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## Ethical Issues in Limb Transplants

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In April 1999, the *Lancet* published an Early Report on the six months' results of the first human hand allograft performed in Lyon in September 1998.<sup>1</sup> The same clinical team performed a double human hand allograft in January 2000. In the interim, a U.S. team at Louisville performed a similar procedure. Yet permission to perform further human hand allografts has again been refused by the St. Mary's Hospital Trust Clinical Ethics Committee, on which one of the authors sits (DD). Following face-to-face evaluation of hand function in the transplant recipient six months after the operation, the committee reiterated its concerns that the level of function attained did not outweigh the risk. Doubts about "the ethics of putting a patient through toxic immunosuppressive therapy for a non-vital operation" were also raised in a commentary on the *Lancet* report.<sup>2</sup> The recipient of the first hand transplant has recently announced that he is actually seeking to have it amputated, saying, "I've become mentally detached from it."<sup>3</sup> This article explores the ethical arguments both for and against limb transplant, and particularly human hand allograft, with emphasis on the issues concerning identity which can be seen in the recipient's reaction.

On one view, hand transplants cross technological frontiers but not ethical ones. They raise no ethical questions that have not been answered long since, in favour of transplantation. There can be no objections except from unregenerate opponents of progress in science—according to one of the very few

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articles in medical ethics to have appeared on the issue of limb transplants. The article concludes in favour of cadaveric hand transplantation, provided professional and procedural standards of competence have been met (including field strength of the clinical team, scientific background of the innovation, and open public evaluation).<sup>4</sup>

Nonetheless, it is broadly agreed that doctors are not obliged to do everything which is technologically possible. We can stave off the moment of death over and over again in terminally ill patients, but there is a widespread dread of pointless "high-tech" intervention. Modern medicine tends to generalise the application of technologically innovative procedures beyond their original target group, as epitomised by the widespread overuse of cardiopulmonary resuscitation.<sup>5,6</sup> Specifically in transplant surgery, "in every instance, the extension . . . to organs beyond the original kidney, such as the heart, liver, lungs and pancreas, has raised questions and controversies in the mind of physicians and the general public."<sup>7</sup> Are limb transplants a step too far down a slippery slope?<sup>8</sup>

Surprisingly little attention has been paid to possible ethical problems in limb transplants. Perhaps this is partly a function of what one study has identified as an "ethics gap" between the medical and surgical literatures in their coverage of biomedical ethics.<sup>9</sup> Some concepts from conventional biomedical ethics may help us elucidate these particular surgical dilemmas: the boundaries of research, burdens and benefits, and patient autonomy.<sup>10</sup> But we will also introduce another set of more speculative and philosophically challenging concepts, which go beyond the scope of conventional biomedical ethics, in order to do justice to some of the unexpected questions that arise in limb transplantation. This second set of issues includes bodily integrity, unnaturalness, and personal identity.

#### RESEARCH BOUNDARIES, BURDENS AND BENEFITS, AND PATIENT AUTONOMY

Unlike life-saving transplants, the benefits of limb transplants do not self-evidently surpass the burdens. The risks of lifelong immunosuppressive medication, as well as the possible development of melanomas and other cancers, mean that a limb transplant may actually shorten life. It has been said of medicine that "the art's most delicate aspect is not to shorten life further, and not to diminish it."<sup>11</sup> Other innovative transplant procedures, such as multi-organ transplants, may be criticised as having such unacceptably high mortality rates that they are properly characterised as more research than therapy, and possibly nontherapeutic research at that. Both the case of four-year-old Laura Davies and the two American pediatric cases described by Friedman<sup>12</sup> bear out this ethical qualm, with extensive lymphoma at autopsy in the latter cases.

One might want to argue, however, that medical science only advances by performing procedures at the limit of current knowledge. In that case, limb transplants would be more like research than therapy, and one could expect the risk-benefit ratio to be different. However, the Lyon and Louisville recipients clearly understood the procedure to be therapy, not research. Nor was this supposed research properly designed and evidentially sound. Simply because a procedure is new and unproven does not make it "experimental" or "research." In any case, the standard for subjects' informed consent to participation in medical research is actually higher than for their agreement to therapeutic procedures.<sup>13</sup>

If limb transplants are not to be judged by research standards, the cost-benefit equation which they entail must be considered under the rubric of therapeutic interventions. The most obvious benefit of most other organ transplants, saving life, does not apply to limb transplants. The nearest similarity is to restoration of function, for example, through corneal transplants. However, artificial limbs currently provide a better level of function than the limb transplants so far performed, which does not hold for corneal transplants.

