

(When) will they have faces? A response to Agich and Siemionov

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Agich and Siemionov are to be congratulated for their attempt to refocus the debate on facial transplantation on those with most to gain: individuals with severe facial disfigurement.¹ They make a good case for the surgical benefits offered by what they term facial allograft transplantation (FAT). Moreover, they fare better than other teams in recognising that candidates for FAT might also have much to lose. The team in Louisville (which has dominated many discussions) had little to say on this issue, writing only rather benignly of the possible “loss of transplanted tissue”.² In contrast, Agich and Siemionov squarely confront this risk and offer the most complete account to date of how the risk will be minimised and rejection dealt with. This is an important development, which can only enhance the discussions that, contrary to what these authors imply, must indeed continue.

According to Agich and Siemionov, their paper also provides a counterbalance to the numerous more sceptical views being expressed in bioethical and media circles—views which are said to rely more on fiction than fact. In response, we wish to argue that, as persuasive as some of their arguments undoubtedly are, the authors will not succeed in stalling this debate for there remain numerous issues that require further attention. We start with a central component of the authors’ argument, their appeal to “clinical need”, and suggest that this is not straightforwardly identifiable. No more straightforward is their suggestion that metaphors and lessons from the creative world have no place in this (or any bioethical?) debate. This seems particularly unlikely when we consider that FAT will not offer the “ideal” solution; perhaps, then, wholesale facial transplantation is or will become the ideal and a film like *Face/Off* can offer some insights. Finally, we query the role and influence of society (and the media) in this context, suggesting that the sheen of the surgeon’s knife should not blind us to other means of addressing the needs of disfigured members of society.

Beginning with this notion of need, Agich and Siemionov rightly seek to remind us that the procedure is indeed directed at a clinical need.¹ They fail, however, to say much about the nature of the need, apparently thinking it sufficient to refer to “the suffering of individuals with severe facial deformities”.¹ An individual so afflicted might well have a variety of needs, such as a need for surgery to improve facial functioning, so as to eat and so on. Even in physical terms, however, the need is not easily identified or explicated. Research shows that there is not necessarily a correlation between the extent of disfigurement and the “suffering” of the individual; indeed, a minor blemish might bring much distress.³ “Need” seems to have a psychological component, both for the afflicted individual and others. We will turn to consider these “others” shortly, but it is first necessary to consider a potential predicament posed (and faced) by the recipient of FAT.

The authors make clear that “candidates for this procedure should undergo rigorous pretransplant assessment including

psychiatric, psychosocial and bioethical”.¹ Such assessment would appear to accord with established ethical standards pertaining to experimental procedures (and, indeed, treatment). As we have argued in more detail elsewhere, however, the possibility of a need/want disjunction could well lead to a situation of Catch 22.⁴ The problem arises that an individual who is sufficiently psychologically robust to pass the relevant test might not *want* to undergo such a procedure—that is, they might well be perfectly content with their appearance. Conversely, an individual who is seriously compromised by their disfigurement might not pass the test and might hence be ruled ineligible. We are not claiming that the disfigured individual (or, indeed, any “patient”) is, by definition, less than maximally autonomous or even non-autonomous. We do believe, however, that further thought needs to be given to this potential problem.

The recipients should, according to Agich and Siemionov, also undergo “bioethical” assessment.¹ Evaluation of a FAT study by a research ethics committee or institutional review board may be what is meant by this plea, but to our minds it also draws attention to the way in which the bioethics community more broadly can and should respond to the prospect of FAT. Bioethical assessment of the proposal (if not of any individual candidates for it) is under way and yet these authors complain that the responses are often “sensationalistic” and borrow too often from “film and science fiction where the procedure is used for cosmetic or nefarious purposes”.¹ We fail to see anything intrinsically wrong with such a method. Indeed, Peggy Battin’s latest collection of writing on ending life contains a short story, *Robeck*, which is more insightful and persuasive than many more directly philosophical treatises on the topic.⁵ Analogies, metaphors, and similes surely have a place in bioethical analysis.

