



HAL
open science

Giving, receiving ... and forgetting? On the social conditions of receiving an anonymous face transplant

Marie Le Clainche -Piel

► **To cite this version:**

Marie Le Clainche -Piel. Giving, receiving ... and forgetting? On the social conditions of receiving an anonymous face transplant. *Sociology of Health and Illness*, 2020, 42 (8), pp.1949-1966. 10.1111/1467-9566.13178 . hal-03851277

HAL Id: hal-03851277

<https://hal.science/hal-03851277v1>

Submitted on 30 Jan 2023

HAL is a multi-disciplinary open access archive for the deposit and dissemination of scientific research documents, whether they are published or not. The documents may come from teaching and research institutions in France or abroad, or from public or private research centers.

L'archive ouverte pluridisciplinaire **HAL**, est destinée au dépôt et à la diffusion de documents scientifiques de niveau recherche, publiés ou non, émanant des établissements d'enseignement et de recherche français ou étrangers, des laboratoires publics ou privés.

Giving, receiving ... and forgetting? On the social conditions of receiving an anonymous face transplant

Marie Le Clainche - Piel

National Centre for Scientific Research, Centre for the Study of Social Movements, Paris, France

Abstract

In 2004, the French National Consultative Ethics Committee expressed strong misgivings about the proposal to include the face among body parts that can be removed from deceased donors for organ transplantation. Yet, the first face transplant was performed a few months later. How do medical teams and patients deal with the singular nature of the face? I argue that what the face represents – from the medium of the donor’s personal identity to an interchangeable organ – is not fixed. It emerges through the practices and can evolve through the interactions between medical professionals and patients. In the postoperative time, I show that patients receive potentially contradictory recommendations about how to integrate the organ: to consider it theirs and forget the donor, but also to thank the donor for the donation and never forget the origin of the graft. Based on the plurality of relationships developed by the patients with their donor, I revisit Maussian interpretative analyses of organ reception. The effects of giving a face vary both in terms of reciprocity and identity: the feeling of debt is variably felt and can be interpreted negatively or positively, and the experience is more or less transformative.

Keywords

organ transplantation, brain-dead donor, face, policy, anonymity

To cite: *Sociology of Health & Illness* Vol. 42 No. 8 2020 ISSN 0141-9889, pp. 1949–1966
doi: 10.1111/1467-9566.13178

This is an open access edition. Original page setting available online:
<https://onlinelibrary.wiley.com/doi/abs/10.1111/1467-9566.13178>

To contact the author: marie.le-clainche-piel@cnrs.fr

Introduction

In the early 2000s, the question arose as to whether the face could be donated as an organ. Could the face truly become an anonymised and interchangeable body part, like a kidney or a heart in the course of organ transplantation? In 2004, the French Comité Consultatif National d’Ethique (National Consultative Ethics Committee, hereafter CCNE), whose opinion has a strong legitimising power (Memmi 1996), called the prospect of a face transplant “illusory” due to the “symbolic power” of the face and its central role in building a person’s identity (CCNE 2004: 17). It considered it “inconceivable” to transfer “one of the major markers” of an individual’s humanity and singularity from one person to another. The Committee held that relatives of a brain-dead person would never be able to accept “the removal” of their loved one’s face for the sole purpose of “restoring hope to a destroyed face”. Moreover, it would be hard for the patient in need of treatment to accept their face being replaced by another: “A person with a grafted face could – the risk cannot be dismissed – start to consider his own face as that of ‘another’s’,” wrote the Wise Men (Les Sages, the nickname for the Ethics Committee members) (Ibidem: 20). Indeed, as this article expounds, reception of an organ is closely monitored social process wherein the relationship between organ donor and recipient, represented by the exchanged flesh, is perceived as potentially dangerous. Despite the consultative committee’s reluctance, the first face transplant surgery took place in the city of Amiens a few months later in 2005. Face transplants have since been performed in 12 countries, with nearly 40 operations, including ten in France¹ (Siemionow 2017, Theodorakopoulou et al. 2017). The operation involves the removal of the face of a brain-dead person – the donor – and its transplant to a disfigured person – the recipient. Depending on the recipient’s needs, the part of the face removed from the donor may be more or less of the entire face (including skin, jawbone, nerves, blood vessels and muscles).

How do medical teams and patients deal with concerns about facial singularity and its limited interchangeability? How does the conception of what the flesh carries influence the donor-recipient relationship? This article analyses these issues with a focus on five French face transplant patients after surgery and the medical team that supervised the process of face integration. I observe that ethical concerns over the confusion of personal identity between donor and recipient have, in practice, prompted most stakeholders to staunchly defend the principle of anonymity of post-mortem organ donation. Anonymity is seen here as being far from limited to a legal principle preventing the disclosure of people’s names. It is considered essential to the patient’s facial incorporation process and hence to the medical success of the transplant. Anonymity supports the transformation of a singular face into an interchangeable organ².

By interchangeable I mean to “make organs and tissues more like universal parts, usable in a variety of recipients” as Linda Hogle formulated it in her own research on organ procurement (Hogle 1996: 678). Working from the perspective of transplanted patients, however, I do not study this phenomenon through the specific lens of a commodification process (Sharp 2000). The greatest issue for the actors that I follow is not to bring bodily matter into the realm of goods. Rather, it is a matter of clarifying the nature of the donor–recipient relationship and the

resulting obligations (Shaw 2015). I have found different assessments of the extent to which transplantation connects them, both in terms of identity and expectations of reciprocity. Furthermore, I show that the anonymisation of the flesh is not achieved without resistance: first, patients are subjected in practice to contradictory advice that limits the scope of anonymisation, and second, not all patients are willing to erase the donor's identity. The case of facial transplants highlights the tension between the personalisation of the flesh and its anonymisation. I therefore argue that the interchangeability of the face is negotiated in practice by stakeholders based on the legal constraints involved, on locally interpreted meanings of organ donation, and as interactions unfold.

The paper is organised as follows. First, I argue that the policy of anonymity is built on a tension: it involves both anonymisation of the organ and an expression of gratitude to the organ donor. Reviewing different research that have studied organ reception processes, I show that this tension has essentially been interpreted in a Maussian scope where the receiver suffers from the impossibility of thanking the donor and returning the "gift". Second, I detail the qualitative methodology of this study on facial transplantation. Third, I present its findings focusing on the actual relationships that patients have forged with anonymous organ donors, and analyse how the medical staff supervises them. In the discussion, I revisit previous interpretations of organ reception to include a broader range of experiences.

