

Full Facial Transplantation

A Bioethical Study from a Catholic Perspective

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For more than twenty years, surgical teams in various hospitals around the world have been investigating and refining the techniques necessary to carry out full facial transplantation. Scientists from Utrecht University in the Netherlands and University of Louisville in the United States, among others, sought approval to carry out this procedure from their institutional review boards for many years. In October 2004, the Cleveland Clinic in the United States became the first institution to receive approval to select potential recipients.¹ In 2006, again after years of pressure from surgeons, similar approval was granted at the Royal Free Hospital in London.² But approval to perform full facial transplantation has been given rarely: in France in early 2008 for Pascal Coler, and at the Cleveland Clinic in the United States for surgery performed in December 2008.³ The obvious question is, why so few approvals?

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¹G. Agich and M. Siemionow, "Until They Have Faces: The Ethics of Facial Allograft Transplantation," *Journal of Medical Ethics* 31.12 (December 2005): 707–709.

²"UK Gets Face Transplant Go-Ahead," *BBC News*, October 25, 2006, <http://news.bbc.co.uk/2/hi/health/6083392.stm>.

³The recent surgery performed at the Cleveland Clinic was a near-full transplant: "Surgeons transplanted 80 percent of a woman's face who suffered severe facial trauma—essentially replacing her entire face except for her upper eyelids, forehead, lower lip and

Ethicists appear to be the prime source of this delay. Hospital ethics committees are reluctant to give the green light to the procedure, yet scientists state that there are a large number of potential recipients willing to accept even the high levels of risk currently involved in order to have facial transplants.

In France in December 2005, Isabelle Dinoire had the world's first partial facial transplant operation. Her lips, nose, and chin had been torn away by her dog and were replaced with donated tissue.⁴ Then, in April 2006, doctors in China performed the second such operation at the Xijing hospital in Xi'an, replacing two-thirds of the face of thirty-year-old Li Guoxing, who had been disfigured when a bear mauled him two years earlier. He was given a new cheek, upper lip, nose, and eyebrow from a single donor.⁵

The first "almost" full facial transplantation took place in France in the early part of this year. For twenty-four years, Pascal Coler had suffered from a severe facial disfigurement caused by neurofibromatosis (Von Recklinghausen's disease), a rare genetic disorder. The surgeon warned him prior to the procedure that the operation could prove fatal, but Coler still wished to proceed. Recent tests have shown that the transplant has removed all traces of the original disease.⁶

Medical Procedures

Four principal allotransplants (transfers of flaps composed of skin with its own blood supply and venous drainage) are currently under consideration for full facial transplantation: skin and fat only; skin and fat together with some or all of the facial muscles, facial nerve, and parotid gland; all of the soft tissue in a subperiosteal transplant; and all the above plus some of the bone structure of the face. As in the case of Pascal Coler, the first full facial transplants are likely to be of skin and fat only, comprising two stages: the harvesting of the transplant tissue followed by the attachment of the tissue to the recipient.

chin. "Cleveland Clinic Surgeons Perform Nation's First Near-Total Face Transplant," news release, Cleveland Clinic, December 17, 2008, http://www.clevelandclinic.org/lp/face_transplant/docs/press-release.pdf. After the operation, bioethicist Arthur Caplan made the worrying suggestion that in the case of rejection, "the woman's doctors should give her the option of assisted suicide. . . . 'If your face is falling off and you can't eat and you can't breathe and you're suffering in a terrible manner that can't be reversed, you need to put on the table assistance in dying.'" "Cleveland Clinic Completes Nation's First 'Almost' Total Face Transplant," *Fox News*, December 17, 2008, <http://www.foxnews.com/story/0,2933,467612,00.html?sPage=fnc/health/beauty>.

⁴Dan Newling and Peter Allen, "First Picture of Woman Given a Face Transplant," *Daily Mail*, December 3, 2005.

⁵Roxanne Khamisi, "World's Second Face Transplant Performed in China," *New Scientist*, April 18, 2006, <http://www.newscientist.com/article/dn9010-worlds-second-face-transplant-performed-in-china.html>.

⁶Katie Franklin, "Tumour Sufferer Has Full Face Transplant," *Daily Telegraph*, March 26, 2008, <http://www.telegraph.co.uk/news/worldnews/1582576/Tumour-sufferer-has-face-transplant.html>.

Correct preparation of both the donor tissue and the recipient site are crucial to a successful outcome. It is likely that a minimum of two of the recipients' arteries and veins will need to be connected to the transplanted tissue to ensure adequate blood flow. Numerous nerve repairs will also have to be made to restore sensation and muscle function. It is expected that the level of sensation achieved will be high.⁷

Are the Risks Too High?

As long ago as the thirteenth century, it was held by individuals such as St. Thomas Aquinas that when someone gives his life for a friend, he does not love the friend more than himself; he is simply attaching more value to the virtuous nature of his gift than to his own physical good.⁸ Applied to facial donation, this would mean that, in the mind of the donor, his appearance after death is less important than the good that can be produced by the gift of his face to another human being. The Church would support the gift of a face by a donor as long as the subsequent transplantation could be carried out in an ethically acceptable manner.

This study sets out to explore, from a Catholic bioethical perspective, the diverse ethical issues that surround full facial transplantations. In examining the ethical issues that present themselves prior to, during, and following facial transplantation surgery, it deals with such issues as donor and recipient selection, consent, research, experimentation, coercion, donor dehumanization, donor death, financial cost, resource allocation, privacy, the expectations of the recipients and their families, psychological support, immunosuppressant therapy, psychological and physical transplant rejection, and the right to life.⁹

Current developments that have an effect on facial transplantation, such as bioengineering, immunosuppressant drug development, and cognitive behavioral intervention, are also examined. I conclude that, since the medical condition being addressed here is not life-threatening, whereas both the transplant and the treatment afterward are life-threatening, there are, from a Catholic perspective, still far too many profound, unresolved ethical issues for full facial transplantations to be an acceptable option at present.

