

# From *Face/Off* to the face race: the case of Isabelle Dinoire and the future of the face transplant

Fay Bound Alberti

## Correspondence to

Dr Fay Bound Alberti, Honorary Senior Research Fellow in History at Queen Mary University of London, Mile End Road, London E1 4NS, UK; [f.boundalberti@qmul.ac.uk](mailto:f.boundalberti@qmul.ac.uk), [fayboundalberti@gmail.com](mailto:fayboundalberti@gmail.com)

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## ABSTRACT

Isabelle Dinoire, the world's first face transplant recipient has died, 11 years after the procedure that brought her unwanted fame and media attention. While medical debates centre mainly on ethical and medical concerns like immunosuppressant use, the psychological hazards of face transplants are still being overlooked. Using medical and media reports and examining the gendering of clinical and patient narratives, this article argues we need to look again at face transplants and their motivation for individuals as well as society.

On 6 September 2016 the world's media reported that Isabelle Dinoire had died. Dinoire originally came to the public's attention in 2005, when she underwent the world's first partial face transplant. Photographs of Dinoire's face post surgery were released by the hospital to a world intrigued and repulsed in equal measure.<sup>1</sup> Between 2005 and December 2015 no fewer than 37 face transplants took place around the world in Spain, Turkey, China and Poland, with varying degrees of success.<sup>2-3</sup> Five of those patients have since died, with an apparent under-reporting in malignancy and revision surgery rates.<sup>3</sup> As the world's first, however, Dinoire's story is widely remembered. Hers is a tragic tale of human frailty, social isolation and medical politics that raises questions about the society in which face transplants take place, as well as the ethics and limits of modern medicine. More than 15 years since her operation, Dinoire's case also raises questions about the expectations of patients and surgeons, the gendering of the patient, the relationship between clinical and media reporting of surgical procedures and the complex cultural contexts surrounding face transplants.

The history of face transplants is largely unwritten, at least from a humanities perspective. There is an extensive and growing literature on the ethical and medical challenges of the procedure.<sup>i</sup> And there is a significant body of work on faces and facial disfigurement in prewar and immediate postwar history,<sup>4-6</sup> as well as in anthropology and sociology.<sup>7-10</sup> There is an important historiography of the development of aesthetic surgery as a discipline<sup>ii</sup> and a largely internalist history of

reconstructive surgery that focuses principally on issues like skills and training.<sup>11</sup> In terms of the medical literature, many of the cultural and psychological factors flagged up at the time of Dinoire's face transplant—in particular the identity and emotional concerns associated with such a radical procedure<sup>12-13</sup>—have recently been sidelined by ethical debates about immunosuppressants and the ideal age limit of candidates.<sup>14-15</sup> Since 2005 surgical teams around the world have been rushing to join the 'face race', arguably encouraged by surgical reports about Dinoire's apparent recovery. The pace of experimentation has been such that some surgeons have called for new surgical and ethical guidelines to be developed.<sup>16</sup> It is possible that the media attention given to face transplants creates unrealistic expectations for patients. There are perhaps 250 000 facially disfigured adults and children in the UK alone, few of whom will be eligible for a face transplant.<sup>17</sup> It can also be argued that under the current medical framework, and despite careful consideration by some surgical teams, we still do not know the long-term impact for patients and families in adjusting psychologically and physically to a literal change of face.<sup>18</sup>

The tragic and early death of Dinoire should mark a pause in the surgical development of face transplants, a time to reflect on what we can learn from her reported experiences about the psychological challenges of the procedure. Yet we know little about Dinoire's life through the scholarly record, though Dinoire's 'before and after' images have been reproduced and consumed again and again in our digital age, making it impossible, as she argued, to live a 'normal' life. Work in the history of emotions reminds us that access to any authentic and *unmediated* feelings of patients is impossible; all such writing is necessarily influenced by the type of reporting, the conventions of the text, the intended audience and more.<sup>19</sup> In many cases, however, these sources are all we have, if we wish to reconstruct the emotional context of Dinoire's experience, and the ways she was positioned (and positioned herself) as a patient.<sup>iii</sup> Like

and *Making the Body Beautiful: A Cultural History of Aesthetic Surgery*. Princeton, NJ: Princeton University Press, 1999. Elizabeth Haiken, among others, has drawn attention to feminist discourses around cosmetic surgery. *Venus Envy: A History of Cosmetic Surgery*. Baltimore: Johns Hopkins University Press, 1999.