The anonymous donation policy under scrutiny

The social role of anonymity: dealing with the socioeconomic and identity aspects of donation

Governments oversee each step of the procedure of an organ passing from one body to another by means of legislation and the work of national health agencies (Healy 2006, Naulin and Steiner 2016). They determine the right and wrong ways of procuring, giving and receiving an organ. In France, the principles organising organ transplantation from cadavers were laid down in 1976 following a move by the medical community to facilitate organ procurement by asking the following question: "How and in which circumstances do we permit doctors to take elements from the bodies of the deceased?" (Thouvenin 1997: 79). The answer was threefold: (1) the deceased donor's consent is presumed unless the person has opted out in their lifetime, (2) there can be no exchange of money between the donor's relatives and the recipient, and (3) neither the donor's relatives nor the recipient can have access to the other's identity.³ Transplant medicine has developed in support of these three principles. However, the increase in the number of people waiting for an organ has prompted much public and academic debate about their efficiency. In a context of growing international incentive to tackle the "organ shortage" by increasing organs' availability (Farrell et al. 2011), questions are being raised. Should living donors and relatives of deceased donors be compensated to encourage organ donation? Should the state restrict the individual's right to opt-out (Hitchen 2008, Sheach-Leith 2007)? Without intending to examine these debates in this article, it is interesting to note these repeated doubts over the economic nature of donations and the enforcement of presumed consent since they contrast with the complete lack of discussion about the anonymity of post-mortem organ donations.

Indeed, although the anonymity of sperm and oocyte donations has been a subject of contention in France for 20 years (De Melo-Martin 2016, Mehl 2008), anonymity between organ donors and recipients has never been called into question. The law states that, “The donor cannot know the identity of the recipient, nor the recipient the identity of the donor. No information may be disclosed that identifies either the person who has donated an element or product from their body or the person who has received it.”⁴ Politicians, ethicists and researchers tend to agree on anonymity being the optimal form of exchange.

The most common argument in favour of anonymity is its capacity to facilitate procurement while limiting socioeconomic risks (Corr et al. 1994, Hoeyer et al. 2015). As shown by Paterson (1997), anonymity is seen, firstly, as preventing donors from interfering in the organ allocation process; secondly, as preventing the creation of obligations between donors and recipients; and, finally, as saving on the organisational costs of maintaining relationships between donors and recipients. The focus on these risks, however, does little to address a second aspect, which this article demonstrates as being key in the case of a face transplant from a deceased donor: anonymity is instrumental in depersonalising the flesh and subsequently allowing its donation.

By extricating the individual from their physical materiality, anonymity promotes organ sharing and redistribution, while their origin becomes meaningless. It helps approach the body as a set of impersonal, interchangeable pieces in keeping with the Cartesian view of organ medicine (Prentice 2013, Schlich 2010). The deceased becomes a collection of body resources and biological markers, tracked by file number rather than by name, as the health agency in charge of regulating the circulation of organs shows: “The donor’s name cannot be communicated to the recipient, and vice versa.”⁵ Resources are given with “no strings attached”, to use the words of an organ donor specialist (Shaw 2010: 613). The anonymisation of the flesh, understood as the erasure of the donor’s civil and personal identity, can consequently be seen as an institutional response to the risk of identity confusion between donors and recipients. With it, the state attempts to regulate the nature of the relationships that people can forge with the exchanged flesh (Rémy and Winance 2010).

The obstacles to anonymity in the case of organ donation

However, the policy of anonymising body parts put into circulation after death comes up against at least two obstacles in practice. Each brings its own questions concerning the reception of an organ from an anonymous deceased donor. The first obstacle relates to the ambiguous conceptions of the human body supported by the bioethical laws. Indeed, although the law orders the removal of the person’s name from the procured material, the donated organ does not acquire the status of a totally depersonalised object. French legislation retains “a personalised dimension to the human body elements” (Thouvenin 1997: 77), as the country defends the non-reification of the human body. This personalised dimension supports the expression of a relationship of solidarity between donors and recipients. The promotion of organ donation goes so far as to base itself explicitly on the transmission of life between donors and recipients. In Margaret Lock’s words (2001: 319), relatives of donors “are not discouraged from thinking of their relatives as ‘living on’ in the bodies of recipients.” Since 1994, relatives of

deceased organ donors also have the explicit right to be informed of the fate of the transplanted organ.⁶

The second obstacle to the anonymisation of the flesh is the result of a paradox and concerns the collective mechanisms that acknowledge donors for their donation. Their origins can be found in criticism of the biomedical conception of the body spearheaded by pioneering medical anthropologists. This criticism emerged in North America in response to the rapid rise and subsequent institutionalisation of transplant medicine that started in the 1980s. Somewhat alarmed by the inexorable spread of the biomedical model of interchangeable body parts, these studies cast a critical eye on the effects of transplantation on donation recipients and alert on the dangers of these new practices (Fox and Swazey 2001; Lock 1999, 2002, Sharp 1995). Published after the translation in English of Mauss' study on giving practices (Mauss 1990), they tend to portray organ donation as a special kind of "gift": a gift of life. But in Mauss' theory "no gift is ever given freely" (Shaw 2007: 299). Instead "giving expresses the ties that bind us to others" and initiates a series of bonds: giving-receiving-reciprocating (Bateman 2016: 454). Assuming this three-step cycle of donation Fox and Swazey developed the concept of the "tyranny of the gift". It expresses the difficulties experienced by some people receiving body parts that have no "physical or symbolic equivalent" (Fox, 1992: 40). The virtual impossibility of fulfilling the counter-gift social obligation is said, in some cases, to generate a negative debt towards the donor (Godbout 2006, Shildrick 2015).

Furthermore, in Mauss' study what is given is always accompanied by the donor's spirit, the *hau*:⁷ "the thing received is not inactive. Even when it has been abandoned by the giver, it still possesses something of him" (Mauss 1990: 15). In the three-step exchange cycle, the *hau* always returns to the donor. It embodies both the expectation of reciprocity and the person giving: "The recipient must dispose of the thing given in a way that respects the 'spiritual essence' of the donor contained in the gift" (Bateman 2016: 454). In cases of biomedical giving practices, where the gift is literally composed of "part and parcel of [the donor's] nature and substance" (Mauss: 1990: 16), the concern with the debt – reciprocity – is coupled with an identity dimension. The integration phenomenon could be associated with the transformation of the recipient's identity (Sharp 1995). Even though facial transplants shed light on these concerns in a particular way, they have been around long before. As Lock says, at the end of an ethnography of transplant practices based on the removal of organs from deceased people in North America, "It's clear that patients do try to become what they think the donor was like [..] There is no doubt that there's a shift in the sense of self," (Lock 2001: 328). Despite forming a major breakthrough, such interpretations of the integration phenomenon tend towards worried scepticism.

This concern has also spread beyond social science research. In some contexts, market exchange has been seen as a means for the receiver to reciprocate: "By transforming the 'gift' of an organ into a 'commodity,' the burden of debt to the giver is expunged" (Scheper-Hughes 2007: 509). In France, however, organ donation institution professionals explicitly refer to the three-step cycle to justify the introduction of collective, anonymous acknowledgement mechanisms (Levy 2018). These acknowledgement mechanisms can be directed at specific

individuals using the institutionalised system of anonymised letters that patients can send to donors' families. They can also be directed at the global population of "organ donors" alive or deceased and typically consist of planting trees on the hospital grounds with a commemorative plaque praising "the generosity of the organ donors". In the findings, I will show how patients relate to these acknowledgment mechanisms. As we can see again with this second obstacle, the legal framework is caught in tension between two co-existing approaches to the relationship between individuals and their flesh: anonymisation and personalisation.