But who should decide on the acceptability of the cost-benefit equation? Here we would normally need to consider both resource allocation—e.g. the expense to the UK National Health Service of lifelong immunosuppressive medication—and benefits to the individual patient. In the case of the Lyon patient, who was paying privately for his own treatment, there was no public resource allocation question (except perhaps insofar as the UK surgeon's time was being diverted away from NHS patients). So the issue resolved itself into a matter of patient autonomy, the third question on our list. The obvious patient autonomy argument in the case of an adult patient is that it is up to the patient to weigh the risks and benefits. If he chooses to accept the risks of an actually decreased life span, his autonomy deserves respect. But why?

Many people would phrase their answer in terms of "whose body is it?", a liberal argument founded loosely on John Locke's assertion in *An Essay Concerning Human Understanding* that "Every man hath a property in his own person." But Locke follows that sentence with another which ought to give us pause: "The labour of his body, and the work of his hands, we may say, are properly his." Locke says we own our labour, not our bodies. And we own our labour because it is the product of our moral agency, which is much closer to what Locke means by "person" than is the physical body.<sup>14,15</sup>

In Locke's terminology, we own that with which we have mixed our labour. It is not literally mixing our bodies with natural resources which gives us a claim to property; that would be an incoherent metaphor. As Robert Nozick has famously pointed out in his fantastical example of pouring his tin of tomato juice into the sea and then claiming he owns the oceans of the world,<sup>16</sup> mixing one substance which I own with another which I do



not possess does not make the second one mine. Similarly, it is not the physical contact between my body and the hoe or the land which entitles me to claim the harvest. If there is anything special about my work, it is not that it is the labour of my body, but that it represents my agency, a part of my self, my person.

Anglo-American common law views tissue taken from the body not as the property of the person from whose body it comes, but as *res nullius*, no one's property. What the law was traditionally concerned with was making sure that the tissue was not taken without consent, not with what happened to it afterwards; after all, it was presumed to be diseased. Of course we need not literally own our bodies to have rights over their inviolability; indeed, this is closer to the conventional position in law. Common law is more concerned with protecting the physical person from assault or other trespass, through the cornerstone of consent, than with establishing property rights in the body. But this is primarily a negative right, to be free of trespass to the person—not a positive right to demand any and all forms of procedure which I may think desirable.<sup>17</sup> So it is simply not good enough to say that I own my body and can request that whatever I like should be done to it.

Is the argument from autonomy more to do with the right to harm oneself if one chooses? We accept that argument in other procedures involving self-harm, such as donation of a kidney by a living donor. But where do we draw the line about self-harm? Donation of a kidney by a living donor entails a clear benefit to the recipient. What about the recent furore about amputation of healthy limbs to "cure" victims of rare body dysmorphic disorders?<sup>18</sup> These patients have an obsessive belief that their body is incomplete with four limbs, but will be complete after amputation. Here there is no benefit to another person, but the surgeon who performed these procedures felt that he was justified by the threats of suicide or self-harm which these patients had made. (In one case, the patient had already asked a friend to shoot off one of her limbs.) Should we say that amputating healthy limbs is *prima facie* wrong—or at least, not part of the goals of medicine? After all, it carries unpleasant connotations of emotional blackmail, and of colluding with the patient's delusions.

That there should be a class of procedures which are *prima facie* wrong, even if patients request them, seems plausible. It is the underpinning notion behind mental health legislation, after all, that people's motives and desires are not always to be taken at face value. This is not just a matter of the law's distinction between the competent adult's *refusal* of treatment, which may occur on any grounds, or no grounds,<sup>19</sup> and the absence of a right to *request* whatever procedure one wants, although that is part of it. In more philosophical terms, the problem of other minds may mean that the clinician cannot ever fully understand the patient's motives for consenting to, refusing, or requesting a procedure; but that does not mean that the clinician has to conclude that the patient's desires must always be respected.<sup>20</sup>

Let us assume, then, that there is a class of procedures which it would be *prima facie* wrong for the clinician to propose (whether or not the patient agreed) and wrong for the patient to request. If there is a class of procedures which are *prima facie* wrong to perform, what is in that class? Amputation of healthy limbs, in the absence of other justification than that so far encountered, is such a procedure, we suggest. The burden of proof is on the clinician who proposes it, or the patient who requests it, to show why it is not wrong, if further argumentation can be produced. But what about gender reassignment? Somehow that now seems more acceptable, but why? How do we know that the content of the class is not simply down to newness, strangeness, or the "yuck" factor?

