

well as providing other information about him or her. For scientific reasons alone then, the identity of the subject cannot be concealed.<sup>6</sup> Furthermore, in a democratic society it is the responsibility of scientists, we think, to inform the general public of the nature of scientific advances. This societal duty must be carefully balanced against and tempered by the requirement to maintain insofar as feasible the subject's privacy and confidentiality. Nevertheless, it seems to us that the surgical/medical team must from time to time hold press conferences that provide essential components of information about the procedure, the condition of the recipient, and the results thus far. All such information, however, should first be presented to the subject in order for him or her to make whatever suggestions he or she chooses regarding its public disclosure.<sup>6</sup> Finally there are the enormous resources of the popular media. It is difficult to imagine how with even the best efforts one can protect the privacy and confidentiality of the recipient-subject when so many reporters and photographers are trying to expose every piece of information discoverable. We can only try to restrict the disclosure of information to that provided by press conferences, scientific reports, and the decisions of the subject him or herself.<sup>6</sup>

We agree with Haughton<sup>1</sup> that the ultimate question regarding facial transplantation research at this stage is: Should it be done? We would reformulate this question as "When should it be done?" or, even more pointedly, "should it be done now?" In a separate communication<sup>6</sup> we develop eight criteria that, we claim, must be fulfilled prior to answering the latter question in the affirmative. The main issue to be addressed – when is approached from the angle of – what is to be gained by waiting? We claim that in all probability advances toward a safer and more effective procedure will be gained by waiting for an extensive period of time. Nevertheless, these advances will in the short term be minimal. There are historical examples of procedures being tried when, it

was easy to foresee at the time that waiting would have produced further advances that would benefit the procedure. The example we cite in our article is NASA's first manned space flight to the moon.<sup>6</sup> The actual flight proved to be successful, of course and as a result space travel took a "giant step for mankind" forward.

We maintain that surgery stands at an analogous point in its history with regard to facial transplantation. We believe, then, the answer to the question "when?" should be "now." For we think that we are now at the point in surgical history when the following conditions stipulated by Haughton<sup>1</sup> are satisfied, "when it does happen, it should be with the expectation of success, the demonstrated skill of the surgical team and the bravery and courage of that first patient who ultimately makes and lives with their choice".

## References

1. Haughton P. Ethical Considerations in Face Transplantation. *International Journal of Surgery* 2004; 2: 79–81.
2. Jonsen AR, Veatch RM and Walters L, editors. *Source Book in Bioethics: A Documentary History*, Washington DC: Georgetown University Press, 1998.
3. Brody BA. *The Ethics of Biomedical Research: An International Perspective*. New York: Oxford University Press, 1998.
4. Levine RJ. *Ethics and Regulation of Clinical Research*. New Haven: Yale University Press, 1986.
5. Loue S. *Textbook of Research Ethics: Theory and Practice*. New York: Kluwer Academic/Plenum Publishers, 2000.
6. Wiggins OP, Barker JH, Martinez S, Vossen M, Maldonado C, Grossi F, Francios, CG, Cunningham M, Perez-Abadia G, Kon M and Banis JC. "On the Ethics of Facial Transplantation Research." *American Journal of Bioethics* 2004, in press.
7. Royal College of Surgeons of England. *Facial Transplantation*, Working Party Report. London: Royal College of Surgeons of England, 2003.
8. Veatch RM. *Transplantation Ethics*, Washington, DC: Georgetown University Press, 2000.
9. Summerton I and Agha R. Sociological considerations in face transplantation. *International Journal of Surgery* 2004; 2: 82–83.
10. Morreim F. "High-Profile Research and the Media: The Case of the Abiocr Artificial Heart." *Hastings Center Report*, 2004, January/February: 11–24.