To analyse how this tension affects social actors, we need to look past the policy level to examine "how [organ donation] laws work in practice" (Healy 2005: 1023) and analyse their many layers. This article is consequently part of a growing body of literature updating the pioneering Maussian interpretative analyses in the light of contemporary experiences. This body of work combines ethnographical approaches to practices with political system analysis (Almeling 2007, Berglund et al. 2012, Crowley-Matoka 2016, Hamdy 2012, Sanal 2011). It draws inspiration from a series of studies examining international regulatory practices for the circulation of body materials (Bilgel 2012, Healy 2006), contemporary organ transplant policies and their history. At the same time, these studies look into actual organ procurement, donation, selling, buying and receiving practices around the world. They suggest that the focus on the negative debt and the risks of identity transformation reveal only part of the range of experiences of organ reception. In line with these approaches, I argue that the relationship between donor and recipient is subject to both government regulations and day-to-day negotiations between actors in the hospital, i.e. the micro and macro sociological levels.

Methodology

I draw on a study of the emergence of face transplants in France and the United Kingdom from 2010 to 2017. However, the absence of face transplants performed by the British teams leads me to focus on the French case in this article. This research involved immersion in the face "transplant chain" (Steiner 2008), including professional communities developing the idea, reconstructive surgery departments initiating it, health and ethical agencies supervising it and associations of people with facial disfigurement who lobby for or against it. In accordance with deontological requirements, the research project received formal approval from the doctoral school of the Ecole des Hautes Etudes en Sciences Sociales (EHESS 2010-83). Each investigated hospital then formally approved my status as an ethnographer following an ethical and health evaluation process. During interviews, the participants gave their explicit oral consent. They were informed that they could withdraw from the study at any time and request a copy of the final anonymised research report.

The study followed the face transplantation process using three methods and data sources: ethnography, interviews and archives (Latour 1988). This multi-method, multi-site investigation was made possible by forging long-term, trusting relationships with the actors at the heart of the process (Marcus 1995, Rémy 2014). This entailed following the "face transplant" object

as it underwent transformation. I observed it shifting from the status of a subject of international scientific discussion in 1990 to ethical controversy in 2004 before becoming a surgical procedure performed in hospitals as of 2005 (Le Clainche-Piel 2013). I then focused on the journey of the facial matter itself: from its removal from an organ donor to its incorporation by a transplant patient. This second part of the study, on the French case, serves as the main empirical source for this article.

The first source of data consists of 90 interviews with 72 respondents. The interviews were audiotaped and transcribed. Respondents were divided between France (54) and the United Kingdom (18), and represented hospital professionals (34), donation coordinators responsible for the procurement of organs (8), members of health agencies (5), members of associations of disfigured people (8), as well as disfigured patients within hospitals (17), from which I singled out transplant patients (5). I conducted two to six semi-structured interviews with each transplant patient, lasting an average of one and a half hours. Apart from occasional meetings in the cafeteria or during consultations, the interviews were conducted in their hospital room during their recurrent stays, with the exception of one afternoon spent in a patient's home and another interview conducted in a café. These repeated interviews with five transplant patients constitute the first source of material used in the following pages, making an original contribution to the previous studies on this topic, which relied mostly on indirect press accounts (Martindale 2014, Talley 2014, Taylor-Alexander 2014).

The second source of data is a long-term ethnographic investigation in the medical community in support of face transplant projects in both countries. In addition to attending surgery conventions from 2010 to 2017, I spent 11 weeks as an intern involved in the day-to-day life of the only two teaching hospitals that perform face transplants. This research method meant that I was able to explore hospital archives (press releases and reviews, letters and files) and contact professionals and patients who could not be reached by the interviews' snowball effect. Gaining access to this small community of actors involved in rare facial transplant operations called for tact and the development of long-term relationships of trust (Browne and McBride 2015).

The third source of data for the analysis consists of documents produced by health and ethical institutions (minutes of meetings, reports from ethics committees, press releases, information campaign posters and brochures), to which I added media archives. I conducted a systematic press review in France and the United Kingdom from 1998 to 2016, listing all the articles covering face transplants in the leading daily newspapers as well as in weekly and monthly publications specialised in science popularisation for a curious, rather than professional, readership. Scientific news articles were compiled from repeated keyword and author searches in the PubMed and ScienceDirect international medical databases. I used these materials to analyse how face transplant patients and professionals handle the anonymous faces of brain-dead donors. The names of the patients and medical staff are fictional. I have also changed some of the details of their descriptions to preserve their anonymity, based on a plausibility rule (Brettell 1993).

Findings: two typical positions regarding the anonymous donation policy

Prior to the post-operative period discussed in this article, transplantation chain actors work to turn the donated flesh into anonymous matter (Le Clainche-Piel 2018). Not only do the institutions deprive the matter of the name of its previous owner, but the surgeons themselves take care throughout the operation to make it neutral, to release it from the donor's persona. In the words used to refer to the flesh and the way they physically handle it, professionals strive to make the singular face an interchangeable organ.⁸ Following the operation, this institutional and professional labour of matter anonymisation is shared with the transplanted patient: how they receive the organ, talk about it and touch it will confirm or challenge the anonymisation process. Does the patient consider the transplanted face to be theirs? Based on the interviews conducted with the transplanted patients, as well as the ethnographic investment of the hospital departments where they are receiving care, I outline two typical positions regarding the anonymous donation policy: (1) performed anonymity, (2) preserved hau. This typology outlines that the relationship with the donor is not uniform in practice despite a common legal framework. They reflect structuring oppositions about the expectations of reciprocity and the effects of transplantation on their identity. But the adherence of each patient to one position rather than another is not fixed once and for all. While patients tend to fit into one rather than the other, they sometimes move between the two during the postoperative temporality and as events unfold.

Performed anonymity

In a direct line of continuity of the matter depersonalisation process that starts in the operating theatre, this position assumes its success. The transplant patients accept the donor-free graft model. Their experience is in line with the specific understanding of the relationship between body and person, matter and identity, supported by the anonymous donation policy. They are aware of the human origin of the flesh and do not treat it as a totally dehumanised therapeutic tool, but they do not share the identity of the donor and the expression of reciprocity is not necessarily directed towards the donor.

Christophe Tonnerre, in particular, embodies the position of performed anonymity. He suffers from neurofibromatosis, a disease whereby skin tumours develop and distort his facial features. At 35 years old, he received a transplant from an organ donor. Working in the entertainment industry, he had already undergone a dozen cosmetic surgery operations before in the hope of reducing the growths that constantly form on his face and distort his features.

However, none had given him a stable appearance for more than a few months. "I waited 35 years to finally be satisfied," he explains. After the transplant, he felt he recognised himself, without the slightest difficulty, right from the moment he first saw his face. To him, the transplanted face seems more "natural" than it has ever been, and when he briefly addresses identity transformation, it is only to talk about how it helped reveal his own personality: his face finally gives him the means to express his identity. He is encouraged by the medical community, like dental surgeon and transplant team member Philippe Forney who writes, in a "report on the ethics of transplants" distributed to the medical staff,⁹ that each face post-

transplant “definitely belongs to the individual history giving it life”. Both attribute to the face the function of expressing the individual identity of the wearer. The face itself is not the bearer of an interiority.