Ethical Issues

Selection of Donor and Recipient

The Catholic Church does not have any problem with the donation of organs and tissues, apart from gonads and brain, as long as there is absolute respect for the

⁷Ibid.

⁸Joseph J. Rickaby, ed., *Aquinas Ethicus: Or, the Moral Teaching of St. Thomas. A Translation of the Principal Portions of the Second Part of the Summa Theologica, with Notes* (London: Burns and Oates, 1892), q. 124 ("Of Martyrdom"), a.3.

⁹The right to life is of particular concern in determining death in potential donors. It will also become a concern if, as Arthur Caplan has suggested, assisted suicide is offered to recipients when facial transplants are rejected.

sanctity of life, for the wishes of the individual with regard to his or her own body, and for mortal human remains.

Pope John Paul II stated his support for organ transplantation when he said, “Thanks to science, and to the professional training and commitment of doctors and health care workers . . . we are challenged to love our neighbor in new ways; in evangelical terms, to love ‘to the end’ (cf. John 13: 1).” He went on to say that the self-offering of Jesus provides us with “the essential point of reference and inspiration of the love underlying the willingness to donate an organ.”¹⁰ Three years later, in *Evangelium vitae*, he returned to the theme: “A particular praiseworthy example of such gestures [self-giving for others] is the donation of organs, performed in an ethically acceptable manner, with a view to offering a chance of health and even of life itself to the sick who sometimes have no other hope.”¹¹

As recently as November 2008, Pope Benedict XVI expressed a similar support when he said, “Tissue and organ transplants represent a great victory for medical science and are certainly a sign of hope for many patients who are experiencing grave and sometimes extreme clinical situations.”¹²

However, the ability to be certain that a donor is dead when organs are removed has been a constant concern for the Church. With the arrival of organ transplantations, the Catholic Church was quick to state its position. In 1956, Pope Pius XII, while emphasizing the Church’s support for the new donor transplant procedures, was careful to emphasize the need for civil authorities to carefully regulate the diagnosis of death before the removal of corneas from donors.¹³ Benedict XVI expressed similar concerns when he requested that the Vatican Academy organize a meeting of senior neurologists to discuss brain death. This meeting took place in September 2006, and a statement titled “Why the Concept of Brain Death Is Valid as a Definition of Death” was issued.¹⁴ Although the Catholic Church still accepts the brain death definition, the debate among both medical and ethical experts continues, with very strong views and beliefs being expressed on both sides.¹⁵

¹⁰John Paul II, Address to Participants in the First International Congress of the Society for Organ Sharing (June 20, 1991), nn. 2 and 4, quoted in Peter Cullen, “Organ Donation: A Catholic Perspective,” *Catholic Medical Quarterly* (November 1998), http://www.catholic-doctors.org.uk/CMQ/Nov_1998/organ_donation.htm.

¹¹John Paul II, *Evangelium vitae* (March 25, 1995), n. 86.

¹²Benedict XVI, Address to Participants at an International Congress Organized by the Pontifical Academy for Life (November 7, 2008).

¹³Pius XII, “The Prolongation of Life,” Address to an International Congress of Anesthesiologists (November 24, 1957), in *The Pope Speaks* 4.4 (Spring 1958): 393–398.

¹⁴A. Battro et al., “Why the Concept of Brain Death Is Valid as a Definition of Death: Statement by Neurologists and Others,” from *Signs of Death: Proceedings of the Working Group of 11–12 September 2006*, Scripta Varia 110 (Vatican City: Pontifical Academy of Sciences, 2007).

¹⁵See E. Facco et al., “Role of Short Latency Evoked Potentials in the Diagnosis of Brain Death,” *Clinical Neurophysiology* 113.11 (November 2002): 1855–1866; and David

It is essential here to differentiate between cosmetic facial surgery, reconstructive facial surgery, and full or partial facial transplantation. In the first, an improvement is sought to facial appearance for cosmetic reasons only. In the second, surgery is used to “rebuild” the face in cases of significant disfigurement, whether accidental or genetic. In both, the risks to the patient’s health are minor, since any tissue added to the face comes from the patient himself. In facial transplantation, however, tissue is taken from a donor and transplanted onto the head of the recipient. This involves considerable risk to the patient’s physical and psychological health, as will be shown in this study. This risk, coupled with the experimental nature of the full-facial transplantation at present, dictates that only recipients in extreme need should be considered for this procedure.

The extent of existing disfigurement must not be the only criteria for selection. The complexity of human psychological response to disfigurement is also a major issue. Many years of research have shown that a patient’s psychological response is not related solely to the severity of the illness. Such factors as previous trauma, available psychological support, existing social environment, and history of depression or other psychiatric illness all play very important roles in psychological response and must be carefully considered.

The selection of a recipient will necessarily be a lengthy and difficult process, largely because of the psychological profiling that must take place. The recipient must be capable of maintaining realistic expectations of the procedure, likely to benefit from it both emotionally and psychologically, and able to expect functional improvements.¹⁶ He or she will need to possess the necessary resolution and strength of mind to endure a long, arduous, and often distressing rehabilitation, as well as a lifelong regimen of immunosuppressant drugs. These drugs have the potential to cause numerous medical complications, some life-threatening; the complications include cancer and liver failure, hypertension, renal toxicity, diabetes, and disturbances in blood lipid levels. The recipient must also be able to face the very real possibility that the transplant might fail, leading to the removal of the transplanted tissue, and either another transplant or lengthy and painful reconstructive surgery.

A recipient must understand that the procedures are still experimental, and that it is impossible for the surgeons to fully explain the risks that must be endured, since these will not be understood until numerous transplantations have been performed. A recipient must also be willing to accept the fact that the transplant may result in considerable psychological trauma, and that the potential impact of this is also unknown.