<sup>iii</sup>For a parallel example using breast implant recipients, see Bound Alberti F. From Paraffin to PIP: The Surgical Search for the Perfect Breast. In: Jackson M, ed. *Routledge History of Disease*. Routledge: London, 2017:335–57.

<sup>i</sup>For a recent summary, see Khalifian *et al*, *Facial Transplantation*.<sup>2</sup>

<sup>ii</sup>Sander Gilman has written on the relationship between the development of aesthetic surgery and the psychiatric profession as well as the importance of visual representation. Gilman SL. *Creating Beauty to Cure the Soul: Race and Psychology in the Shaping of Aesthetic Surgery*. Durham; London: Duke University Press, 1998

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many other medical firsts, including the heart transplant, Dinoire's procedure took place in a climate of nationalistic pride, and public fear and uncertainty. Her identity as a patient was affected by gendered expectations about appropriate female behaviour as well as standards of socially acceptable appearance. Dinoire's relative non-existence in the scholarly record as a living, breathing, experiencing and emoting human being, moreover, makes a sharp contrast to media reports of a troubled and unhappy woman whose face transplant was not, in the end, the 'miracle' cure that it promised to be.<sup>iv</sup>

The world's first partial face transplant, which took place at the Centre Hospitalier Universitaire of Amiens, created a media storm as soon as the hospital released its postoperative photographs.<sup>v</sup> Images of Dinoire's exposed jaw and missing nose were positioned alongside her newly transplanted face in which a triangle of recently attached flesh remained visible.<sup>20</sup> Nobody expected France to win what had become an international face race in the transplantation field.<sup>vi</sup> Ethical concerns have since arisen about the competitive drive behind face transplants in France, the USA, China, Spain, Belgium, Turkey and Poland.<sup>21</sup> But in 2005 surgeons around the world were still striving to be the first to undertake this innovative procedure, just as they had been in 1967, when Christiaan Barnard completed the world's first successful heart transplant.<sup>22–23</sup> The stakes and the rewards were high. Soon after the transplant, the 'miracle' maker Barnard appeared on the cover of *Time* magazine.<sup>24</sup> He later acknowledged the operation's extraordinary impact on his life: 'On Saturday I was a surgeon in South Africa, very little known. On Monday I was world renowned'.<sup>25</sup> Of course Barnard had critics. Observers were concerned, in apartheid South Africa, that this breakthrough might mean black people would become 'spare parts' for whites, as the poet and political activist Ali Mazrui warned, and there was also a genuine social fear that surgeons were playing God.<sup>vii</sup>

These kinds of social and spiritual concerns have shadowed medical experimentation since the rise of modern science, as suggested by Mary Shelley's *Frankenstein* (1818). Indeed, accusations of 'Frankenstein science' have hovered around transplantation since its origins, as testified by stories of 'identity swap' or moral contagion central to a plethora of science fiction works since the 1920s.<sup>viii</sup> Before the close of the 20th century,

public attitudes towards face transplants as a futuristic and morally threatening procedure coalesced in the science fiction thriller *Face/Off* (John Woo, 1997).<sup>ix</sup> As argued below, this fear of personal transformation by which one might entirely supplant the identity of another has plagued public (mis)understandings of the procedure. Perhaps unsurprisingly, then, the first face transplant took place amid a context of moral and ethical uncertainty. Just because we *could* doesn't mean we *should*, argued Peter Butler of London's Royal Free Hospital the year before Dinoire's operation.<sup>26</sup> The Royal College of Surgeons agreed, urging surgeons not to carry out face transplants until more was known about the moral, ethical and psychological impact of a procedure that challenged the basis of our human identity.<sup>27</sup> After all, faces make us what we are, signalling our individuality, our genetic inheritance, our ethnicity and so on. A disrupted or disfigured facial appearance is understandably therefore a source of significant social stigma and emotional distress.<sup>28–30</sup>