In our first interview, this does not prevent Christophe from drawing with his fingers the line between what the transplant added and what was already his. And after drawing the contours of his face, from behind the ears to the base of the neck, going up to the scars on the scalp, he concludes, “I have the face of another.” The completeness of his transformation does not herald the extent of his identification with the person who wore the face before him. Christophe speaks of his post-transplant face as an impassive mask that he had to bring to life, on which he can stamp his personality. In an account of his transplantation experience, he talks about the importance of not “considering the donor as a different part” of him, because that “would amount to thinking of us as two separate entities having to coexist.” On the contrary, says Christophe, “When I see myself, I am looking at myself” and not “a mask” representing the donor.

The issue is also biological. Physical rehabilitation guides the ownership process. Like him, all patients talk about graft incorporation as a job, on which they sometimes work with physiotherapists and speech therapists. They mention physiotherapy exercises for their facial expression and training to close their mouths or blink. Dominique Tesbal, a 40-year-old woman with arteriovenous malformation who had most of her face removed in order to receive the transplant, recounts the meticulous organisation for the re-appropriation of her facial abilities. Since the transplant, her time revolves around rehabilitation sessions, including three weekly appointments with physiotherapists: “I have one who works on softening up the transplant, another who works on the inside, and one who does the jawbone.” Every patient emphasises “body time”, which involves giving the body time to forge links between the grafted and initial parts of their anatomy.

However, at the same time, patients are asked by the surgical team to never completely forget the foreign origin of the transplant. Indeed, losing sight of the otherness of the graft – at the very least immunologically – is perceived as a risk that the patient might not pay enough attention to the anti-rejection drug treatment. This treatment lowers the body’s immune functions so that it does not reject the transplanted organ. Also, to restrict the potentially contradictory nature of this reminder of otherness compared with the encouragement to own the face, surgeons systematically provide information about the donor’s age group and gender. Transplanting a woman’s face onto a man, or vice versa, is perceived as an additional source of difficulty that “patients [do] not need,” as surgeon Claude Ethez put it.¹⁰ It creates a paradox: while anonymity is perceived as essential to the integration of the face, some information on the origin of the transplant is used at the same time to ensure full acceptance of the graft. By ensuring that patients have a certain similarity with the donor, medical professionals place some limitations on the principle of anonymity. Taking into account certain social affiliations of organ donors and recipients – race, age, gender – is not entirely a specificity of facial transplants (Gravlee 2009, Kierans and Cooper 2013), but it is usually justified for reasons of biological

compatibility and not for psychological or identity difficulties. Thus, constructing the interchangeability of the flesh does not mean that it becomes universally shareable.

Furthermore, the role that transplant recipients play in promoting organ donations nationally means that they are encouraged, at different moments on their journey, to thank and talk about the anonymous donor who made the transplant possible. Christophe relates his experience in this area:

“When journalists ask me ‘Do I think about the donor?’, the first time I was asked that question was on Michel Serra’s radio show, and I remember I answered, ‘No.’ But as I was saying ‘No,’ I was thinking, ‘Oh no, that’s too blunt, I’d better ... not justify, but explain myself.’”

Question: “Did that question surprise you?”

“Yes, and I said, ‘No.’ So suddenly, I had to explain (laughs)! And, as I often say, the best way to pay tribute to the medical team, the donor and their family who agreed to the donation is to live, be happy and have plans for the future.”

I then interview him shortly after media coverage of a meeting in the United States between a face donor’s relatives and the recipient, and I ask him what he thought of this event. Christophe had not heard about it. But then he adds:

“If it helped someone in the relationship, I think it would be the donor’s wife, because symbolically speaking, people who accept organs being removed from their deceased loved one say to themselves, ‘Somehow he is living on in the recipient.’ So, it must have been a relief for that lady. Now, I’m not sure that it’s a plus for the recipient. Because if they meet and get talking, if they see each other regularly, they will get to know each other better, to know about the ups and downs, just like everyone has, and I think, as a recipient, to carry the donor’s history, and if you’ve had the benefit of a donation, it’s because the person is dead, well that’s a heavy burden!”

Anonymity protects him as a recipient, because it keeps him from carrying the “heavy burden” of the donor’s history and protects him from the potential moral cost of meeting the deceased’s relatives. Therefore, “Anonymity makes the donation become admissible,” (Caillé and Godbout 2007: 77), and he himself is glad that he is not in a position to come into direct contact with the donor’s relatives:

“If I wanted to write to the family to thank them, I could do so, but I would have to give my letter to the doctor who would forward it on. So I wouldn’t know who he is, or them, you see. But I don’t see the point, because if they were standing in front of me, I might see them as the donor’s family and they might see me, well, as our father or brother who somehow lives in this man. So, the human relationship, like the two of us here and now, would be distorted. So, I say it’s better to leave it alone, and the beauty of organ donation is the anonymity and the fact that it is free. So it’s better that way.”

To this day, none of the patients I met have taken up this option, but an anonymous thank you letter to the donor’s family is the only possibility open to patients who would like to get in touch with the family. This measure is designed to help recipients to recognise the giver’s gesture,

but not to develop a relationship. Anonymisation “stifles any idea of creating concrete human bonds,” observes Lock (2001: 319). As advised by the French Biomedicine Agency (Agence de la Biomédecine 2017), Christophe says he prefers to pay tribute to the donation by living his life to the full, promoting organ donation on a daily basis and thanking all “donors” – rather than just “his own” donor – when speaking in public. Although he does not wish to know his donor’s name or embrace his personal identity, he fully identifies with the social role of a grateful receiver whose life has been transformed by the anonymous gesture. Above all, he does not wish to associate his graft with a person other than the person it helped to reveal, namely himself. Among the five patients, Christophe embodies the most the performed anonymity position. But identification with the donor is also far from being a major preoccupation for the majority of transplant patients I met.¹¹ Like him, most of them received a transplant from an organ donor following a reconstruction journey using more common techniques, and they have seen their faces change time and again. The desire to live without the social and medical hardships associated with disfigurement – from stigma to surgery –, and to (re)become anonymous in the crowd themselves tends to outweigh the concern about the origin of the face.

Preserved hau

Nevertheless, some patients resist the directions of professionals and public intermediaries who strive to convey the right way to receive the transplant and acknowledge the donor’s gesture. They try to give donors their place, even to the point of preserving elements of their person and history. The position of preserved hau bears testimony to this, as it assumes challenging the accomplishment of the matter depersonalisation process and staving off the anonymity constraint. Each patient can tend towards this position on specific occasions. For instance, Dominic connects to the woman who donated her face by praying for her every year. She lights a candle on the anniversary of the transplant, which is also the anniversary of her donor’s death.

But this position is also particularly embodied by one patient – Jeanne Dupuy – and is highlighted by the criticism she provokes. Jeanne, a 40-year-old patient, was a recent admission to the maxillofacial surgery department when she was offered the possibility of a transplant. She lost part of her face in a domestic accident. A trained saleswoman and stay-at-home mother, she agreed to the face transplant “to get back to a normal appearance.” Like Christophe, she talks about the work on recovering the motor functions in her face. But unlike him, she talks about the fact that her physiotherapy sessions are moments to talk about the transplant and “the donor”. She is not trying to forget the other’s presence in herself. Once again, we can hypothesise that the temporality of the repair plays a role in the strongest adoption of this donor–recipient relationship: Jeanne is the patient who was transplanted the fastest after her disfigurement. She did not see her face change many times before the transplant. She went from one face to another within a few months.