It is clear, then, that full facial transplantation should be carried out only on a recipient with very strong willpower and character. It is also clear that such indi-

Evans, “What Is Brain Death: A British Physician’s View,” presentation at the Pontifical Academy of Sciences conference, Vatican City, February 2–4, 2005, www.geocities.com/organdonate/finisvitae.html?200728.

¹⁶Peter E. M. Butler, Alex Clarke, and Richard Ashcroft, “Face Transplantation: When and for Whom?” *American Journal of Bioethics* 4.3 (Summer 2004): 16.

viduals are likely to be the ones most able to cope with their existing disfigurement and to take a cautious view of the risks involved in full facial transplantation. It may well be, then, that a significant proportion of the individuals requesting full facial transplants will be those who are less able to cope psychologically with the procedure. This emphasizes the importance of meticulous screening by the medical teams when selecting potential recipients.

Some Catholic bioethicists hold that when the purpose of facial transplantation is to “acquire, when lacking, what is generally regarded as a normal, attractive appearance for one’s gender, . . . this surgery is wholly reasonable.”¹⁷ If the purpose of the surgery is simply the enhancement of sexual attractiveness or the concealment of normal aging, however, then the justification of the costs and risks need to be questioned. It is wrong to place the value of physical appearance above that of the human person, and a transplant for purely cosmetic reasons might well do so. As the first transplants are certain to be subject to rigorous scrutiny by both the medical profession and the media, it is likely that these will be carried out for totally acceptable reasons in this regard. However, this point must be born in mind if this procedure ever becomes more commonplace.

Risk versus Reward

Another important consideration is the balance between risk and reward. The question of whether the benefits will outweigh the known and calculated risks needs to be answered in every case. Case-by-case scrutiny is essential, as the psychological profile of each potential recipient will be different, as will the precise medical circumstances, the available support mechanisms, and the potential recipient’s own attitude to risk.

The concept of burden is also very important. The burdens placed on the recipient must not outweigh the benefits to be gained from the procedure, regardless of whether the burden is measured in suffering, discomfort, psychological distress, financial cost, or media exposure.

Research and Experimentation

The dearth of case histories has already been mentioned as a major concern. Not only does it place pressure on medical professionals to “create” case history by carrying out full facial transplantations as soon as possible, but also it makes it impossible for surgeons to carry out their obligation to fully inform patients about the risks and potential outcomes of what can only be described at present as an experimental procedure. For a patient’s consent to be legally and professionally acceptable, it must be adequately informed, not coerced, and given unconditionally. It is difficult to see how it is possible to comply with the first and last of these requirements at the present time.

¹⁷Benedict M. Ashley, Jean deBlois, and Kevin D. O’Rourke, *Health Care Ethics: A Catholic Theological Analysis*, 5th ed. (Washington, D.C.: Georgetown University Press, 2006), 109.

The first full facial transplant patients will therefore be guinea pigs, in effect. If the potential dangers were not of a life-threatening nature, this risk might be ethically acceptable, the potential benefits perhaps outweighing the risks. But this is not the case here. The lifelong immunosuppressant drug regimen that the recipient will have to follow will almost certainly shorten the recipient's life, and will certainly cause numerous health problems. The recipient will probably have to wait a considerable time before a suitable donor is found. After transplantation, there will be an anxious wait to see if the graft has been successful. The risk of rejection is high, and lengthy reconstructive procedures leading to additional scarring are likely if the transplant is rejected.

The psychological strain will be intense, and the psychological impact on the recipient is likely to be very burdensome. Disappointment is a real possibility, its extent depending on the expectations of the recipient.

In the most recent edition of *Health Care Ethics*, Rev. Benedict Ashley, O.P., and his coauthors offer practical guidance for Catholics on the conditions necessary for experimentation to be ethically acceptable:

- The knowledge sought through research must be important and obtainable by no other means, and qualified people must carry out the research.
- If possible, appropriate experimentation on animals and cadavers must precede human experimentation.
- The risk of suffering or injury must be proportionate to the good to be gained.
- Subjects should be selected so that risks and benefits should not fall unequally on one group in society.
- To protect the integrity of the human person, free and informed voluntary consent must be obtained.
- At any time during the course of the research, the subject (or the guardian who has given proxy consent) must be free to terminate the subject's participation in the experiment.¹⁸

Is it possible for experimentation in the field of full facial transplantation to be carried out under these conditions? It is certainly possible to argue that the research is important, is not obtainable by any other means, and that qualified individuals will undertake it. Experimentation has already been done on animals, but more is required both on animals and on cadavers.¹⁹

The proportional nature of the risk of suffering or injury will be difficult to judge. Because of the highly individual nature of each transplantation case, it may well prove impossible to develop an adequate understanding of the potential for

¹⁸ Ashley et al., *Health Care Ethics*, 14.

¹⁹ Arthur L. Caplan, "Facing Ourselves," *American Journal of Bioethics* 4.3 (Summer 2004): 18. It should also be noted that the accurate and correct determination of death remains an important concern in the use of cadavers.

psychological damage and, to a lesser extent, the likelihood of transplant rejection. It should, however, be possible to ensure that no one group in society bears the burden of this experimentation.

The issue of “free and informed voluntary consent” is likely to prove very difficult to achieve, yet the consent of the recipient must be obtained because of the experimental nature of the procedure. With the present lack of knowledge, it may well prove impossible to provide a potential recipient with the knowledge needed to make an “informed” decision. Recipients will have recourse only to some theoretical papers, like that of Renée Mirkes, O.S.F., and a limited number of actual case studies.²⁰ It is also likely to prove difficult for a patient to withdraw consent, because of the nature of the experimentation. Withdrawal would require the removal of a transplanted facial flap, and require a painful and lengthy reconstruction process, with probable additional psychological trauma.