How challenging to the individual and collective understanding of selfhood, then, is a transplanted face and the merging of two identities, one living and one dead? In the words of the medical anthropologist Linda Hogle, 'you're really transplanting more than the tissue itself [with face transplants]. You're bringing someone's identity and overlaying it on the recipient's body'.<sup>31–32</sup> Face transplants have a potentially significant impact on the recipient, and on his or her family, the donor family, the extended medical team and society as a whole.<sup>x</sup> Moreover, it was not just the physical difficulties of face transplants that concerned commentators, or the hazards of identity formation, but the implementation of a daunting and lifelong immunosuppressant regime with no guarantee of success.<sup>12–33</sup> The very drugs that enabled the transplant were known to cause cancer. There was also public fear of a real 'face/off' by which the transplant recipient would look distressingly like the donor. That concern at least was dismissed by surgeons. As Butler and his team demonstrated, the recipient's new appearance would be determined by the underlying bone and muscle; the transplanted face would be something of a composite between two faces, old and new.<sup>34–35</sup> That straddling of old and new identities, however, seems to have been one of the elements of her postsurgical identity that Dinoire found so challenging.

What do we know about Dinoire herself? To answer that question we must turn to non-clinical and non-academic literature, largely because the surgical literature deals principally with the mechanics of her physical recovery.<sup>36–38</sup> Both clinical and media reports sketch out the facts: that Dinoire's medical encounters began in May 2005 when she took an overdose of sleeping tablets and was savaged by her dog. Clinical reports state that surgeons 'transplanted the central and lower face of a brain-dead woman onto a woman aged 38 years who had

<sup>iv</sup>Dinoire was described as a 'miracle woman' by *The Sun* newspaper: <https://www.thesun.co.uk/news/1736875/woman-who-received-the-worlds-first-ever-face-transplant-dies-of-cancer-aged-49-11-years-after-the-ground-breaking-operation/> accessed September 2016. In early reports by her surgeons, Dinoire figures only as 'a woman aged 38 years who had suffered amputation of distal nose, both lips, chin, and adjacent parts of the cheeks'.<sup>37</sup>

<sup>v</sup>Preminger BA, Fins JJ. Face Transplantation: An Extraordinary Case with Lessons for Ordinary Practice. *Plastic and Reconstructive Surgery* 2006;118:1073–74. See also Devauchelle B, Delaporte F. *La fabrique du visage: de la physiognomonie antique à la première greffe*. Turnhout: Brepols, 2010. A number of different organisations were involved in Dinoire's operation, most notably the Department of Maxillofacial Surgery at Amiens University Hospital and the Department of Transplantation Surgery at Lyon University Hospital, which managed Dinoire's immunosuppressant regime. Devauchelle, *et al*, *First Human Face Allograft*, acknowledgements.

<sup>vi</sup>Devauchelle *et al*, *First Human Face Allograft*: 203. For more on the history and development of the face transplant, see Bound Alberti F. *Face Transplants. A Cultural and Emotional History*. Forthcoming.

<sup>vii</sup>Bound Alberti F. *Matters of the Heart*. introduction.

<sup>viii</sup>See for example Weine R. dir. *The Hands of Orlac*, 1924, Arnold N. dir. *Hands of a Stranger* (1962), Franju, G. *Les Yeux sans visage* (Eyes Without a Face), 1960, Bausman DL. *Repo! The Genetic Opera*, 2008.

<sup>ix</sup>The film sees FBI agent Sean Archer (John Travolta) trying to bring terrorist Castor Troy (Nicholas Cage) to justice by swapping faces. The procedure did not require a specialist team or rehabilitation protocols; just one reluctant surgeon. It also left no scarring, required no elaborate cocktail of drugs and effected a total identity swap: differences of height, shape and body language disappear through a sleight of hand that fools even Archer's wife.