Yet within the hospital walls, the relationship she has built with her donor is seen as problematic, and is closely monitored by the team. Three tools are used to help patients develop a good “relationship with themselves” (Fassin and Memmi 2004: 22) and to manage transplant acceptance: speech, re-education of facial functions and brain imaging. Estelle Tremaud, Jeanne

Dupuy's case psychologist since her arrival in the surgery department, describes the warning signs she noticed during re-education and her advice to the patient, in a therapeutic follow-up report:

“The patient should be familiar with the outside of the transplant, but also with the inside of the oral cavity. She has trouble integrating this part, as seen from the fact that she cannot stand feeling a finger in her mouth, even her own. She must mourn the face that was hers before the accident. The hardest part is to appropriate this part from someone else, and not observe it as a spectator. She must accept her new image and see it as her own. Standing several times a day, every day, in front of a mirror, carefully peering at the transplant, searching for the slightest sign of rejection and doing her exercises over and over again, does not help her integrate the face as a whole. She notices every little difference compared with what she used to look like: chin hairs, lip thickness, skin texture. [.. .] Our patient needs to learn to use a face she does not know. As she moves on, she will need to gain control of it and own its mobility. She needs to find herself; find a personality, her new personality. [.. .]. In her quest for identity, she needs to forget who she was.”¹²

The difficulties she has touching the graft worry the psychologist, as does her penchant for noticing changes in her appearance compared with her face before the accident. Estelle conflates in her commentary the concern to have new facial features and the one to have those of another person. In order to “integrate the face”, Jeanne is advised to avoid giving the donor an identity and also to forget who she was before the graft. Her attitude is even criticised within the group of transplant patients — who hear about each other from the press, hospital talk and sometimes when they meet in person — in particular by Christophe:

“I think it's really personal; she has not accepted her transplant. Because she seems [.. .] to see the donor as a bit like a sister and she sometimes talks to her in front of her mirror. I find that unhealthy, because to me she's in a vicious circle that prevents her from coming to terms with her transplant. [.. .] To think about it, to talk about it non-stop, that's hardly a sign of acceptance.”¹³

In the same way as psychologists set timeframes for periods of mourning before they are considered pathological, there is a period in the incorporation process where duality is acceptable and beyond which it becomes, in Christophe's words, “unhealthy” and evidence of unfinished incorporation when it should have been completed. Indeed, by maintaining a donor–recipient relationship, Jeanne is jeopardising the depersonalisation process – and the preserved anonymity position – which Christophe himself embodies. She is compromising one of the foundations of the transplant system, concerning the separation of a person from their body. As Philippe Forney writes in his previously mentioned report, “The perception of the face transplant integrating phenomenon, which, through the face, permeates the subconscious and personality of the restored individual, belongs to the ancestral myth of the chimera, and to a cinematographic fantasy.” Any other approach to the transplant becomes illegitimate and is reduced to a fanciful, even pathological, register (Sharp 1995: 365).

Where patients present no evidence of transplant incorporation in the usual way, doctors and surgeons use other tools to supplement or contradict the transplant patient's words: brain imaging, in particular, provides the types of confirmation and objectivity expected. From brain reactions to stimuli in the grafted area, neurologists provide surgeons with an assessment of graft integration in internal representations of the subject's body (Dumit 2004). The MRI image shows different areas of the brain, each associated with a part of the body. In the case of face transplant, surgeons observe the brain's area associated with the mouth and face. If it is more prominent after the transplant than before, then the MRI is used as an objective proof that the patient has integrated their new face. These images are commonly presented at surgical conferences to demonstrate the patient's "right fit" (Pomahac et al. 2014). The representation of the body detected in the brain can be used to probe beneath the patient's words to conclude that they have integrated the matter into their "body scheme". This is the case for Jeanne: because she accepts her graft in an unacceptable way – not completely relieved from the identity of her donor – the information from the scan takes priority over the information she gives herself. Brain imaging translates the individual body, this "self-incorporation characterising the individual," to use Lock and Scheper-Hughes' expression (Lock and Scheper-Hughes 1996). The brain completes, and sometimes replaces, a psychological assessment as objective evidence of incorporation (Dodier and Rabeharisoa 2009, Rose 2005), as surgeon Forney attests again in his report when he writes, "Subjective fears [...] cannot resist the objective analysis of neurocognitive facts as shown by our functional MRI studies."

Thus, what could be Jeanne's way of expressing her "positive debt" to her donor (Godbout 2007: 176) meets with resistance from both professionals and patients. This resistance is not specific to face donation and can be found in the few accounts of transplanted patients who openly discuss this aspect. Such is the case with Claire Sylvia, a heart transplant recipient in the United States – where it is not uncommon for recipients to meet the deceased donor's relatives – who has given her donor a personality and resists the neutralisation of the transmission of elements of her person (Sylvia and Novak 1998). She tells the story of her transplant by describing a revelation about organs having their own identity:

"All my life I have been told that [...] the human heart is just a pump. An incredibly important pump, but only a pump, a monotonous, mandatory machine. According to this view, which is the accepted one in contemporary Western medicine, the heart contains no feelings and carries no wisdom, no knowledge and no memories. And if one person's heart

has previously resided in another person's body, that fact has no particular meaning or implication. I used to believe these things, but today I know differently (ibidem: II)."

These cases show that there are individuals who refuse to fully abide by the anonymous, depersonalised organ donation policy. Organs "inhabit the body[ies]" of consecutive people, they serve their function — the heart pumps — but are not reduced to it, and cannot be entirely depersonalised. They can even carry "knowledge and memory[ies]", if we let ourselves think

in those terms. Anonymity, as an institutional imperative, limits the expression of such relationships (Shaw 2015).

For the medical team responsible for Jeanne Dupuy, this point of view is problematic. Not only does it challenge their own efforts to separate the donor from the face, but it also creates what they call “the risk of psychological rejection of the graft.” Without providing clear explanations of this mechanism, it is clear for many medical actors I met that the lack of psychological acceptance of the transplant as a depersonalised organ could lead to its organic rejection.

The CCNE’s opinion was largely based on this potentially fatal risk of rejection. They were worried about the serious implications of rejection when it comes to the face: “It would not be a psychological rejection of part of the self, but of the self altogether,” (CCNE 2004: 17). Psychologist Estelle Tremaud justifies long-term monitoring of recipients based on the same concern: “The transplant could be psychologically rejected.” Again, the problem is not that the patient knows that the graft comes from a dead organ donor, but that they can consider that the flesh remains associated with the deceased person. Patients should take care of the graft by never forgetting that it comes from a dead organ donor, but at the same time without seeking information about the person who wore the face before them.