It is interesting that the American Society for Reconstructive Surgery and the American Society of Plastic Surgeons, in a joint paper, state that because of the experimental nature of full facial transplants, the surgeries should be subject to the evaluation of an independent research ethics committee in order to protect those involved.²¹

In summary, it is clearly difficult to see how the above listed conditions could be satisfactorily met at the present time.

Cost–Benefit Ratio

The cost of all stages of the medical procedures needs to be examined. The partial face transplant carried out in China was reported to have cost 200,000 yuan (approximately US\$25,000). Further surgery, if required, and the postoperative medical regimen would involve substantial additional costs.²² The estimated cost of a full facial transplant operation in the United Kingdom is £25,000 for the operation itself, and between £6,000 and £10,000 thereafter for follow-up and medication. Of course, any complications, which are likely, could increase this figure. On top of this are the intense demands placed on the specialist medical teams that perform the surgery and provide subsequent care, because of the constant monitoring required, the likelihood of additional surgery, and the media attention. The costs of providing psychological preparation, support, and counseling to the recipient and to members of the recipient’s and donor’s families will also be considerable, both in time and resources, and will be an ongoing burden on the health service providers. This too must be borne in

²⁰Renée Mirkes, “Facial Transplantation and Self-Identity,” *National Catholic Bioethics Quarterly* 8.1 (Spring 2008): 46–56. Recent case reports include J. Dubernard and B. Devauchelle, “Face Transplantation,” *Lancet* 372.9639 (August 23, 2008): 603–604, and B. Devauchelle and L. Badet, “First Human Face Allograft: Early Report,” *Lancet* 368:9531 (July 15, 2006): 203–209.

²¹“Facial Transplantation: ASRM/ASPS Guiding Principles,” American Society for Reconstructive Surgery and American Society of Plastic Surgeons, January 2006, <http://www.microsurg.org/ftGuidelines.pdf>.

²²“Doctors Vying for Chinese 1st Face Transplant,” *China Daily*, December 21, 2005.

mind when calculating the cost-to-benefit ratio. These demands will inevitably lead to a reduction in the ability of the physicians to care for other patients.

In the United Kingdom, costs to the nationalized health service also raise complex ethical issues. Health service managers have to deal with funding limitations and complex budgetary systems. They have to consider the how an expensive medical procedure, such as a facial transplantation, will affect other patients in the health service. In making difficult resource allocation decisions, it is normal for the ethical principles of autonomy, beneficence, and justice to be invoked.²³ Their use varies according to the function of those who apply them. When considering autonomy, service providers tend to concentrate on issues of privacy, liberty of the individual, and freedom of choice. Policy makers make use of the same principle but also bear in mind any potential harm that may be caused to others. Those approaching the issues from a public or organizational position give greater value to the welfare of others or of society as a whole.²⁴ Beneficence involves promoting the welfare of others, doing good, and not causing harm, and is usually interpreted in light of societal, population, or organizational needs. Service providers, though, tend to focus primarily on the rights of the individual. Justice is the core value of public health, concentrating as it does on equality of opportunity, access, and benefits. Policy makers and managers will usually also consider the protection of the vulnerable and disadvantaged in society. They take into consideration health, culture, education, and economics. Their target is distributive justice, marked by the equitable and appropriate distribution of limited resources. All the above criteria must be fully considered and decided upon before any transplant is allowed to take place.

The Rights to Truth and Privacy

Ashley, deBois, and O'Rourke maintain that individuals "have a right to the truth about their health because they have the primary responsibility for this. They also have a right to privacy about those aspects of their life that do not directly affect others."²⁵ The right to the truth in the case of facial transplantation signifies full disclosure about the potential outcomes, both physical and psychological; about the experimental nature of the procedure; about the dangers associated with immunosuppressive drugs, about the possible effects upon their families and friends, about the limited relevant case history that exists, and about the options available in the event of transplant failure. It also signifies the right to know about all relevant developments and the likely effects these will have in the future.

The recipient is entitled to privacy, although this may be difficult to achieve in the early cases, when media interest is high. It is crucial to minimize the inevitable psychological trauma for the recipient, and media interest must be managed to achieve this.

²³Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 3rd ed. (New York: Oxford University Press, 1989).

²⁴P. J. Madox, "Administrative Ethics and the Allocation of Scarce Resources," *Online Journal of Issues in Nursing* 3.3 (December 31, 1998), <http://www.nursingworld.org/>.

²⁵Ashley et al., *Health Care Ethics*, 213.

No one apart from the recipient has any right to information as to the recipient's identity or personal details. There will be a natural wish on the part of the medical teams and others involved to publicize the transplant, especially the first successful cases. To do anything in this regard that could compromise the privacy of patients would contravene their privacy rights.

Expectations

The 2003 Working Party Report of the Royal College of Surgeons of England places great importance on the preparation of recipients. It mentions that patients must be prepared for the potential costs of undergoing a facial transplant, particularly psychological costs; these may include the stresses involved in a long wait for a donor, major surgery, the wait after surgery to see if the graft is successful, the consequences of possible graft rejection, the reactions of others to the recipient's altered appearance, and the critical need for compliance with immunosuppressant therapy.²⁶

It is crucial that the transplant recipient have realistic expectations of the outcome of the transplant surgery and as accurate a mental picture as possible of the likely initial outcome of the operation, the likely progression and timescale, and the possible problems that may occur.

A full facial transplant is very hazardous. A musculocutaneous graft such as a facial flap has a high probability of failure, and success cannot be achieved at present unless the recipient takes immunosuppressant drugs for the rest of his or her life. The psychological burden posed by this may be too heavy for an individual to bear. Clint Hallam, the first hand transplant recipient, found compliance with immunosuppressive therapy too difficult and eventually asked to have the transplanted hand amputated.²⁷ Psychological problems are also likely if the transplant fails to meet expectations. Such problems have been reported following hand transplantation and include difficulties adapting to a transplant that is always visible to oneself and others.²⁸ Face transplants are expected to be more difficult to cope with than hand transplants.