Having said this, we recognise also the authors’ concern that the analogies drawn might be false or sensationalistic. We are mindful also of the English jurist Glanville Williams’s admonition that slippery slopes are “the trump card of the traditionalist, because no proposal for reform is immune to [it]”.⁶ But is it really so erroneous or fanciful to draw on films like *Face/Off* in the present context? We think not, and we believe that Agich and Siemionov might also have cause to revise their opinion somewhat, after we explore an implicit strand of the argument for allowing FAT.

We are told that current techniques yield results that “are usually not strikingly better” than the presurgery disfigurement.¹ Facial allograft transplantation, we must assume, will do better. While therefore making a *prima facie* case for the surgical benefits of FAT, the authors maintain that it will only be able to “achieve an acceptable degree of expressivity”; we are not, they claim, into the realm of identity transfer or even the transplant of fully functional, expressive faces.¹ Yet if the procedure will not initially be able to offer the ideal,

Abbreviation: FAT, facial allograft transplantation

then surely the authors recognise there is a case for developing and enhancing the techniques. Indeed, once the trials are under way, the procedures will surely improve, as is the nature of scientific progress. If there is a "clinical need" to improve function and, moreover, appearance then what reason is there for stopping short of the ideal? We suggest that in approaching the ideal we might well come closer to wholesale facial transplantation, which in turn suggests that it is neither wholly inappropriate to use this term nor wise to overlook the long term disbenefits (as well as the benefits) that might flow from FAT as currently envisaged.

Agich and Siemionov nevertheless cleave to the view that FAT does not "extend the goal of transplantation from legitimate life saving to questionable life enhancement".¹ Surely, however, the procedure is all about "life enhancement", as the authors argue throughout. The key word is obviously "questionable" and, as we hope to have demonstrated, the move toward more questionable applications cannot be ruled out conclusively at this juncture.

What is certainly questionable is the role and influence of society in this context. We wholeheartedly endorse Agich and Siemionov's condemnation of intrusive and insensitive social attitudes.¹ It is, however, instructive to note that they appeal not only to clinical need but also to social attitudes in making their case for FAT. This raises a host of questions. Surely a vital ethical concern is the social attitudes themselves? Is there not even the risk that the candidate will submit him or herself to FAT because of a real or imagined pressure to "normalise"? Indeed, what signal is being sent to society and by society to disfigured individuals? Once the procedure is offered, will surgical correction become the expectation? As Strauss points out, "when something is correctable, our willingness to accept it as untouched is reduced".⁷ Finally, who will pay (society or the individual)?

Social attitudes and norms are most obviously accessible in, and influenced by, the media, and Agich and Siemionov again express concern that the media coverage has been insensitive and sensationalistic.¹ It is certainly the case that the media needs to be more circumspect in its presentation of FAT and, indeed, other medicoethical developments.⁸ The authors seem to want to go further, however, when they bemoan the fact that even the reports of expert committees have proven "unable to quell media discussion".¹ We doubt whether quelling such discussion would be appropriate, for the media surely has a role in involving the public, although we accept that the debate should be conducted in an informed and responsible manner.

Agich and Siemionov therefore do well in presenting the case for FAT and, while they have a vested interest in the procedure going ahead, their arguments demonstrate a firm commitment to responding to the needs of individuals with facial disfigurement. The balance has not shifted decisively in favour of proceeding, however, for there remain issues that need further analysis and discussion. Sensationalism might

not be instructive but analogising can be, and bioethicists should continue to weigh the pros and cons in as public a forum as possible. After all, an "extreme" case like the identity transfer depicted in *Face/Off* can help to clarify our thinking. Facial transplantation certainly challenges our often assumed acceptance of surgical intervention. Other forms of (consensual) "mutilation", such as sadomasochistic sexual practices or duelling, are occasionally frowned upon and even criminalised. The reason why we accept surgery is surely tethered to some notion of the public interest, as distinct from that which is (merely) interesting to the public. Here, bioethicists can offer valuable insights, as is, for example, powerfully exemplified in Alice Dreger's analyses of conjoined twins.⁹ Who should undergo FAT and whether the proposal effects a social good or rather affirms social prejudices are issues that remain open for discussion. Diversity should be celebrated or at least accepted and, at the very least, efforts must be taken to ensure that alternative mechanisms for addressing the concerns of those with disfigurements (such as counselling and programmes for educating society at large) do not fall by the wayside.

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