Spoken and written stories of “medically inexplicable” rejections circulate around hospital departments, underpinning this view. For example, surgeon Damien Bordelais tells the story of a man with a heart transplant who lost his graft once his donor’s identity was revealed as a way of justifying the legal and therapeutic framework set up:

“[After the transplant] all the doctors’ tests were positive: the patient showed no sign of rejection. The transplant was considered successful. Until the day the donor’s mother came to his door. She broke the medical staff’s rules of anonymity, found the recipient’s name and sought out his address. She told him about her deceased son, gave him a picture of him and invited him to attend a service in memory of the anniversary of his death. Following her visit, the patient began to suffer from cardiac rejection, which was inexplicable medically speaking.”¹⁴

The story goes on, as the surgeon explains that, following the visit by the donor’s mother, the immunosuppressive treatment stopped working and “a powerful rejection mechanism” was set in motion. The latter leads to the patient’s death after several hospitalisations that are not enough to stop this unfathomable reaction. At the end of his story, the author concludes that it is essential to preserve the “secret” of the donor’s identity, in order to “prevent rejection through a global approach of the transplant, both somatic and psychological.” Through this story, the tension between matter transfer and personal identity transfer is intensified. Doctors recall a key principle of transplant medicine, which is supported by the anonymity policy in France: body parts can become to some extent interchangeable as long as they have been deprived of the personal identity of the donor. They testify of the collective work required to achieve this process.

Discussion: revisiting Maussian interpretations of organ donation

These findings show that, in line with state regulation of the relationship between people and their flesh, the relationship between recipients and their donors is closely supervised in practice. Caregivers (psychologists, physiotherapists, speech therapists, nurses and surgeons), as well as other patients, scrutinise the relationship that each transplanted person develops with their new face. Medical professionals make sure that the recipient does not associate the donor's identity with the matter they have done their best to anonymise.

We understood anonymity as both a public policy and a practical process that supports the transformation of a singular face into an interchangeable organ. Patients do their best to stick to and maintain this approach of the body as a set of interchangeable pieces. The anonymous donation policy thus supports much more than the prevention of socioeconomic risks. Anonymity is perceived as a necessity for the construction of the recipient's identity and the therapeutic success of the transplant. In this discussion of these findings, I look back over the contradictions that nevertheless emerge from the implementation of the policy of anonymity. Lastly, I argue that these results update the understanding of the phenomenon of organ reception in terms of both reciprocity and identity.

This article shows that anonymisation imposes a series of constraints that can become contradictory for transplanted individuals. On the one hand, patients are warned against seeking information about the graft's previous owner. They are encouraged to consider the exchanged matter as theirs, and different types of evidence are expected to prove that the organ has been properly integrated into their body scheme. Doctors object on the basis of the danger of "psychological rejection" to any attempts to give an identity to the person carrying the organ before their death. On the other hand, I have identified a number of obstacles that prevent recipients from forgetting the donor. The first is a paradox, since statutory information is provided about the donor (age and sex) to encourage acceptance of the anonymous organ. In other words, patients are asked to identify themselves with the donor to limit otherness.¹⁵ The acceptable degree of anonymity of the donation and interchangeability of the organ is negotiated in practice.

A second obstacle to medical support for donor-free organ integration is justified by the immunological risk of rejection: patients are told to never forget the foreign human origin of the graft and to take a drug treatment for the rest of their lives. The medication is a daily reminder of otherness. A third barrier is found less among hospital professionals than among health agencies and the media. It concerns the transplanted patient's acknowledgment of the donor. Patients are asked to be grateful for the generosity of the person's gesture and sometimes to thank them in a national context of organ donation promotion.

In the face of these legal, medical and social constraints, patients develop several types of relationships with the donor. The two typical positions I have identified – performed anonymity and preserved *hau* – prompt us to revisit the Maussian interpretative analyses of the reception of an organ. Social science researchers trained after the release of *The Gift* almost invariably look for signs in recipients of an unpaid debt to their donor. Anthropologist David Le Breton does so in a paradigmatic way with his presentation of the case of Jeanne Dupuy.

To a journalist's question, "To what extent is the organ received acceptable?", the anthropologist answers, "That's the problem with transplantation. To receive someone else's heart or lungs is to receive a part of others. That's one of the problems with this woman [...]. There is no donation without debt. She finds herself in debt to a dead person, so in debt to someone whom she will never be able to repay. There is a break in the exchange circuit: when there is a donation, there must always be a counter-donation, otherwise there is guilt and it becomes a poisoned gift."¹⁶ It is as if the tyranny of the gift was not considered as a risk anymore, but as inevitable. However, it does not account for what happens in practice. Not only do recipients not necessarily experience nagging feelings of guilt, but also the debt can be positive. These results invite us to go back to Mauss' broader concept of giving. As Simone Bateman wrote: "the idea that the gift of an organ cannot be returned is a reading of Mauss's essay that gives precedence to the idea of direct reciprocation as opposed to the possibility of deferred reciprocation" (2016: 459). The reciprocity due to the donor can take various forms and temporalities: living one's life to the full, writing thanks, praying and talking about the donor are only some of the suggestions made by the face transplant patients.

Our findings also update the approach of organ donation in terms of identity and transformative effects. Parallel to the concern about the debt of the recipient, organ transplant tend to be perceived as having almost always consequences in terms of identity: "Since the object is literally incorporated as a part of the self" it would be "inevitable [that] it forces one into transformation" (Sanal 2011: 13). The dangers of receiving the donor's *hau* would then constitute a "profound reason not to take part in a donation relationship" (Godbout 2007: 176). While this perspective has been important in showing the limits of a biomedical discourse that presented organ transplantation as a body repair system without any impact on people's identities, it should not be converted today into a socio-anthropological expectation that weighs on patients' narratives. As this article shows, the restructuring of the self and everyday life can also take various forms and degrees. The transformation of the self, when it intervenes, can take on different meanings, including that of a revelation of oneself as illustrated by Christophe. The flesh bears a plurality of meanings depending on the legal framework, the practices and the interactions between patients, medical teams, health agencies and the media. Although the case of face transplantation singularly highlights this phenomenon, it potentially concerns every transfer of bodily matter where there is the possibility for "personal qualities to be transposed from one person to another" (Dickenson 2008: 149). Whether they are transfers for therapeutic purposes, such as organ and blood donation (Titmuss 1972), or for reproductive purposes as in gamete donation (Hertz and Nelson, 2018), they beg the question: What does the bodily matters carry, and what does this imply in terms of identity and reciprocity?

Conclusion

In this article, I discuss what the anonymous policy implies in practice for patients receiving a face transplant and the medical teams overseeing the integration process. I show that actors face a tension between anonymisation and personalisation of the flesh. Not only do patients express different relationships with the donor, but some practices contradict the process of

anonymisation of the flesh. I show that what the flesh represents – from the donor’s personal identity to an interchangeable organ – is not fixed, but emerges through the practices and interactions. Based on these findings, I discuss Maussian interpretative literature and its heuristic limitations in rendering the diversity of contemporary experiences of organ transplantation. I propose to deepen our understanding of the phenomenon of organ reception and the donor–receiver relationship by taking into account the plurality of stories of reciprocity and transformation. Going forward, more research is needed at the international level for a comparative exploration of the articulation between legal framework, medical practices and conceptions of the flesh in cases of bodily donations.