Immunosuppressant Therapy

Immunosuppressant therapy must commence immediately after surgery and continue for the rest of the recipient's life. Immunosuppressive drugs make all kinds of infections more likely and multiply cancer risks significantly—side effects that can shorten the patient's life.²⁹ These side effects are well known, so reliable information can be provided to any prospective recipient prior to transplantation.

²⁶P.J. Morris et al., *Facial Transplantation: Working Party Report* (London: Royal College of Surgeons, 2003), 10–11.

²⁷“Surgeons Sever Transplant Hand,” *BBC News*, February 3, 2001, <http://news.bbc.co.uk/1/hi/world/europe/1151553.stm>.

²⁸Martin M. Klapheke, “Hand Transplantation and Psychiatric Issues,” University of Louisville Health Sciences Center, Jewish Hospital, St. Mary's Healthcare, and Kleinert Kurtz Hand Care Center, <http://www.handtransplant.com/procedure/psychiatric-issues.asp>.

²⁹Morris et al., *Facial Transplantation*, 7–8.

Some side effects, if they occur, may require a change in the immunosuppressant therapy regimen, which in turn has the potential to lead to the rejection of the facial transplant tissue. It is clear that the potential consequences of tissue rejection could be devastating for the recipient.

Transplant Rejection

Rejection of the transplanted tissue is a real possibility; hence the importance of adherence to the immunosuppressant regimen. Skin is particularly prone to rejection, having already proved to be a major cause of failure in composite tissue transplantation.³⁰ Isabelle Dinoire, the French patient who had a partial face transplant, had two episodes of early acute rejection which were controlled by very large doses of immunosuppressive drugs. The potential consequences of tissue rejection could be devastating for the recipient.

Immune rejection is likely to be a principal reason for the failure of full face transplants. Acute rejection, as in cases of upper limb transplants, can often be corrected by use of increased levels of immunosuppressants. Chronic rejection is likely to be more of a problem, since it normally causes progressive replacement of the skin by fibrous tissue, leading to loss of graft mobility and functional failure.

Unfortunately, immunosuppressant drugs have not proved as effective against chronic failure as against acute rejection. The Royal College of Surgeons of England Working Party predicted that acute rejection in the first year following transplantation will account for the loss of about ten percent of grafts, and chronic rejection leading to loss of graft function will affect between 30 and 40 percent of grafts over the first five years.³¹ Richard Huxtable and Julie Woodley predict that a minimum of one in five transplants will be rejected in the first three years after attachment. They comment that there does not appear to be a viable option yet for recipients whose new faces are rejected.³²

Support for the Recipient

The 2003 Working Party Report also states that facial transplantation is likely to give rise to the following stressors, psychosocial challenges, and adaptive demands in the transplant recipient:

- Fears about the viability of the transplant
- Fear of the aftermath of possible rejection
- Anxiety about the potential side effects of immunosuppressant medication
- Feelings of personal responsibility for the success or failure of the graft

³⁰J. H. Herndon, "Composite-Tissue Transplantation—A New Frontier," *New England Journal of Medicine* 343.7 (August 17, 2000): 468–473; and Morris et al., *Facial Transplantation* (2003), 7.

³¹Morris et al., *Facial Transplantation* (2003), 7.

³²Richard Huxtable and Julie Woodley, "Gaining Face or Losing Face? Framing the Debate on Face Transplants," *Bioethics* 19.5–6 (2005): 505–522.

- Fears about lifestyle changes that will need to be made
- Integration of the transplant into existing body image and sense of identity
- Emotional responses to the reception of the donated facial tissue such as gratitude and guilt³³

To these we can add fear of a limited ability to communicate facially, fear of personal rejection of the end result, fear of peer attitudes, fear of public reaction, fear of “celebrity status” and publicity, and fear of failure.

Mirkes explains that “the procedure’s primary psychological risk is the emotional upheaval caused by an ‘identity’ change, the prediction that a facial graft recipient will, post-transplant, experience a virtual emotional tsunami from the realization that their new face transforms them into a new person.” She goes on to explain that “with the transplant of a visible organ, a deep identity split occurs, because one’s self-image is modified substantially.”³⁴ This shows the absolute requirement for expert psychological support prior to, at the time of, and following transplantation. The recipient is likely to move between these problem areas, so the support must be continuously available long term.

Support for the Families

The recipient’s family will provide part of the support required for dealing with the problems mentioned above. Family members will require preparation and training if they are to be able to provide this support. They will also require preparation for the possible emotional and psychological outcomes for themselves and the recipient, and guidance as to how they can help.

It is important to remember that the recipient’s family itself will face an anxious post-operative period of waiting to see whether the graft is successful, and will have to endure their own emotions and feelings in regard to the transplanted face. They, too, will require psychological preparation for this, and ongoing support.

The donor’s family also must not be forgotten. They will require support to deal with their emotions and feelings following the transplantation of their loved one’s face and following the subsequent burial or cremation.

Transplant Rejection

Huxtable and Woodley explain that, whereas other “external” transplants offer functional benefits, facial transplants as proposed at present only offer improvements in aesthetic appearance. The primary motivation to undergo the procedure, then, will be the perceived psychological benefits associated with improved facial appearance. Researchers have already discovered that transplanted tissue can feel “foreign” to a recipient. They illustrate this by referring to the case of M., an adolescent who in 1999 was adjudged by an English High Court not to be competent in deciding to refuse a heart transplant. M. stated, “I don’t want to die but I would rather die with

³³Morris et al., *Facial Transplantation* (2003), 9.

³⁴Mirkes, “Facial Transplantation.”

fifteen years of my own heart. If I had someone else's heart I would be different from anyone else—being dead would not make me different from everyone else.”³⁵ Like M., the individual recipient can be full of insecurities, such as not wanting to be different.