<sup>x</sup>I am using the term 'extended medical team' to refer not only to surgeons and physicians but also to all those involved in a patient's care and rehabilitation, including anaesthetists, nurses, psychologists and physiotherapists. For related use see: <https://www.rcseng.ac.uk/government-relations-and-consultation/the-extended-surgical-team> (accessed Jul 2016).

suffered amputation of distal nose, both lips, chin, and adjacent parts of the cheeks'. After the transplants and at the end of one week, the patient could eat, and speech improved quickly.<sup>37</sup> Media reports are more detailed. The dog was a Labrador-cross called Tania. Dinoire, a 38-year old divorcee, had argued with one of her daughters and took the tablets simply to forget, she has said; she did not intend to die. Other times, Dinoire said it was a deliberate overdose. She had suffered depression for many years; her divorce had been quite recent and she had been unemployed for over a year. Whatever the case, when Dinoire woke up, her life was changed irrevocably. In a BBC interview, Dinoire recalled seeing 'a pool of blood next to me. And the dog was licking the blood. But I couldn't imagine that it was *my* blood or *my* face. Or that he had chewed me'.<sup>39</sup> Still groggy and confused from her overdose, Dinoire sat up and tried to light a cigarette, an act she described as 'an automatic gesture' (and a habit that would come to haunt criticism of Dinoire in newspaper accounts). Confused that she could not keep the cigarette between her lips, Dinoire crawled to her bedroom to look in the mirror.<sup>40</sup> That is when Dinoire discovered the full extent of her injuries. She had no lips, no chin and no nose. As she later recalled in an interview with *Le Monde*, that was the moment she realised that 'it was not a dream, it was reality. I had no face'.<sup>40</sup>

Dinoire spent the next few months of her life in hospital. Almost immediately her surgeons decided not to undertake facial reconstruction, but to go ahead with a face transplant. Facial reconstruction remains the usual treatment for trauma patients.<sup>xi</sup> At the hospital, the team was ready to undertake the procedure and Dinoire appeared to be a suitable candidate. Dinoire seems to have agreed immediately, though conversations with her surgeons were necessarily private. Once that decision had been made, it was a waiting game: an undamaged face from a woman matching Dinoire's blood group, age and ethnicity had to be found. Dinoire described how she spent days waiting at the hospital. Sometimes a helicopter would land, bringing in a casualty. With mixed feelings, she would 'wonder, is this the one? Could this be the donor? ...When you're waiting for someone to die, to get their face, it's hard to think about these things. But that was the reality'.<sup>39</sup> In September a call was put out to local hospitals that a donor was being sought. In November the waiting ended when the recently deceased Maryline St. Aubert, also 38 years, was pronounced a suitable donor. The unusual request was made of the dead woman's family, and their consent was given.

The surgeons involved have acknowledged there was a considerable degree of secrecy around what happened next. In the early hours of 27 November 2005, Bernard Devauchelle, a maxillofacial surgeon, got to work removing the face from the donor. Devauchelle was assisted by Jean-Michel Dubernard, a transplant surgeon who was also a former Deputy in the French National Assembly. In an operation that took 50 people more than 15 hours, another team of surgeons, led by Sylvie Testelin and Benoît Lengelé, started work on Dinoire's face, removing scar tissue and individualising muscles, vessels and nerves. Dinoire's new face was implanted, the facial vessels sutured, and

surgeons stood back to watch as colour 'shot back into the graft. The lips immediately turned pink'. It was at that stage, Testelin reported, that ownership of the face transferred to Dinoire, 'because she gave her blood in the tissue'.<sup>39</sup> Dinoire recounted the moment her bandages were removed and Testelin handed her a mirror: 'I could see, there was no longer a hole. It was fantastic. Even if it didn't look so good at that time, with all the bandages... I had a nose. I had lips. It was marvelous... I could see in the eyes of the nurses it had been a success'. From that moment, Dinoire concluded, "I told myself that they had saved me". Elsewhere she is said to have described the transplant as akin to a 'religious experience'.<sup>41</sup>

This remarkable narrative betrays an ongoing subtext in Dinoire's relationship with her surgical team. She had been 'saved' and could 'see in the eyes of the nurses,' a slippage between her own experience of looking in the mirror for the first time and the compassion and empathy that she found on the face of her carers. Testelin recalled that she also cried at that moment of unveiling—at that moment she was no longer a surgeon, just 'human'.<sup>39</sup> Elsewhere there is a fairytale, gendered quality to this story, brought about by the power dynamic between a male surgeon and his female patient. Dubernard was awarded the prestigious Medawar Prize for his contribution to transplantation. In his acceptance speech Dubernard invited comparisons with *Sleeping Beauty*, brought back to life by her prince/surgeon:

The donor's face was so beautiful that I still see her image among the stars in my dreams. When the clamps were released, the color shot into Isabelle's white lips. This was one of the most moving and magic moments of my life.<sup>42</sup>

After the operation and her unveiling, Dinoire reportedly made a good physical recovery. She was 'listening to the radio and watching television' in her hospital room. She was at last 'able to eat solid food—including strawberries, omelettes and chocolate cake', *People* magazine reported, and to do so 'without dribbling'.<sup>43</sup> What a contrast to reports from before the operation, when Dinoire was in pain, frightened and barely able to breathe, with saliva flowing freely down her exposed skin. Then, she could not bear to look at herself in the mirror, let alone 'inflict it to others ... it was monstrous, traumatic, unshowable'. The anticipated judgements of others, too, built on Dinoire's fears that she would never again be 'presentable in front of humans'.<sup>39</sup> In Dinoire's testimony, as in Testelin's, images of the 'monstrous' and the non-human are set against the image of Dinoire before her surgery—teeth bared and unable to smile. It took a new face for her to re-enter the realm of the human.

Dinoire's concern about being ostracised highlights the importance of social responses to facial disfigurement and the extraordinary pressures on patients to conform, whatever the cost. Yet critics have since argued that it was not ethical to perform a face transplant on Dinoire.<sup>22 44</sup> That she was not emotionally or psychologically able to cope with the procedure, having apparently attempted suicide, and that it was not possible for her to give informed consent, since she could not realistically know how it would be to wear the face of another. It is also widely suggested that the hospital where Dinoire was treated did not offer sufficient protection from the press, or from a voyeuristic public.<sup>xii</sup> Moreover, Dinoire would have been aware of

<sup>xi</sup>Of course facial reconstruction has its own problems and it often creates a patchwork tapestry that, transplanted from elsewhere on the patient's body, lacks the thinness and flexibility of skin from the face. See Lantieri L. Face Transplant: A Paradigm Change in Facial Reconstruction, *Journal of Craniofacial Surgery*, 2012;23:250–3.

<sup>xii</sup>Kruvand, and Vanacker, Facing the Future. When the Cleveland Clinic performed a face transplant on Connie Culp in 2008, her surgeons

the possibility that the surgery would bring fame to her and her surgical team. According to *The Times*, Dinoire signed a deal before her operation which meant she would profit from the sale of photographs and a subsequent film. Dinoire and the medical team at Amiens University Hospital are understood to have signed such contracts with the British documentary Michael Hughes, more than 3 months before the transplant took place.<sup>45</sup> Dinoire also participated in a book about her journey that was entitled *Isabelle's Kiss*, a subject that, as detailed below, acquired significance in media reporting.<sup>46</sup>

Dinoire's surgeons subsequently acknowledged that the public attention she had received was detrimental to her health, noting that her physical recovery ('excellent') was taking place faster than her mental recovery (only 'good enough').<sup>xiii</sup> Photographs of Dinoire's 'before and after' face, interviews with Dinoire's neighbours and even shots of Dinoire in hospital had appeared in the world's newspapers. Dinoire later complained that it made her feel persecuted. She endured enough public ridicule before the transplant, when she wore a surgical mask in order to hide her disfigurement and, it is implied, her shame about her appearance. Then, when she made an occasional errand out of the hospital, 'people recoiled, showed me the finger [and] evoked the avian flu', presuming that Dinoire was fearful of some kind of contagion. After her transplant, when Dinoire tried to resume a normal life, the pressures were rather different: 'it was excruciating. I live in a small town and so everyone knew my story...Children would laugh at me and everyone would say, "Look it's her, it's her".' In the beginning, she felt like a 'circus animal': 'everyone would say: *Have you seen her? It's her. It's her...*And so I stopped going out completely'.<sup>41</sup> Seven years after the operation, the scars were still visible, and one of her eyes still drooped. Over time the attention became less 'brutal' and Dinoire more defiant: 'if people stare at me insistently, I don't care anymore, I just stare back!'

