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Bilateral hand transplantation: Supporting the patient's choice☆

M. Dumont*,[a], L. Sann [b], A. Gazarian [c]

Ecole normale supérieure, ED 540, 45 rue d'Ulm, 750005 Paris, France

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Summary Bilateral hand transplantation, as a fairly new reconstructive option for amputees, raises major ethical questions. This article, which is based on the reflections arising from the rich experience of Lyon's team in this field, addresses the topic of supporting the patient in his choice for or against this procedure. How should autonomy be understood in this particular setting? The developing field of composite tissue allotransplantation needs to establish a common thinking on this subject. The article emphasises that, even if it is their right to decide, patients have to be carefully supported to help them make the most consolidated choice possible in this challenging procedure. We deal with the question of the choice between the uncertainty in this innovative procedure and a life-threatening treatment to alleviate a handicap. We outline that the entire process of hand allograft is a unique opportunity for the patients to strengthen and exercise their autonomy in interaction with the medical team.
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Bilateral hand transplantation is a fairly new reconstructive option for bilateral upper limb amputees. Since the first (unilateral) successful surgery in 1998, it has raised, and still raises, ethical questions.

The two main questions are as follows: hand transplantation is almost unique in the world of transplant surgery, in that it offers a significantly disabled patient a treatment, a chance of significantly improved function, but in return for a significant likelihood of shortening his/her life expectancy. The transplanted hands, the acquisition of which is a long process, are liable to be rejected in the long

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* Corresponding author. 96 rue Jean Sans Peur, 59800 Lille, France.
E-mail address: martin-patrick.dumont@ac-lille.fr (M. Dumont).
[a] Philosophy, ED 540 (École normale supérieure, Paris, France).
[b] Paediatrician, president of the Ethics Board of the Femme-Mère-Enfant Hospital in Lyon-Bron, France.
[c] Orthopaedic Surgery Department, Clinique du Parc Lyon, Lyon, France.

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run, leading to a new amputation and possibly a new transplantation. These two ethical questions are fairly new in transplantation because the longest survival possible is usually a benefit for the patient, as is a better quality of life, and because the rejection of the transplant, ultimately in a non-vital setting, poses other problems than in the case of a vital organ. The non-vital nature of this treatment thus bypasses some complications that are encountered in other transplants: the direct or indirect side effects, lifelong immunosuppressive therapy essential to the survival of the grafts, and chronic rejection in the long run.

How can we then establish the reasonable nature of such a treatment? What are the ethical criteria that need to be considered before committing to it? To understand the reasonable and legitimate nature of hand transplantation, we need several elements: a calculation of the risks and benefits for the patient in as much detail as possible, which entails a fine understanding of the bilateral amputee's life and of his/her transplant request; we also need to ensure that the patient's decision is strengthened and realistic; and finally, such a decision is not without requirements from the medical team itself. This would not be about studying the issue of the risks and benefits, which has already been studied elsewhere,[1] but rather about studying the criteria of a reasonable choice on the patient's part and the constraints that fall to the team for this, both in terms of supporting his/her decision and of ethical commitment in the treatment. How can we support patients in their choice of hand allotransplant?

Criteria of reasonable risk-taking by the patient supported by the team

The absence of urgency to decide

When facing the important risks and constraints involved in bilateral hand transplant, the patient's resolve is essential. It is then essential that the medical team test the *realistic* nature of the transplant candidate's expectations and help him/her get such realistic expectations. It is known that trauma victims who lose some part of their body and some related functioning react by taking risks because of loss aversion. Therefore, in this respect, they may underestimate the risks.[2] They can also face the treatment in a spirit of misplaced revenge towards a fate that was unfair to them when depriving them of their hands.

The functional, psychological, and existential repercussions of the amputation are deep and require guidance first before any suggestion of a transplant possibility. It is then essential that some time be given to the patients, time to make an effort to adapt to the trauma that they went through, get the treatments available aside from a transplant (namely prosthesis) and embrace their new condition as well as possible and its limits and possibilities. Faced with the risks incurred as part of the transplantation, it seems in fact that being able to manage without hands would be preferable. It is nevertheless possible that a transplantation be requested afterwards, a request that will have to be both examined and guided.

A choice under uncertainty

Patients who ask for a bilateral hand transplant must give their informed consent. It is then essential that predictable risks and benefits are presented to them honestly while ensuring that they understand the different aspects of the treatment, particularly the possibility in the long run of chronical rejection of hands that would be theirs only for a while.

The difficulty here is that the risks and benefits are tinged with uncertainty, as is the case with essentially every treatment, but most significantly with an innovative treatment such as hand transplantation. Even if the immediate risks are quantifiable, risks of the surgery itself, risks of the long-term effects of the immunosuppressive therapy, and the chronical rejection risk is still difficult to assess; it is nonetheless a possibility and has already once led to the removal of the allograft.[3] The benefits, even if the results are likely to be reproducible, have a greater uncertainty because of the small number of patients treated as of now. It is then about considering even the possibility of a comparatively weak advantage to assess the reasonable nature of the initiative. Thus, we find ourselves in a situation where a fully *informed* consent seems impossible to attain.

Indeed, enlightening a situation perfectly would come down to reducing the part of choice it involves to nothing: if we were capable of enlightening the different options of a choice and their respective consequences perfectly, the choice to be made would clearly appear on its own and be obvious: 'if I always saw clearly what was true and good, I should never have to deliberate about the right judgement or choice',[4] said Descartes. Then we would not have to decide but actually only consent to what would be, from this point forward, as obvious evidence.

It is nonetheless possible to refuse even an obviously better choice, and we still have to validate it. In such a case, we still need the essential step of consenting to this option, particularly in a medical context where this is done on ourselves for our own benefit but by someone else. Descartes emphasised this essential role of one's will to accept to give momentum to the option that clearly appears as being the best: 'when an obvious reason pushes us to one side, morally speaking, we can hardly choose the opposite side, however in absolute terms, we can. Indeed, it is always possible to stop ourselves from going after a clearly known good or to admit an evident truth, provided we think it is something good to assert our free will in this way'.[5]

However, in a situation where there is still uncertainty, as is the case with any medical initiative and even more so with innovative surgeries such as hand transplantation, errors become possible. It seems then that abstention is recommended as long as we do not have all the information. However, in the field of innovating treatment, it is not possible to hope for complete enlightenment, and in a way, this is true of most of our acts and even the most validated medical procedures: 'How many things do we do on an uncertainty!'[6] The received consent, however, needs to be as informed as possible and within the limits of our present knowledge,

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