*Address for correspondence: Marie Le Clainche – Piel, National Centre for Scientific Research, Centre d’étude des mouvements sociaux, 54 Bd Raspail, PARIS 75006, France. E-mail: leclainchepiel@gmail.com

Acknowledgements

This research was made possible with the financial support of the Ecole des Hautes Etudes en Sciences Sociales and PRES Hésam. I thank the patients, nurses, surgeons and ethicists who have accepted the presence of an ethnographer at their side. I am grateful to the institutions that have rewarded this research (PSL University, Paris University Chancellery, AMADES), as well as to Thomas Angeletti, Nicolas Dodier, Laurence Kaufmann, Annemarie Mol, Catherine Rémy, Anne Revillard, Philippe Steiner who challenged me to share my results internationally. Finally, I thank the editorial board of *Sociology of Health and Illness* and the anonymous reviewers for their insights and constructive suggestions on this paper.

Notes

1 Teams in the United Kingdom have been developing facial transplant projects since the early 2000s, but no operations have as yet been performed (Le Clainche-Piel, 2018).

2 Within the international medical community, facial transplantation falls into the category of composite tissue allotransplantations (CTA): not a simple tissue but not exactly an organ either. The category encompasses a range of body parts that have been the subject of experimental transplants since the turn of the millennium – such as the hands, uterus and penis. In practice, however, the procurement of organs and composite tissues is carried out jointly and their donation follow similar procedures.

3 Act 76-1181 on organ removal, 22 December 1976. Author’s translation

4 Public Health Code, Article L 1211-5. Author’s translation.

5 Interpretation of the law by the Biomedicine Agency: <https://www.dondorganes.fr/questions/124/quelle-est-la-loi-sur-le-don-dorganes>. Author’s translation.

6 Act 94-653 on respect for the human body, 29 July 1994, Author’s translation.

7 The concept of “hau” is primarily a Māori legal concept and the use made of it in this article, based on Mauss’s study and socio-anthropological heritage, cannot reflect its

complexity. For an analysis of the evolution of the meaning ascribed the notion of “hau” and an indigenous critique of Mauss’s use, see Georgina Stewart (2017).

8 During the procurement process actors use different words to describe the ontological transformation of the flesh: visage, face, graft, mask. For an analysis of this process, see (Le Clainche-Piel, 2020).

9 Report on the ethics of face transplants, surgical department archive, consulted February 2015.

10 Interview, August 2014.

11 Julien Biaudet draws on a survey questionnaire to describe a strong “commitment to the anonymity rule” among his 426 heart transplant patients: 82.2% of respondents agreed with the statement, “Organ donations can only be done in strict anonymity,” (Biaudet 2013, 187–188).

12 Potentially identifying elements have been modified.

13 Interview, February 2016.

14 Draft of Damien Bourdelais’s medical ethics research circulated in the surgical department, consulted January 2016.

15 This arrangement with the constraint of anonymity is not unique in the donation of bodily materials. It echoes a distinction made in the case of gamete donation where accessing non-identifying information about an individual’s origins does not entail lifting donor anonymity (Mehl 2008).

16 Interview, February 2015.

References

Agence de la Biomédecine (2017) Rapport Annuel de l’Agence de la Biomédecine. Paris: ABM.

Almeling, R. (2007) Selling genes, selling gender: egg agencies, sperm banks, and the medical market in genetic material, *American Sociological Review*, 72, 3, 319–40.

Bateman, S. (2016) When Marcel Mauss’s *Essai sur le Don* becomes *The Gift*: variations on the theme of solidarity, *Theoretical Medicine and Bioethics*, 37, 6, 447–61.

Berglund, S., Gunnarson, M. and Svenaeus, F. (eds) (2012) *The Body as Gift, Resource, and Commodity: Exchanging Organs, Tissues, and Cells in the 21st Century*. Huddinge: Södertörns högskola.

Biaudet, J. (2013) *Au cœur de la greffe : la socialisation secondaire des transplantés cardiaques*. Doctoral thesis, Nancy: Université de Lorraine.

Bilgel, F. (2012) The impact of presumed consent laws and institutions on deceased organ donation, *The European Journal of Health Economics*, 13, 1, 29–38.

Brettell, C. (1993) *When they read what we write: the politics of ethnography*. Westport, Conn: Bergin & Garvey.

Browne, B. and McBride, R.-S. (2015) Politically sensitive encounters: ethnography, access, and the benefits of “Hanging Out”, *Qualitative Sociology Review*, 11, 34–48.

Caillé, A. and Godbout, J.T. (2007) *L’esprit du don*. Paris : La Découverte.

Comité Consultatif National déthique. (2004) Avis n° 82 sur l’allotransplantation de tissu composite (ATC) au niveau de la face (Greffe totale ou partielle d’un visage).

- Corr, C.A., Coolican, M.B. and Nile, L.G. (1994) What is the rationale for or against contacts between donor families and transplant recipients?, *Critical Care Nursing Clinics of North America*, 6, 3, 625– 32.
- Crowley-Matoka, M. (2016) *Domesticating Organ Transplant: Familial Sacrifice and National Aspiration in Mexico*. Durham: Duke University Press.
- De Melo-Martin, I. (2016) How best to protect the vital interests of donor-conceived individuals: prohibiting or mandating anonymity in gamete donations?, *Reproductive Medicine & Society Online*, 3, 100–18.
- Dickenson, D. (2008) *Body Shopping. The Economy Fuelled by Flesh and Blood*, London: Oneworld publications.
- Dodier, N. and Rabeharisoa, V. (2009) Les transformations croisées du monde psy et des discours du social, *Politix*, 73, 9–22.
- Dumit, J. (2004) *Picturing Personhood: Brain Scans and Biomedical Identity*. Princeton: Princeton University Press.
- Farrell, A.-M., Price, D. and Quigley, M. (eds) (2011) *Organ Shortage. Ethics, Law and Pragmatism*. Cambridge: Cambridge University Press.
- Fassin, D. and Memmi, D. (eds) (2004) *Le Gouvernement des Corps*. Paris: Editions de l'EHESS.
- Fox, R.C. and Swazey, J.P. (1992) *Spare Parts: Organ Replacement in American Society*. New York: Oxford University Press.
- Fox, R.C. and Swazey, J.P. (2001) *The Courage to Fail*. New Brunswick: Transaction Publishers.
- Gravlee, C. (2009) How race becomes biology: embodiment of social inequality, *American Journal of Physical Anthropology*, 139, 47–57.
- Godbout, J.T. (2006) Le don au-delà de la dette, *Revue du MAUSS*, 27, 1, 91–104.
- Godbout, J.T. (2007) *Ce Qui Circule Entre Nous: Donner, Recevoir, Rendre*. Paris: Editions du Seuil.
- Hamdy, S. (2012) *Our Bodies Belong to God*. Berkeley: University of California Press.
- Healy, K. (2005) Do presumed-consent laws raise organ procurement rates, *DePaul Law Review*, 55, 1017–43.
- Healy, K. (2006) *Last Best Gifts: Altruism and the Market for Human Blood and Organs*. Chicago: The University of Chicago Press.
- Hertz, R. and Nelson, M. (2018) *Random Families: Genetic Strangers, Sperm Donor Siblings, and the Creation of New Kin*. Oxford: Oxford University Press.
- Hitchen, L. (2008) No evidence that presumed consent increases organ donation, *British Medical Journal*, 337, 1614.
- Hogle, L. F. (1996) Transforming "Body Parts" into Therapeutic Tools: A Report from Germany, *Medical Anthropology Quarterly*, 10, 4, 675-82.
- Hoeyer, K., Jensen, A.M.B. and Olejaz, M. (2015) Transplantation as an abstract good: practising deliberate ignorance in deceased organ donation in Denmark, *Sociology of Health & Illness*, 37, 4, 578–93.
- Kierans, C. and Cooper, J. (2013) The emergence of the “ethnic donor”: the cultural production and relocation of organ donation in the UK, *Anthropology & Medicine*, 20, 3, 221–31.
- Latour, B. (1988) *Science in Action. How to Follow Scientists and Engineers through Society*. Cambridge: Harvard University Press.