---

*International Journal of Surgery* 2004; 2: 82–83

---

## Sociological Considerations in Face Transplantation

I. Summerton<sup>1</sup> and R.A. Agha<sup>2</sup>

<sup>1</sup>International University of Health Sciences, Munich, Germany

<sup>2</sup>Editor-in-Chief, *International Journal of Surgery*

Correspondence to: Ms Ivana Summerton, Adunistr. 5A, 81369 Munich, Germany

Barker et al's thoughts on face transplantation were most interesting, thought provoking and controversial.<sup>1</sup> Surgery is not a subject with whom one outside of the medical profession feels comfortable and facial surgery would certainly not be considered an after-dinner topic. It is for reasons of human discomfort with facial disfigurement that such developments are viewed as a leap as opposed to gradual progress. The 1996 Hollywood thriller – "Face Off" depicts the "big screen" interpretation of face transplantation and its implications, but behind the science fiction and the directors camera there is an emerging reality which must be discussed by all sections of society.

Medical advances such as the donation and transplantation of organs are widely accepted practices in the majority of today's societies. To date, those in need of organ transplants are dependant upon the organs of the deceased for what is ultimately a life saving (or "life giving") operation. Because the purpose of the organ transplantation is to sustain life society finds it acceptable. But what exactly constitutes "life-saving"? As face transplantation becomes a reality this question will need to be answered. Is a face just another organ or is it more than that? Such an operation could be viewed by the masses as non-critical. However, one suffering from severe facial disfigurement might have a different view.

Face transplantation would indeed be a life altering experience for an individual with facial disfigurement. It could be considered as

potentially life-saving by preventing suicide and even life-giving by increasing the individuals participation in society and potentially opening up new opportunities for them such as marriage, a better job going out to dinner without being stared at or ridiculed. There are many who suffer with diseases such as cancer, birth defects or accidents. These are often random "events" or "processes" which are often not the patients fault but for which they are ridiculed and stared at by society following their operation or treatment which has led to a more permanent disfigurement – the management for which is often not satisfactory.<sup>1</sup>

Our interpretation of what is acceptable comes from what we consider to be "the norm" within our environment. Humans have long since been fascinated with facial features be it disfigurement or beauty. Looking "normal" is the desire of anyone with a facial disfigurement as we are usually judged upon our appearance – "first impressions count". For the majority facial disfigurement is not an issue we tackle on a daily basis and we would rather not address it. When we are faced with it we therefore do not know how to react – we either stare or look away. As a child we may recall being told by our mother "Don't stare, it's rude" as curiosity in the presence of someone with facial disfigurement takes hold, without realising its affects on the recipient. If one was to engage people with facial disfigurement in a 'normal' manner they may well say "it's nice to be treated like everyone else for a change". Facial disfigurement is very much a 'living' reality for many and a challenge they face

every day. The 'challenge' being laid down by the reactions of people to their disfigurement.

Social exclusion, ridicule and depression become internalised as part of 'life' and everyday experiences which are hard for non-sufferers like us to comprehend. For such a people could facial transplantation simply be viewed as cosmetic? Because we place such importance on our physical appearance, particularly our faces, the decision to donate ones face is one that would require a great deal of thought. For some relatives the image of a faceless burial would be almost as painful as the loss itself, while others would see the donation of such a vital organ as giving some purpose to the death of a loved one by improving the life of another.

As technological developments continue numerous ethical issues will arise and need to be addressed through debate, broad consultation and consideration. However, it is important for society to

empathise with those dealing with facial disfigurement and not to be prematurely dismissive of a procedure like face transplantation. As it is the reaction of society itself to those with facial disfigurement that leads to their willingness to accept the risks and uncertainties of the procedure over and above the certainty of living with facial disfigurement. Ultimately, face transplantation will be less effective if the recipient could be recognised as having had one. The same cycle of ridicule and felt anxiety would remain. It is important for society to change as well, just as ethnic, racial and religious diversity is accepted and indeed even embraced, we must all do more to educate ourselves and others about facial disfigurement and move towards greater acceptance of variation.