The prime motive for undergoing facial transplantation is the acquisition of psychological benefits. It is, however, very difficult to be sure of the psychological resilience of a prospective recipient. As stated earlier, it is likely, in fact, that the very individuals who do not feel the need to seek out these psychological benefits, and who are unwilling to expose themselves to the considerable risks of transplantation, may be those who are best able to cope with the psychological pressures it will impose.

Recipient screening may limit the incidence of psychological rejection of the transplanted tissue. However, it is almost inevitable that, as with other transplants, there will be cases of facial transplantation in which the psychological burden proves to be too heavy to bear. Full facial transplants are expected to be especially difficult to cope with, because of their total, permanent visibility to others; the limited facial functionality leading to difficulties in verbal and nonverbal expression; the highly complex psychological and emotional issues of identity, self-confidence and recognition; guilt and gratitude toward the donor and the donor's family; and the stress related to expectations and feelings of responsibility for the success of the transplant. It is a moral responsibility of the surgical team to ensure that sound psychological guidance is proactively provided before, during, and after the transplant.

Current Developments

Bioengineering

Bioengineering is a very fast moving field. It brings together scientists and academics from different disciplines to develop new materials and technologies. In the medical field it brings together medical clinicians, researchers, cell biologists, nuclear physicists, and mathematicians, among others, in order to advance the field of medicine. In the area of heart disease, for example, such diverse disciplines as fluid dynamics, arterial geometry, protein function, and gene transfer are all involved in the search for answers to existing problems.³⁶

In facial reconstruction, bioengineers seek to develop new technologies in the areas of implants, medical imaging, diagnostics, biopolymers, and membranes. This research and development work promises to have a significant effect on the treatment of facial disfigurement through the development of tissues that would not require immunosuppressant drugs, and the possible regeneration of the patient's own facial tissue.

³⁵Huxtable and Woodley, “Gaining Face or Losing Face?” 516.

³⁶University of Canterbury, “About Bioengineering,” <http://www.bioengineering.canterbury.ac.nz/about.shtml>.

In 2002, for example, Larry Hench and Julie Polak, researchers at Imperial College London who are working on a new generation of biomaterials for regeneration and repair of tissue, explained that the body's own genes are capable of controlling the tissue repair process using new bioactive materials.³⁷ In 2003, researchers at the University of Illinois successfully turned adult stem cells into bone and cartilage.³⁸ Both lung cells and knee cartilage have now been reproduced from embryonic cells, and the entire articular surface of a rabbit's lower femur has been grown.³⁹ In 2008, Paolo Macchiarini of the Hospital Clinic of Barcelona used a patient's own stem cells to create an artificial airway to replace the bronchus to her left lung, which had collapsed after she suffered a serious tuberculosis infection. Five months after the operation, the patient's lung function was normal for a woman of her age, and there were no signs of rejection and no need for immunosuppressant drugs.⁴⁰

In 2004, researchers at Johns Hopkins University created a new class of artificial proteins that can assemble themselves into a gel and encourage the growth of selected cell types.⁴¹ By sending different biological signals to cells, this material will help scientists develop new means for repairing injured and diseased body parts.

In 2008, scientists at Harvard University managed to take pancreatic cells that produce enzymes in mice and successfully reprogram them to produce insulin. Doug Melton, codirector of the Harvard Stem Cell Institute, said the same approach could be used to generate motor neurons for patients with amyotrophic lateral sclerosis, to make cardiac muscle cells for heart attack victims, and to create other crucial cells

³⁷"Next-Generation Biomaterials to Help Body Heal Itself," Imperial College of Science, Technology, and Medicine, February 11, 2002, <http://www.imperial.ac.uk/P3190.htm>.

³⁸Phil Sneiderman, "Self-Assembling Proteins Could Help Repair Human Tissue," *Johns Hopkins University Gazette* 33.28 (March 29, 2004), <http://www.jhu.edu/~gazette/2004/29mar04/29repair.html>.

³⁹The destruction of embryonic stem cells is not acceptable to the Catholic Church. Embryonic cells usually come from induced abortions. An embryo "has a right to its own life," and killing an embryo is the same as killing any human being; it is murder. Even the removal of stem cells from the blastocyst stage is "critically and irremediably" damaging to the embryo, and is therefore a "gravely immoral act." Pontifical Academy for Life, "Declaration on the Production and the Scientific and Therapeutic Use of Embryonic Stem Cells" (August 25, 2000). See also Ronald Munson, *Raising the Dead: Organ Transplants, Ethics, and Society* (Oxford, UK: Oxford University Press, 2002), 246, 255. If stem cells are obtained from a spontaneous abortion, and are freely given for research after embryo death by the baby's parents, this may be acceptable to the Catholic Church. Even then, the purpose of the donation must be such that respect for the embryo or fetus is maintained. Unless this is guaranteed, no donation should be made. See Francisco J. Basterra and F. Javier Elizari, *Bioethics* (New York: Hyperion Books, 1994), 158. Finally, if the possibility of scandal exists, the Catholic Church would oppose the use of any fetal cells.

⁴⁰Sarah Boseley, "'My Unique Chance': How Claudia Castillo's Landmark Operation Changed Her Life," *Guardian*, November 19, 2008, <http://www.guardian.co.uk/society/2008/nov/19/organ-donation-medicalresearch>.

⁴¹Sneiderman, "Self-Assembling Proteins."

that can repair damage wrought by a range of illnesses. This development could, within a few years, lead to the ability to take any human cell and convert it into facial tissue, thus removing the requirement for stem cells for such purposes.⁴²

Deformable modeling of facial tissue has been developed to allow craniofacial surgeons to try out different surgical techniques and see the results before deciding which is the most appropriate, and high-technology implants are being developed to aid facial reconstruction.