Public scrutiny was arguably more pronounced because Dinoire was female and therefore more prone to being observed and judged about her physical appearance than a man might have been. Dinoire's lips, one side of which drooped, because of impaired nerve function, was widely commented on in both scholarly and media reports.<sup>47</sup> There was a salacious hint to newspaper reports that she might never 'kiss again,' a casual yet laden statement that echoes the surgeon's depiction of Dinoire as *Sleeping Beauty*.<sup>xiv</sup> This kind of commentary, coupled with the psychological recovery and the awareness that at any moment her body might reject her new face, must have put Dinoire under almost constant stress. In the year after her transplant, Dinoire had two separate episodes when her body began to reject the donor tissue and her face became swollen and red. Her antirejection drugs were adjusted and increased, and the episodes passed. In 2015, *Le Figaro* magazine reported that Dinoire's body was again rejecting the transplant, and she lost the use of part of her lips.<sup>xv</sup>

made sure that their public relations strategy learned from the perceived mistakes made in France. See reference 39.

<sup>xiii</sup>Devauchelle cited in: [http://www.nytimes.com/2005/12/14/science/as-a-face-transplant-heals-flurries-of-questions-arise.html?\\_r=0](http://www.nytimes.com/2005/12/14/science/as-a-face-transplant-heals-flurries-of-questions-arise.html?_r=0) (accessed September 2016).

<sup>xiv</sup><http://www.telegraph.co.uk/news/worldnews/1564787/Isabelle-Dinoire-may-never-kiss-again.html> (accessed April 2016). This kind of commentary also ignores the fact that Dinoire was undergoing rigorous physical therapy behind the scenes to refine the motor skills that made speech—and kissing—possible.

<sup>xv</sup><http://www.lbc.co.uk/worlds-first-face-transplant-patient-isabelle-dinoire-dies-136588> (accessed September 2016). This latest bodily rejection was widely reported only after Dinoire's death.

This extraordinary medical journey must have brought untold losses for Dinoire and required a profound psychological adjustment. She did acquire a new face, and through the dog attack (which she described as her 'accident') lost her own: the face that viewed the world and was seen by others.<sup>xvi</sup>

"The most difficult thing is to find myself again, as the person I was", Dinoire is quoted as saying, "with the face I had before the accident, But I know that's not possible".<sup>20</sup> She acknowledged that she would be forever attached, physically and emotionally, to her donor. It was an ambivalent form of gratitude. Dinoire described how she found a hair on her chin: 'I had never had one. You knew it's yours but at the same time 'she' is there. I am making her live, but that hair is hers'. Other times this sense of inhabiting the same body as another filled her with disgust: 'Having the inside of the mouth of someone else' touching her tongue... 'it was atrocious'.<sup>48</sup> And yet Dinoire also felt appreciation: 'When I look in the mirror, I see a mixture of the two [of us]. The donor is always with me...She saved my life'. Dinoire searched the internet for information about her donor soon after her operation, saying that she wanted to meet the woman's family, to thank them for their 'magical donation'. And when newspapers broke the story that Dinoire's donor had hanged herself, Dinoire reported feeling a kind of sisterhood with the dead woman.<sup>49</sup> In death, as in life, that connection remained intact.

It is impossible to know how different Dinoire's life might have been if she had not undergone a face transplant, if she had received more traditional facial reconstruction surgery, or if she had never come into the public eye at all. Would she still be alive? Healthy? Happy? Face transplants continue to be seen as a pathbreaking form of treatment that can overcome some of the considerable challenges of facial disfigurement and provide patients with the chance of a truly new life. It is difficult to gain a historical perspective on events as they are unfolding. It is far harder when those events are themselves the subject of media scrutiny and speculation. Dinoire's death was only reported in September 2016, nearly 5 months after the event.<sup>50</sup> The hospital claims this was to protect her family from more media scrutiny. It also claims that, despite media reports to the contrary, and well documented work linking immunosuppressants and cancer, there was no link between the drugs that Dinoire was taking and the tumours that killed her.<sup>51 52</sup> Whatever the cause of Dinoire's cancer, her traumatic experiences and untimely death should raise significant questions about the ethics of how she was treated, and how we might better handle medical firsts, as well as the emotional and physical future of face transplant recipients.