**Conflicting Interests** – None declared.

## Reference

1. Barker JH, Vossen M and Banis JC Jr. The Technical, Immunological and Ethical Feasibility of Face Transplantation. *International Journal of Surgery* 2004; 2: 8–12.

## Response to: Summerton and Agha Sociological Considerations in Face Transplantation

L.A. Furr<sup>1</sup> and J.H. Barker<sup>2</sup>

<sup>1</sup>Assoc. Professor/Vice-Chair, Department of Sociology, University of Louisville

<sup>2</sup>Director, Plastic Surgery Research, Department of Surgery, University of Louisville

Correspondence to: John H. Barker, MD, PhD, Director, Plastic Surgery Research, 320, MDR Building, 511, South Floyd Street, Louisville, Kentucky, 40202, USA

Summerton and Agha<sup>1</sup> raise many of the social issues generated by the prospect of conducting facial transplantation surgery. We share their appreciation of the importance of the social dimensions inherent in this procedure; in fact, it is our position that social considerations provide a significant amount of the energy that drives the aspirations to conduct this surgery.

Risks in transplantation surgery have been acceptable to most societies because, as Summerton and Agha correctly assess, these surgeries are understood to be life-saving. When measured to this criterion, face transplantation on first notice appears to fall into the category of "life-improving" and thus is not deserving of the same consideration of risk acceptance as perhaps heart or lung transplantation. Summerton and Agha, however, offer a provocative question in this regard when they ask, "What exactly constitutes 'life-saving?'"

It is unquestioned that the social impact of facial disfigurement is profound. Macgregor's classic study tells us that the primary problems experienced by people with facial anomalies are indeed socially based. In all social interactions, Macgregor<sup>2</sup> tells us, disfigured faces are "reflected in the reactive behavior of the nondisfigured". The constant intrusion into privacy, rejection, being the target of curiosity and ridicule, and strained relationships and interactions are what people with facial defects report are among the main stressors in their lives. The theme running through the interviews with people with conspicuous facial flaws is the strong desire, as Macgregor states, to be accepted as "members of the human race".

Why are people with disfigured faces sanctioned socially and treated differently? In sociological terms, facial disfigurement can be considered a deviant status in that the individual's appearance departs from normative standards. Societal responses to the facial

anomaly are largely punitive, although there is nothing inherently wrong with anyone's personal appearance. The maltreatment of victims of disfigurement stems from the social construction of the rules of what appearance should be. Physical attraction is socially defined, and the more one deviates from the normative standard, the sharper the social consequences of the violation of those rules. Persistent social condemnations of some "thing" socially defined as deviant typically lead persons with that quality to incorporate the perception of deviance into their sense of selfhood.<sup>3</sup> In other words, the person's identity merges with the deviant status and society's definition of it and the deviance label becomes central to how these individuals see themselves and behave.

People with facial disfigurement are deviant, not by their own choosing or action, but because their trauma, disease, or congenital condition has broken a social rule of appearance. Facial disfigurement is only real because social definitions attribute meaning to appearance and respond to it in conflicted ways. Facial transplant surgery holds the promise of removing persons from a status they do not want and for which they are unjustifiably punished in social interactions. If social rules define the disfigured face as deviant, then social rules should consider strategies to remove the stigma. Transplantation will not make society stop stigmatizing and stereotyping, but it may allow individuals relief until broad-sweeping changes in social and cultural values emerge.

**Conflicting Interests** – None declared.

## References

1. Summerton I and Agha R. Sociological Considerations in Face Transplantation. *International Journal of Surgery* 2004; 2: 82–83.
2. Macgregor FC. Facial disfigurement: Problems and Management of social interaction and implications for mental health. *Aesthetic Plastic Surgery* 1990; 14: 249–257.
3. Schur EM. Labeling Deviant Behavior. New York: Harper and Row, 1971.