- Le Clainche-Piel, M. (2013) Éthiques et pratiques en innovation chirurgicale : le cas de la greffe du visage, *Sciences Sociales et Santé*, 31, 59–85.
- Le Clainche-Piel, M. (2018) *Ce Que Charrie la Chair. Approche Sociologique de L'émergence des Greffes du Visage*. Doctoral thesis. Paris: EHESS.
- Le Clainche-Piel, M. (2020) Faire du visage un organe anonyme. Chirugiens et patients transplantés aux prises avec la politique du don anonyme en France, *Sociologie*, 11, 2, 149–66.
- Levy, M. (2018) State incentives to promote organ donation: honoring the principles of reciprocity and solidarity inherent in the gift relationship, *Journal of Law and the Biosciences*, 5, 2, 398–435.
- Lock, M. and Scheper-Hughes, N. (1996) A critical-interpretive approach in medical anthropology: rituals and routines of discipline and dissent. In Sargent, C.F. and Johnson, T.M. (eds) *Handbook of Medical Anthropology: Contemporary Theory and Method*. Westport: Greenwood Press.
- Lock, M. (1999) Cultural aspects of organ donation and transplantation, *Transplantation Proceedings*, 31, 1–2, 1345–6.
- Lock, M. (2001) *Twice Dead: Organ Transplants and the Reinvention of Death*. Berkeley: University of California Press.
- Lock, M. (2002) Human body parts as therapeutic tools: contradictory discourses and transformed subjectivities, *Qualitative Health Research*, 12, 10, 1406–18.
- Marcus, G.-E. (1995) Ethnography in/of the world system: the emergence of multi-sited ethnography, *Annual Review of Anthropology*, 24, 95–117.
- Martindale, A.-M. (2014) Recycling faces and identities? Allegra A Virtual lab of legal anthropology, [online]. Available at: <https://allegralaboratory.net/recycling-faces-and-identities/>. (Last accessed 1 August 2019).
- Mauss, M. (1990) [1954] *The Gift: The Form and Reason for Exchange in Archaic Societies*. New York: W.W. Norton.
- Mehl, D. (2008) Connaître ses origines ? In Michel, W. (éd.) *Nos Enfants*. Auxerre: Editions Sciences Humaines.
- Memmi, D. (1996) *Les Gardiens du Corps : Dix Ans de Magistère Bioéthique*. Paris : Éditions de l'EHESS.
- Naulin, S. and Steiner, P. (2016) *La Solidarité à Distance: Quand le Don Passe Par les Organisations*. Toulouse : Presses Universitaires du Midi.
- Paterson, F. (1997) Solliciter l'inconcevable ou le consentement des morts, Prélèvement d'organes, formes de circulation des greffons et normes de compétence, *Sciences Sociales et Santé*, 15, 1, 35–74.
- Pomahac, B., Gobble, R.M. and Schneeberger, S. (2014) Facial and hand allotransplantation, *Cold Spring Harbor Perspectives in Medicine*, 4, a015651.
- Prentice, R. (2013) *Bodies in Formation: An Ethnography of Anatomy and Surgery Education*. Durham: Duke University Press.
- Rémy, C. and Winance, M. (2010) Pour une sociologie des frontières d'humanité, *Politix*, 90, 2, 7–19.
- Rémy, C. (2014) Accepter de se perdre. Les leçons ethnographiques de Jeanne Favret-Saada, *SociologieS*, [online]. Available at: <http://journals.openedition.org/sociologies/4776>.

- Rose, N.S. (2005) *Governing The Soul: The Shaping of the Private Self*. London: Free Association Books.
- Sanal, A. (2011) *New Organs Within Us. Transplants and the Moral Economy*. Durham: Duke University Press.
- Scheper-Hughes, N. (2007) The tyranny of the gift: sacrificial violence in living donor transplants, *American Journal of Transplantation*, 7, 3, 507–11.
- Schlich, T. (2010) *The Origins of Organ Transplantation: Surgery and Laboratory Science, 1880–1930*. Rochester: University of Rochester Press.
- Sharp, L.A. (1995) Organ transplantation as a transformative experience: anthropological insights into the restructuring of the self, *Medical Anthropology Quarterly*, 9, 3, 357–89.
- Sharp, L.A. (2000) The commodification of the body and its parts, *Annual Review of Anthropology*, 29, 287–328.
- Shaw, R. (2007) The gift-exchange and reciprocity of women in donor-assisted conception, *The Sociological Review*, 55, 2, 293–310.
- Shaw, R. (2010) Perceptions of the gift relationship in organ and tissue donation: views of intensivists and donor and recipient coordinators, *Social Science & Medicine*, 70, 4, 609–15.
- Shaw, R. (2015) Rethinking the conceptual toolkit of organ gifting, *The New Zealand Medical Journal*, 128, 1422, 63–8.
- Sheach-Leith, V. (2007) Consent and nothing but consent? The organ retention scandal, *Sociology of Health & Illness*, 29, 7, 1023–42.
- Shildrick, M. (2015) Staying alive, affect, identity and anxiety in organ transplantation, *Body & Society*, 21, 3, 20–41.
- Siemionow, M. (2017) The decade of face transplant outcomes, *Journal of Materials Science, Materials in Medicine*, 28, 5, 64–9.
- Steiner, P. (2008) Organ donation: an analytical typology, *Revue Française de Sociologie*, 49, 5, 125–52.
- Stewart, G. (2017) The “Hau” of research: Mauss meets Kaupapa Māori, *Journal of World Philosophies*, 2, 1–11.
- Sylvia, C. and Novak, W. (1998) *A Change of Heart: A Memoir*. New York: Grand Central Publishing.
- Talley, H.L. (2014) *Saving Face: Disfigurement and the Politics of Appearance*. New York: New York University Press.
- Taylor-Alexander, S. (2014) *On face Transplantation: Life and Ethics in Experimental Biomedicine*. Basingstoke: Palgrave Macmillan.
- Thouvenin, D. (1997) Don et/ou prélèvement d’organes, *Sciences Sociales et Santé*, 15, 1, 75–97.
- Theodorakopoulou, E., Meghji, S., Pafitanis, G. and Mason, K.A. (2017) A review of the World’s published face transplant cases: ethical perspectives, *Scars, Burns & Healing*, 3, 3–4.
- Titmuss, R.M. (1972) *The Gift Relationship: From Human Blood to Social Policy*. New York: Vintage Books.