

Ethical, Social and Legal Intricacies on Facial Transplant

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ABSTRACT Facial tissue has become a clinical reality and is gaining popularity as the preferred surgical option for patients with devastating facial deformities due to disease, trauma or congenital malformation. Conventional facial reconstruction method can be lengthy, laborious, inflicting unbearable pain and may require prolonged hospitalization. On the contrary, restoration of aesthetics and functionality by facial tissue allotransplant is superior and has minimized all of those undesirable affects mentioned above. Nevertheless, these surgical options are associated with complex social, ethical and legal aspects. The primary objective of this review is to provide a glimpse of the history of facial transplantation and discuss the critical issues related to facial transplant.

INTRODUCTION

Dr. Joseph Murray, a plastic surgeon, is considered to be the pioneer in the field of organ transplantation. He and his team successfully performed renal transplant in the year 1954 and since then, organ transplantation rapidly evolved to involve other organs such as heart, liver, lungs and small intestine. It has become a life-saving procedure for those suffering from critical medical conditions (Fecteau 2016).

In May 2005, Isabelle Dinoire fell unconscious due to an overdose of sleeping pills. Her dog, desperately trying to rouse her, had gnawed away at her face. The doctors ruled out the choice of a routine face reconstruction because the injuries to her mouth, nose and chin were too extreme (Lanchin 2014). They proposed the first facial transplantation, which eventually turned out to be a very successful one. Since then until April 2014, 28 such facial transplantations have been conducted worldwide (Senthilingam 2014).

After 20 years of intensive preclinical research, the first facial transplantation was approved by the institutional review board in 2005. The first case was a partial facial transplantation at the Amiens University Hospital in Northern France on November 27, 2005.

Facial transplantation is especially helpful in reconstructing specialized structures in the face,

particularly eyelids, nose and lips. This is because their complex functions cannot be restored with autologous tissues. Facial transplantation will restore the physical functions of a human face, like breathing, speaking, swallowing, smiling and showing other emotions. There are also additional psychosocial benefits because patients regain their confidence with a near-normal facial appearance (Lanchin 2014).

Nevertheless, out of the 28 surgeries done, four recipients have died (Richard Norris 2014). The deaths have sparked a new controversy over the benefits and risk of the procedure, as well as alternatives available. The experts and public questioned the risk-to-benefit ratio of face transplant. The aim of this manuscript is to discuss the current challenges of facial transplant from various aspects, including ethical, psychological and social aspects.

METHODOLOGY

ProQuest, PubMed, Ovid, Science Direct and Google Scholar were the search engines of choice for this report. The journals chosen were written in English and the year of publication was year 2000 and after. Articles that discussed facial transplant and its ethical aspects were included whilst other forms of transplant were excluded. The keywords used were change of identity, facial

transplant, dilemma, reconstructive surgery, ethical aspects, benefits and risks.

OBSERVATIONS AND DISCUSSION

Identity Issues

After receiving the transplant, the patient will appear neither like his original self nor the donor's face. This is because the anatomic details of donor and recipient are different, and the transplant will take on the structural support of the recipient.

A change of face may disrupt the process of recognition. People around the patient, especially children, might not be able to recognize the patient until they adapt to the new face. The effect of facial transplantation not only depends upon the donor and recipient, but also on the people around them. Does the public who is not standing in the recipient's shoes understand the physical pain and discomfort of having facial deformities? Is the society ready to accept the outcome of facial transplantation?

The issue of identity is very complex after the receipt of a facial transplant and it may vary with every case. Face defines and it plays an even more vital role in social interactions. It is the key to how others recognize one, and with facial transplant, an individual with severe face deformities receives a new facial appearance from a deceased donor. While providing the patient with a solution to his impaired face, does facial transplantation also bring along a new identity? Will the person remain as how he truly is before the transplantation? Kiwanuka and co-authors showed the concerns over the impact of identity issues on facial transplant recipients in a medical literature review. They discovered the issue of "identity change/psychological effects" as one of the most common issues recurring through the world's experience with facial transplantation (www.wolterskluwerhealth.com). Richard Norris is a face transplant recipient who suffered 15 years of a hermit-like life after a shotgun accident in 1997 dismissed the belief that a face transplant patient has the likelihood of encountering an identity crisis (www.huffingtonpost.com). But according to Mr. Bluhm, a co-author of "Someone Else's Face in the Mirror: Identity and the New Science of Face Transplants", explains how face transplant recipients "find themselves" in the mirror after a face transplant may

rely on how closely they link their identity with appearance (Novotney 2011). With a face that is different from their original one, they are likely to have difficulties of integrating the graft into their body image and identity. The recipient of world's first partial face transplant patient suffered from depression and found her old photographs highly disturbing even two years after her transplant (Novotney 2011).

Cost of Facial Transplantation

Facial transplantation is currently in the midst of development, with more new technology to be learnt. The cost of face transplant may vary from USD 250,000 to USD 350,000 (Siemionow and Gordon 2010; Devauchelle et al. 2006 and Siemionow et al. 2010). The price may fluctuate due to variability of healthcare systems in the country and graft-recipient operation cost (Siemionow and Gordon 2010; Ruegg et al. 2012). The long-term post-operative management and lifelong immunosuppression therapy are to be borne by patients. If they are unable to cover the cost, they would have to stop the therapy, which might result in graft rejection. Hence, government-based funding and insurance-based support are needed for such cases. Hospital and organizations play a role in disseminating role in the future, which will increase awareness among the public. Various personal and societal benefits of facial transplant should be spread in order to spark the enthusiasm of insurance companies and the public. The outcome of these efforts depends on the society's interest on this procedure (Edward and Mathes 2011).