We still do not know what the long-term psychological consequences are of living with another person's face. Though we have seen from at least one Chinese case that non-adherence to immunosuppressants can be deadly, Dinoire's own case arguably highlights the mental as well as physical risks.<sup>53</sup> There are also important, largely ignored gender issues to consider around the themes of face transplants and facial reconstruction, especially with regard to what constitutes an 'acceptable' appearance. Most face transplant surgeons are male.<sup>xvii</sup> And there is traditionally a subtext of heroism, of the great man of science—in

<sup>xvi</sup>Dinoire also grieved the loss of her dog, which was euthanised after the attack.

<sup>xvii</sup>A notable exception is Maria Siemionow, the surgeon who transplanted Connie Culp's face in 2008. Culp was the first person in the USA to receive a face transplant: <http://www.telegraph.co.uk/news/picturegalleries/worldnews/5284586/Connie-Culp-the-woman-who-received-the-worlds-most-extensive-face-transplant.html> (accessed September 2016).

this case two men, Devauchelle and Dubernard—who, like Christiaan Barnard as the face of the *Time* magazine in 1967, achieved something that in earlier generations had been unthinkable. Dubernard, in particular, has a history of medical firsts; he was responsible for the first successful hand transplant, an equally controversial procedure.<sup>54</sup> It seems important to note, given this narrative of individual accomplishment, that a range of medical professionals was involved in Dinoire's treatment.<sup>xviii</sup>

Moralising judgements about Dinoire's postsurgical behaviour also form part of this gendered discourse. Dinoire remained a heavy smoker after her operation. The media response was predictably condemnatory, both of Dinoire's disregard of medical advice and of what appears to be a perception of inappropriate feminine behaviour. Thus the *People* magazine used emotionally laden rhetoric, describing the 'divorced mother of two' as the subject of much press speculation, especially given that: 'she has visited a bar, that she has been chain-smoking cigarettes', and, it is implied, not living as responsible a lifestyle as could be expected given that she had been saved by science.<sup>43</sup> She had even been seen consuming 'the odd glass of red wine'.

Since Dinoire's operation the pace of face transplants has sped up all over the world.<sup>3</sup> The history of medicine reminds us that when science takes a perceived leap forward, it has become a matter of pride for nations to join in. The narrative of scientific firsts is therefore overwhelmingly one of competition, of a race to undertake innovative new surgery, whatever the long-term outcome.<sup>22</sup> Until Dinoire's death, however, the question of whether we *should* be undertaking face transplants seemed to have fallen by the wayside. It is now possible that the question will be raised again, and more virulently than before. Or it might simply be that Dinoire's death is dismissed as nothing to do with the immunosuppressants, her tumours linked to another cause. In that context her postsurgical difficulties in rehabilitating to the world might also be rejected. Dinoire just wasn't the 'ideal patient,' simple as that. There is no doubt that her transplant gave Dinoire a chance to return to 'the planet of human beings—those with a face, a smile, facial expressions that let them communicate', as she put it to the French newspaper *Le Monde*. 'I am alive again'.<sup>40</sup> But what kind of life was it? And who or what ultimately failed Dinoire? The transplant? Her surgeons? Her own body? Or us?

One of the ongoing issues highlighted in this paper is the discrepancy between medical and media accounts of face transplants, and the inability of psychological experiences to be accessed or assessed through conventional surgical literature, even though face transplants are widely understood to give rise to multiple questions around identity, and social and self-acceptance.<sup>55</sup> We need to start thinking about psychological experiences and mental health as part of the bigger picture through which we judge the efficacy of all medical procedures, whether or not they involve radically challenging operations like face transplants.<sup>56</sup> It is clear that individual surgeons do think through these matters, at least those who have given appropriate

consideration to ethical and emotional issues and have painstakingly developed protocols that are adhered to, rather than functioning as a box-checking exercise. (Personal conversations with Maria Siemionow, Nichola Rumsey and Alex Clarke.) But this perspective does not receive sufficient attention in the clinical and scholarly literature on outcomes, nor in the public discourse, including media reporting, by which we talk about facial disfigurement and transplantation. It is arguably here that the field of medical humanities, with its emphasis on narratives and metaphor and its questioning of the limits and conventions of selfhood can help shape surgical treatment and support patient rehabilitation.<sup>57 58</sup>