These developments in medical bioengineering have a very significant role to play in facial reconstruction. Deformable modeling will reduce the need for experimentation by allowing surgeons to carry out “virtual” procedures, calculate the final result before commencing a transplant, and shape their reconstructive work accordingly. The development of tissue from the recipient’s own cells not only decreases enormously the risks of rejection, taking away the requirement for immunosuppressants with their dangerous side effects, but also provides the possibility of cosmetically perfect tissue matches as opposed to approximate ones. Although the use of embryonic stem cells for such purposes is not acceptable, it is also not ideal. The use of the recipient’s own stem cells for medical bioengineering purposes is acceptable and far more promising.

The question has to be asked is whether these advancements are worth waiting for. Benjamin Wu, a leading bioengineer, has said that he feels that with the speed of development, and the very high caliber of the researchers working in bioengineering, it might well be possible to rebuild large parts of the face from bioengineered material within the next fifteen years or so.⁴³

Immunosuppressant Drug Development

Numerous significant developments in the field of immunosuppressant drugs have also been made over the last few years. For example, the proteasome, a large protease complex in cells, was formerly thought to be useful only in the removal of mis-folded or spent proteins. It is now understood to be instrumental in many aspects of immune responses. A proteasome inhibitor has already been used to prevent allograft rejection in mice, with significantly more tolerable side effects than existing drugs.⁴⁴ A new drug, CP-690550, inhibits the enzyme JAK-3, effectively suppressing the immune system without affecting other systems of the body. These and similar developments offer real hope for a reduction in the current level of adverse side effects from an immunosuppressant drug regimen.

⁴²Karen Kaplan, “Diabetes Researchers Convert Pancreas Cells to Produce Insulin,” *Los Angeles Times*, August 28, 2008.

⁴³Wu Benjamin, e-mail message to Bernard Farrell-Roberts, December 11, 2006.

⁴⁴J. Wu, “On the Role of Proteasomes in Cell Biology and Proteasome Inhibition as a Novel Frontier in the Development of Immunosuppressants,” *American Journal of Transplantation* 2.10 (November 2002): 904–912.

Cognitive Behavioral Therapy

Cognitive behavioral therapy has proved to be very effective in helping patients deal with social phobia, anxiety, panic, and post-traumatic stress disorder. Can it also be effective in cases of severe facial disfigurement? Cognitive behavioral therapy works by breaking down what appear to be overwhelming problems into smaller parts, then examining these to see how they are connected and how they affect the individual. These parts are thoughts, emotions, physical feelings, and actions. Each one of these can affect the others, forming a vicious circle of altered thinking, feelings, and behavior. By breaking them down, and thus seeing the sequence clearly, however, patients can better control a situation and work out the best way to deal with it for themselves.

In 2000, a report in the *British Journal of Psychiatry* examined the psychological difficulties experienced by people with facial disfigurement.⁴⁵ According to the report, in the United Kingdom alone at least 390 thousand people suffer from facial disfigurement, and a large proportion of them suffer from social phobia as well. The report states that the more disfigured the individual, the higher the incidence of psychological disturbance. The report concludes that cognitive behavioral therapy would be effective for facially disfigured people, that it could be delivered cost-effectively by means of self-help packages, and that the pre-surgery provision of therapy dealing with exposure and social contact could well be of use. However, some concern was expressed regarding the long-term effectiveness of this therapy.

In 2002, the *Journal of Evaluation in Clinical Practice* published a paper on the effectiveness of cognitive behavioral interventions among thirty-six patients in a disfigurement support unit.⁴⁶ The study showed significant improvements among them in social anxiety, appearance-related stress, general anxiety, and depression, both at the end of intervention and six months later. Also reported were improvements in positive affect and satisfaction with life, partly due to improvements in the interviewees' own perceptions of the noticeability of their disfigurement.

Sound pre-transplant CBT may well be able to lessen the psychological impact of the surgery on recipients, and in some cases may even take away the need for facial transplantation by enabling the patient to cope better with their disfigurement. This latter point is important, given the very high risks associated with facial transplants at present. It may also help patients defer decisions regarding surgery until more options are available and the risks of surgery reduced. Although the potential usefulness of CBT among patients with facial disfigurement does not appear to be in doubt, more research is required to answer questions about its long-term benefits.

⁴⁵Robert Newell and Isaac Marks, "Phobic Nature of Social Difficulty in Facially Disfigured People," *British Journal of Psychiatry* 176 (2000): 177–181.

⁴⁶Liv Kleve et al., "The Effectiveness of Cognitive-Behavioural Interventions Provided at Outlook: A Disfigurement Support Unit," *Journal of Evaluation in Clinical Practice* 8.4 (November 2002): 387–395.

Postponement

The developments mentioned above present another ethical dilemma. In light of the significant dangers associated with donor tissue and rejection, is it acceptable for a potential recipient to proceed with a transplant now, or should he or she wait until alternative bioengineered materials with fewer risks are available? Also, is a potential recipient justified in choosing to go ahead with a transplant now, when new immunosuppressants are being developed with less harmful side effects? Of course, it is not possible to predict when these products will be available or, indeed, if they will ever be available, but experts appear to believe they will. At the very least these new developments will offer new options, which must be taken into account; they thus make it more difficult to justify the very high risks of transplant surgery today.

The Catholic Church teaches that the human body is not only the body of the person, but also “a temple of the Holy Spirit within you, which you have from God” (1 Cor 6:19).⁴⁷ There is a supernatural reality brought about by the indwelling and continual presence of the Holy Spirit. The redemption of the body, brought about through Christ’s sacrifice on the cross, elevates all human bodies to a new holiness, a holiness that demands that every human should not sin against his body but should control one’s body in holiness and honor.⁴⁸ This places on human beings the obligation to honor their bodies as temples of the Holy Spirit, and not to defile or mutilate them. In the context of facial disfigurement, it is important to remember this and not concentrate only on the cosmetic beauty of the body as perceived by modern society.

