## **HUMANITIES** | MEDICINE AND SOCIETY **#** MENTAL HEALTH

## **Saving faces**

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ollowing the first successful hand transplant in 1998, doctors were confident that they could transplant faces. But it took another seven years for the first face transplant to be attempted. Although there were robust objections to the surgery based on the risks posed by the antirejection medication, the major barriers were social, having to do with the

One of the unsettling — and fundamentally important — things about face transplant surgery is that it insists on an expanded definition of what constitutes health and wellness, and what can be done to achieve it. At the same time, it exposes biases against people with facial disfigurement so substantial as to create risks and challenges akin to death.



special status of the face as an index to identity, and conceptual, having to do with resistance to understanding facelessness and so-called "social death" as a legitimate health risk. Social scientists have defined social death as social isolation, loneliness, ostracism, loss of personhood, change of role and identity, harm and disfigurement. By including social death in the evaluation of patient need, face transplants can certainly be considered life-saving.<sup>2</sup>

Many hospitals and surgeons submitted requests to institutional review boards for ethics review that were denied consistently, including the hospital that performed the first partial transplant in 2005, the Centre hospitalier universitaire Nord in Amiens, France. The Cleveland Clinic had ethics board approval for the surgery since 2004, but was waiting for exactly the right candidate. This was part of the clinic's careful long-term strategy to minimize pushback and generate widespread con-

sensus that the surgery was mandated ethically and medically.<sup>3</sup> They were taking their time to prevent a media backlash and gain widespread support. They were scooped.

In November 2005 in Amiens, Isabelle Dionoire, whose face was mauled by her dog after an overdose of sleeping pills, received the world's first partial face transplant. She was rushed to the hospital, which had been denied approval for the surgery in 2004, but the decision "left the door open for the nose and mouth 'triangle' to be transplanted."4 Dinoire's doctors jumped through that door. Quickly. Within six months of admission to the hospital, Dinoire had a new face. In contrast, when Connie Culp received her face transplant at the Cleveland Clinic, she had already undergone 27 surgeries and had been living with her injuries for six years.3

Subsequent debates were sharp, heated and dominated by a mix of bioethics, references to science fiction and concern about the psychological risks of sharing faces. A lot of the initial discussion focused on Isabelle Dinoire herself; the psychologic implications of having a new and foreign face were particularly acute for this survivor of attempted suicide. The news media accused her doctors of circumventing due process to "win the face race." 5 Her physicians initially denied that Dinoire was injured through attempted self-harm. She later confirmed her suicide attempt, which raised doubts about the integrity of her medical team.

The French team rushed (rightly), confident that the technical, surgical, pharmaceutical and institutional pieces were in place. From their perspective, Dinoire's injuries were so acute that the surgery was obviously justified and, with her consent, even required.

That is a highly individual and deeply unstable calculation to make, and one that depends on mental health, social factors and contexts unique to one individual. For seven years after the first successful hand transplant, most ethicists and review boards would not make that calculation in favour of face transplant surgery, even though surgeons and patients were demanding it. They did not want to quantify mental health against threats to long-term health. They did not see the daily or regular experience of social death or ostracism as equivalent to shortened life expectancy.

There were serious bioethical and health issues at stake: face transplant recipients (like recipients of almost all transplants) have to take immunosuppressant medication to avoid rejecting their new faces. People can and do live long and apparently healthy lives without faces, many of them with no interest in a face transplant. Death and illness are both potential complications of the antirejection medication. Bioethicists argued that the face transplant and its accompanying medical regime made physically well people into sick ones with shortened life expectancies, and greater exposure to illness and disease.6 For bioethicists, the surgery was unjustifiable. But such a calculation is based on a very narrow definition of wellness, one that does not take into account mental health, social context and the experience of daily life. The risks posed by living faceless must also be taken seriously.7

What made the risk-benefit calculation even more challenging was that the surgery had never been done before. Despite the success of the hand transplant, no one knew what the risks really were. No one knew how patients could give informed consent, when not all the information was present. And it never would be: no one can know for sure how someone will react to a new face that is not their own. Those are serious challenges to the risk-benefit analysis, but the health and psychological benefits of a face — any face — would, for many, outweigh the risks of its foreignness. The bioethical objections to the surgery raise the

question: What is a greater psychological challenge, living with the transplanted face of another (that ultimately ends up looking like a combination of donor and recipient) or living without a face?<sup>7</sup>

To date, 37 face transplants have been performed worldwide — eight of these in the United States. Each new intervention is reported with a minimum of debate and controversy about either the medicine or the ethics involved. The debates have ceased. Media coverage of the surgeries focus on human interest stories, detailing the experiences of the recipients both before and after their surgeries. These are stories of people getting their lives back and emerging as better versions of themselves — because their lives were lost. The social death narrative is reinforced with every story, underscoring the idea that life without a face was not a life. Faced with death (of a sort), the surgery and the antirejection medication are risks, but they are life-saving and, thus, not only allowable but necessary.

Those are not the only reasons controversy faded, despite its original intensity.

The surgery worked. And the science of face transplants just did not capture the public's imagination in the same way as the science fiction of it did. This procedure can be watched in documentary form. It can be seen in three-dimensional models and computer simulations, and read about in numerous technical and popular media. It is still amazing, but it is not scary anymore.

But even that is not the whole story.

The US military has funded most face transplants in America; the procedure is not yet covered by insurance. When the military's role emerged more publicly, face transplants were no longer just cosmetic intervention designed to make people look (and feel) better, they became a way to pay a debt to those injured in service to their country. Any lingering sense that the surgery was self-indulgent (rather than life-saving) and, given the medical risks, unnecessary, all but disappeared in light of the military connection.

The decline in criticisms of the surgery is absolutely a positive development,

allowing recipients to undergo this muchwanted and much-needed procedure with substantially less scrutiny. There is no doubt that their lives change dramatically for the better with the help of this medical intervention. At the same time, we have lost the incentive to re-examine fundamentally our own biases against facial disfigurement. The acceptance of the surgery has signalled an acceptance that living life faceless is akin to not living at all. That does not happen in a vacuum: social death is caused by social forces. It need not be that way. The expanded definition of wellness should be lauded and reinforced. The treatment of people without faces certainly should not.

Rather than developing new ways of encountering others that look beyond appearance, instead we rely on surgical procedures to make it easier to look at people face-to-face. What would it be like to look at people face-to-faceless? Face transplant surgery is one alternative to social death. Surely, there are others.

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