and phenomenologist Maurice Merleau-Ponty²⁴ said, "I live in the facial expression of the other, as I feel him living in mine ...". Donna Williams, who has written of her experiences as an autistic person who is unable to express herself emotionally, reacts to Merleau-Ponty's quote by explaining that what told her that she did exist was seeing in

someone else's eyes that they had seen her.²⁵ She also notes that the presence of another can be used to learn more about oneself (p 97).

John Hull, Professor of Religious Education and Dean of the Faculty of Education and Continuing Studies at the University of Birmingham, Birmingham, UK, has written of his experience of losing his sight, and of being no longer able to see faces. He writes, "To what extent is the loss of the image of the face connected with loss of image of the self?" (p 29). Dr Hull believed that once he lost his sight and no longer had the visual memory of his face or the faces of his family members, that his self was in jeopardy, for to be seen is to exist (p 183).

The charity "Changing Faces", which was developed in London by James Partridge, a person with facial disfigurement, and Nicola Rumsey, a psychologist, expresses the social construction of identity eloquently, "We live not in our own heads' but exist, and are made whole, in the reflective mirrors of others" (p 173). Changing Faces encourages people with facial disfigurement to step out into the world. "Only then can they be aware of others for their own sake, and be seen as an individual, a person, and not as a marker of their own social stigma or limitations. And the way, possibly the only way, to become reconciled and rebuild a life is to use not the mirror on the wall but the mirrored perceptions of oneself that others bring" (p 179). The French National Ethics Consultation Committee⁵ made a similar remark in their report on facial allograft transplantation. They note that because we cannot see our own face, we must rely on artificial mirrors and natural mirrors (others) to get to know ourselves.

The ability to express oneself, to express one's feelings and emotions is also an important aspect of identity. Expressivity is needed to really be seen by others. Ludwig Wittgenstein²⁶ said, "The human body is the best picture of the human soul". Mary, a woman who lost face expressivity and muscle control for unknown reasons, believed that she was reduced to a person, to a "her" in the eyes of others because she was unable to relate to them through her face (Cole,²⁵ p 10). James, who developed a condition called Mobius syndrome that does not allow him to move his facial muscles and express himself, explains the importance of facial expressivity for identity: "I can read faces but I can't give a face in return. In that sense I am invisible or blank" (p 129).

Expressivity is also needed in order for one to fully feel emotions and to develop a robust sense of self-identity. Our emotions are not simply something that occur in our minds, they depend on embodiment (p 191). Even the French National Ethics Consultation Committee⁵ noted that our ability to express affects our feelings. In describing the case of James, Jonathan Cole²⁵, author of *About face*, the fascinating book from which these cases are drawn, says, "It was as though the displaying of emotion on the face enabled its full feeling and expression within ... Without the ability to show to others, a full social existence was scarcely possible, and without these relationships the inner feelings could not develop" (p 179). And certainly, inner feelings are an important part of our understanding of our own identity.

Thus, whether or not facial allograft transplantation will allow for an increase in expressivity is important. The French National Ethics Consultation Committee⁵ is sceptical of the ability to regain expressivity. They note the complexity of the facial nervous system and the multiplicity of small facial muscles. They note that it is reasonable that some form of expressive mobility could be regained, but caution that this depends on the gravity of the existing scarring on the face before surgery (p 14). They claim that there is little likelihood for regaining complete mobility of expression (especially with a full allograft; p 17). Dr Peter Butler, the surgeon responsible for the first hand transplant, has predicted that the patient will

only regain expressivity after extensive nerve regeneration has occurred. He warns that at first the transplanted face will provide a better aesthetic appearance but may actually decrease function and expressivity.²¹ In summary, the extent of expressivity that the transplant recipient will regain is unknown at this point, as a full facial allograft transplantation has not been performed, and only two partial transplants have been performed, with short-term outcome data.

A third significant difference in identity issues between disfigurement and transplant is that it is during transplant that the recipient comes to wear the identity of another person—a dead person. Although the recipient will not "look like" the donor (because the recipient's underlying bone and muscle remain intact), knowing that the skin is from another person could make a significant impact on the identity issues that arise for the recipient. Consider two cases: (1) you are hooked up to a machine that distorts much of your psychological make-up-it deletes some memories and beliefs and mixes up others; (2) you are hooked up to a machine that changes your psychological make-up equally but it does so by transferring many memories and beliefs from another person into you. Although in both cases you have had a significant change in identity, in the second case part of your new identity is from another person. Having part of your identity from another person is a unique identity issue that arises in facial allograft transplantation, but not in disfigurement.

CONCLUSIONS FOR THE TRANSPLANTATION DEBATE

Through both theoretical and first-person accounts I have examined the identity issues involved in organ transplantation in general, and I have argued that the identity issues involved in facial allograft transplantation are both similar to those involved in general transplantation and also unique because the face is so closely linked with personal identity.

Although the face is for most people more closely linked with identity than other transplantable organs, there is certainly variation in individual psychologies. There may be a person who believes that the heart is more closely linked with identity than the face. There are certainly organ recipients who do not have the subjective experience of someone living on inside them, and certainly not everyone who receives a face transplant will have the subjective experience of their identity consisting partly of another person. With this variation noted, it seems arbitrary to claim that the identity issues involved in facial allograft transplantation render it unethical, whereas the identity issues involved in other types of organ transplantation do not.

Thus, a conclusion that can be drawn from the transplantation debate (with respect to the identity issues) is not that facial allograft transplantation is unethical, but that for it to be ethical, the informed consent process for the transplant should inform potential recipients of the identity issues involved. Of course, further exploration of the connection between personal identity and ethics in facial allograft transplantation is needed and this could be performed through empirical studies of those receiving facial allograft transplants.

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