Although the Catholic Church understands disability and disfigurement to be an absence of a good that should be there, it also holds that good can come out of these situations, and often does. It is too easy to ignore the good that can come from disability, disfigurement, and suffering to those who are afflicted with them and to society. The tendency today is to try to eradicate from society all suffering and superficial ugliness, instead of seeking out and honoring the underlying beauty. Parents of handicapped children talk of the wonderful gift that their child has been to them, the happiness they all share, and the enrichment that their child has brought to their lives. Parents who have lost a child through ill health at an early age often say the same. Through the suffering of ourselves and others, our lives are often enriched, our understanding deepened, and our positive influence on others enhanced.

In my research I have come across many stories of tremendous bravery, terrible suffering, and magnificent witness to the goodness intrinsic in human beings. In seeking to find cosmetic solutions to terrible disfigurement, it is very important to go beyond the disfigurement to the beauty lying underneath, and protect this, too.

⁴⁷ *New Jerusalem Bible* (New York: Doubleday, 1985).

⁴⁸ John Paul II, *The Theology of the Body* (Boston: Pauline Books, 1997), 207.

Summary of Ethical Concerns

When Pope John Paul II addressed the International Congress of the Transplantation Society in 2000, he reaffirmed his support for organ and tissue transplantation in no uncertain manner. He said, “The decision to offer without reward a part of one’s own body for the health and well-being of another person” is “a gesture which is a genuine act of love.” He also made precautionary references to “certain critical issues,” which include the ethical acceptability of any transplant; the limits imposed by human nature itself as opposed to technical possibility, and the moral unacceptability of commercialization of human organs.⁴⁹ The Pope also made it clear that despite the best of motives for donorship, the procedures involved in any transplant must be ethically acceptable. Here lies the greatest obstacle to full facial transplantation being an acceptable option today.

First, there needs to be certainty of the donor’s death prior to the removal of transplant tissue. This is a major issue especially for Catholics, for whom all life is sacred. Such is its importance that Pope Benedict XVI, at a recent conference on organ donorship in Rome, reminded his listeners that “individual vital organs cannot be extracted except *ex cadavere*.”⁵⁰ Despite broad agreement in western medical science on both the determination of death and the definition of the state of death, significant disagreement remains.

Second, consent of the donor, or the donor’s family, remains a significant issue. Because of the lack of case studies and experience with facial transplants, it is difficult to see how it will be possible to provide the information about potential physical, medical, and psychological outcomes of the transplant, that is required for informed consent. Yet both secular and Catholic medical ethics demand that informed consent be obtained.

Ethicists are still reluctant to give consent for full transplantation, although they are apparently moving closer. In November 2003, for example, the Working Party of the Royal College of Surgeons of England concluded that there were too many ethical issues for full facial transplants to be carried out at that time.⁵¹ In November 2006, however, the working party cautiously agreed that full facial transplants could take place, but with conditions.⁵² Martin Milling, a plastic surgeon and a member of the working party, said, “The patients will be the pioneers as much as the surgeons. That includes the donors, the recipients, and their families—a very large number of people. The duty of care to these pioneers can’t be exaggerated.”⁵³

⁴⁹ John Paul II, Address to the Eighteenth International Congress of the Transplantation Society (August 29, 2000), nn. 2 and 3.

⁵⁰ Benedict XVI, “A Gift for Life,” Address to Participants at an International Congress Organized by the Pontifical Academy for Life (November 7, 2008).

⁵¹ Peter Morris et al., *Facial Transplantation* (2003), 20.

⁵² Peter Morris et al., *Facial Transplantation: Working Party Report*, 2nd ed. (London: Royal College of Surgeons, 2006), 37–40.

The report concludes that transplants could take place as long as fifteen named conditions are met. Several of the issues identified as problem areas in 2003 appear again on the 2006 list, including the burden of immunosuppressant therapy, the lack of sufficient information on which informed consent can be based, the incomplete understanding of the risks, the lack of adequate medical expertise, the cost, and the requirement for long-term support for the recipient.

The report highlights the risk of acute or chronic rejection, a concern for all members of the research population. Professor Nicola Rumsey, a psychologist specializing in research into appearance, and a member of the working party, stated that “the fear of losing the face completely would be extremely damaging psychologically. A repeat transplant is not very likely, so a patient would have to go back to a traditional reconstructive procedure. This is viewed as an area of significant concern, with no available solution as yet.” She went on to say that “if the face were rejected, the symptoms would be a loss of mobility and the ability to express emotion. . . . Having to go back to square one, or square minus one, would be horrible.”⁵⁴

Two of the conditions mentioned in the report refer to the costs of transplantation and ongoing care. Costs may become a complication if it is felt that they outweigh the benefits to the recipient and adversely affect the medical services that are available to others. Another condition refers to the need for effective psychological support for the recipient and family. Because there is so little case history in facial transplantation, we have no way of knowing whether that support will be effective. Thus, on closer examination, what appears in the report as permission to go ahead does not bring the performance of full facial transplantation any closer. A similar hesitancy has been shown by the Royal Free Hospital in London, which agreed in late 2006 to the selection of prospective donors and recipients, but has yet to grant permission for a full facial transplantation to be performed.

Bioengineering is surely the most promising development for facial reconstruction. It involves no immunosuppressant or donor-death issues, and appears to be the most likely eventual solution to the problem of severe facial disfigurement.

It is difficult to see how full facial transplants could be acceptable from a Catholic ethical perspective at this time. The disfigurement is not life-threatening, whereas transplantation itself, and the treatment afterward, are life-threatening. For the risks to be deemed ethically acceptable, there must be a very compelling reason for transplantation, and the benefits must be to the recipients themselves, since they are the ones at risk.

⁵³Nigel Hawkes, “Surgeons Urge Face Transplant Safeguards,” *Times Online*, November 13, 2006, <http://www.timesonline.co.uk/tol/news/uk/article635746.ece>.

⁵⁴Ibid.