Donor and Their Families

Preservation of dignity and respect to donors and their families is a must. As face is visible and highly personal, the integrity of the body should be restored. The donors' families may hope to have an open casket viewing of the donor. To respect this wish, a silicon mask can be created with a mold to restore facial defect of donor (Pomahac et al. 2012). It can be distressing for the grieving family to see part of their deceased family member's face present on another individual. There is a dispute over whether the recipient should be allowed to know the identity of donor. It is not surprising that recipients

would yearn to know the identity of donor who grant them a life-changing opportunity, and express their gratitude towards the donor and donor's family personally. Anyone who has knowledge about the case is free to reveal the details (Wiggins et al. 2004). However, the donor's family has the right to remain anonymous, and this right should be respected. In France, the law made to make sure the identity of donor remains confidential (Lachin 2014).

Should the family of donor be made aware of the identity of the recipient? The families who lost their loved one may agree to the donation due to the feeling that the deceased continues to live on as another individual. Daughter of face donor Cheril Denelli-Righter said it was a gift to see her mother live on through the recipient of her mother's face (Pow 2014). There is a possibility that the family may develop emotional attachment to the recipient, assuming their loved one is still alive.

Religion

Challenges also exist due to objection raised by believers of various religions. Some religious groups are against the idea of organ donation and transplantation because of the principle of bodily integrity that states that the body is entrusted by god and human are merely the temporary users (Blok 2006). Whereas others believe that prayer is the effective first choice of healing (Oliver et al. 2011). They are taught to replace modern medicine with spiritual healing. There are also individuals who believe that an intact body is necessary for resurrection, thus objecting organ donation (Blok 2006). Tibetan Buddhists believe that the soul remains in the body for days after cessation of breathing, and the body should not be disturbed until the departure of the soul (Oliver et al. 2011). It is believed by some Hindus that humans do not own the body and it should be returned to its original source in its entity. An individual will be changed by organ donation and transplantation, and ultimately influence his reincarnation (Blok 2006). The Jews strongly believe that the body should be complete for burial and any unnecessary interference with body should be avoided (Oliver et al. 2011). There are three taboos on the dead that would prohibit cadaveric organ donation, that is, delaying burial of the deceased, desecrating a cadaver, and accepting benefit from a cadaver (www.youpublish-

er.com). Shinto, as the largest religion of Japan has much influence on the believer's thoughts on facial transplantation. It is believed that humans are pure at birth and gain impurities while living (Namihira 1990; Daar 1994). Thus, a cadaver is considered impure and will bring bad luck if defiled.

Informed Consent

An informed consent is a process where physicians relay necessary information to a competent patient, allowing the patient to make a voluntary choice to accept or refuse a treatment (Appelbaum 2007). Informed consent is both ethically and legally crucial to facial transplantation. A patient who is awaiting facial transplantation must have a clear and realistic understanding of the complexity and facets of the treatment. The physician or nurse must discuss the risk of transplantation, such as immunosuppression, graft rejection, the psychosocial impact after the procedure and media attention with the patient. Apart from that, there are difficulties when the medical team informs a patient about his post-transplant appearance (Paradis et al. 2010). The facial transplantation serves the aim of providing disfigured patients with a normal appearance, but there are uncertainties of how "normal" it would be. The outcome of the procedure is the hybrid of the donor and his original appearance (Paradis et al. 2010). Moreover, there is ongoing debate on the integrity of informed consent. A new transplantation may take a different form compared to the previously performed procedures, generating new benefits and risks that are not stated in the consent document (Clark 2005).

At the same time, it is paramount for the patient to be fully autonomous to give consent. However, it is a challenging process to validate whether the patient has truly grasped the information and voluntarily agree to the treatment. There is a tendency of assuming that the patient has sufficient information and is competent in making his or her decision when there is no proof suggesting otherwise (Edwards and Mathes 2011). A patient will give consent based on his or her own values and understanding. A patient's judgment may be compromised by the high hopes of positive results, thus irrationally weigh the costs and gains of facial transplantation (Clark 2005). Bearing hopes for a favorable outcome and attempting to minimize emotional distress,

patients may avoid learning about the potential morbidity of face transplantation, and various burdens subsequent to the procedure (Edwards and Mathes 2011). This is an avoidance coping process known as “cognitive avoidance” (Elliot et al. 2011).

Hospital and Surgeon Licensing

It is mandatory for the surgical center in a hospital to obtain a license to provide surgical services. Since it is still in the early stage of facial transplantation, the issue of licensing for facial transplantation is yet to be discussed and formulated (Ludwig and Day 2011; Swing 2007).

Future Direction

Modification in legislation and establishment of new laws will be required to close the existing loopholes that initiate arguments and protests. In the USA, a new set of rules was passed to ease the effect legal process and increasing the number of facial transplantations, like other organ transplants (Lupkin 2014). The feasibility of face transplantation and role hospitals in disseminating the future and benefits of this procedure so that more government-based and insurance-based support may help the patients on the high cost of the medical care.

CONCLUSION

Facial transplantation is now a realistic surgical option for patients with severely disfigured faces. This procedure will enable them to improve the quality of life and restore self-confidence in disfigured patients. The current strong arguments on the ethical issues are one of the hurdles of providing therapeutic care that disfigured patients’ desire. Knowledge in the ethical, psychological and social aspect of facial transplantation will be enriched with more and more transplants completed.

RECOMMENDATIONS

Since the facial transplant is evolving as a more acceptable surgery, the ethical and legal issues related to surgery need to further be investigated and regulated.

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