Ultimately, Dinoire's reported experiences raise questions about the experience of face transplant recipients and surgical ethics, and about society as a whole. In most cases of facial transplantation and reconstruction, patients describe the need to *fit in* with others, to gain social approval. James Partridge of the medical charity Changing Faces, himself the survivor of a car accident that left him severely burnt, has spoken out about the kind of social judgements that make people ashamed of how they look.<sup>59 60</sup> Dinoire was mocked for wearing a mask before her operation and taunted about her appearance afterwards. The Mississippi firefighter Patrick Hardison reported feeling like a 'normal guy' again after receiving a full face transplant in 2015.<sup>xix</sup> A significant explanation for this response is, of course, that facial reconstruction work is not just 'cosmetic' but functional; like Dinoire, Hardison had difficulties eating and breathing as a result of his injuries. But most of the time people with severe disfigurement report social problems as a direct result of their outward appearance. Hardison described his children fleeing in fear from his disfigured face as an experience 'worse than dying'.<sup>61</sup> This social stigma, the desperate desire to fit and to look as 'normal' as possible helps explain a surge in interest in face transplants by patients affected by facial disfigurement, most of whom have already been through multiple reconstructive operations (personal communication with Maria Siemionow). It also highlights the difference between medical and social models of disability, wherein attempts to 'fix' faces, however laudable, cannot make up for the parallel need to fix a society dominated by impossible standards of physical perfection.<sup>62</sup>

Medical developments like face transplants have their own momentum; they are historically driven by ambition, technology, ideology and training as well as by need. I am not suggesting that the need is not there. Nor do I wish to downplay the extraordinary, often unthinkable challenges that are confronted by people with severe facial disfigurement, or the skills of the medical teams that offer new possibilities for living. One of the main challenges levelled against Dinoire's surgeons, as we have seen, was over their choice of patient. But given the unknowable future and the physical and psychological challenges of a shared identity, it is likely that there is no such thing as an 'ideal' face transplant recipient.<sup>xx</sup> Living with the face of another person and accepting all the challenges to one's physical and mental health that might bring, seems a big ask of anyone.

Siemionow M. *The Know-How of Face Transplantation*. London: Springer, London, 2011.

<sup>xviii</sup>The 'great man of science' narrative tends to overlook the many different kinds of care that a patient receives, particularly from nurses. Dinoire's team of professionals included not only surgeons and transplantation specialists but also psychiatrists and dermatopathologists, immunologists, anaesthesiologists, haematologists, operating and care nurses, research assistants and coordinators. Devauchelle *et al*, *First Human Face Allograft*, acknowledgements.

<sup>xix</sup>Hardison had been severely disfigured after his protective mask melted on his face. His full face transplant is currently the most extensive to date. <https://www.theguardian.com/us-news/2016/aug/24/firefighter-face-transplant-patrick-hardison> (accessed September 2016).

<sup>xx</sup>The quest for the 'ideal patient' is considered in Taylor-Alexander, *Bioethics in the Making*. These questions are also raised, though not resolved, by Bluhm C, *et al*.<sup>47</sup>

Moreover, all surgical interventions are necessarily, like media responses, laden with gendered expectations about appropriate appearance and behaviour.<sup>xxi</sup> Clinical psychologists suggest that it is the responses of other people, and an individual's uncertainty about how to respond to emotions like disgust and curiosity, that makes disfigurement so difficult to endure.<sup>63–66</sup> We might speculate that in today's world of selfies and self-scrutiny the drive for perfection is increasingly pervasive.<sup>67</sup> The very act of getting older triggers fear and disgust, let alone a traumatic facial disfigurement or a surgical procedure as radical as a face transplant.<sup>68</sup> What should this mean for the future of patients like Isabelle Dinoire? In considering the ethical and moral dimensions of face transplants, perhaps it is society as much as surgery than needs to come under the spotlight.

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<sup>xxii</sup>Elsewhere I explore the gendered expectations of the first hand transplant recipient. See Bound Alberti F. *Face Transplants*. Forthcoming.

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