For our purposes, we only need to establish that the patient autonomy argument does not trump all. It may be wrong to take advantage of another's willingness to harm himself: motives are complex creatures.<sup>21</sup> Following extensive media coverage of a total artificial heart transplantation in 1982, some volunteers were even willing to "donate" their hearts in the interests of advancing science, though they had no cardiac pathology.<sup>22</sup> In the hand transplant case, the risk is not necessarily certain death, and the benefit of the procedure is to the person undertaking the risk; but there may still be a distinction between respecting the patient's "right" to harm himself and being the agent of possible harm. In interviewing the Lyon recipient, the St. Mary's ethics committee was struck by evidence of possible thought disorder: he denied that his own arm, which had been reattached but failed to "take," was really his, whilst he strongly believed that he would eventually find his "own" arm again when an allograft was performed. With the hand showing signs of rejection two years later because of his failure to take immunosuppressive medication consistently, he now says, "As it began to be rejected, I realized that it wasn't my hand after all."<sup>23</sup> Perhaps he failed to take his immunosuppressive medication precisely because he was under the delusion that the transplanted arm was his own long-lost limb.

How much room is there for critical examination of the patient's motives? The answer to this question depends on how one conceives of autonomy and the interaction between doctor and patient. Emanuel and Emanuel<sup>24</sup> define four models of the doctor-patient relationship:

1. The paternalistic model, in which the doctor knows best;
2. The informative model, in which the doctor merely conveys information and the patient decides;
3. The interpretative model, in which the doctor acts as a counselor or adviser, helping the patient to clarify values;
4. The deliberative model, in which the doctor acts as a friend or teacher, eliciting the patient to critically examine his or her values in a process of communication and deliberation.



In the Lyon case, the surgeons seem to have followed the informative, legalistic model. The patient was asked to sign a detailed consent form and a legal contract, detailing risks in surgery and anaesthesia together with post-surgical risks of possible drug-related complications, malignancies, infections, and long-term psychological complications.<sup>25</sup> The surgical team certainly gave the recipient enough information by the usual professional standards, and indeed more than enough to satisfy the rather minimal requirements of English law.<sup>26</sup> Yet one may doubt the scientific basis of the information given, and therefore the validity of the informed consent. As hand allograft is an "experimental" procedure, there is an insufficient body of evidence on the basis of which patients can be informed. The team in Louisville chose to give the patient a reduced dose of immunosuppressive medication, reasoning that "because a hand transplant is not a life-saving procedure, the drug treatment will be less aggressive than that of other organ transplants."<sup>27</sup> It is not clear whether the U.S. recipient consented to receive a "riskier" treatment regime, and if he did, on what evidential basis.

The interpretative and deliberative models imply that the surgeons should actually focus on the patient's reasons for wanting a hand allograft, given the risks involved. In the Lyon case, this raises some interesting questions. For nearly ten years, following the reamputation of his right forearm after an initial replantation failed, the recipient had refused an aesthetic or functional prosthesis. Was there an element of inability to accept the loss of his hand, and the failure of its replantation? The deliberative model draws our attention to such questions: patient autonomy is not a catch-all answer in this view, but rather the beginning of a questioning process. "The conception of patient autonomy is moral self-development; the patient is empowered not simply to follow unexamined preferences or values, but to consider, through dialogue, alternative health-related values, their worthiness, and their implications for treatment."<sup>28</sup> Of course, there is a considerable risk of slipping over into the paternalistic model here: of overbearing doctors overriding the patient's own values, rather than helping to draw them out. In limb transplants, however, where the motives may be complicated and the benefits might actually be outweighed by the harms, that seems much less of a risk than the converse: failing to examine the patient's decision jointly.

Let us review the issues raised thus far, and evaluate their impact on the ethical status of limb transplants. In this section we have raised three possible ethical objections to human hand allograft in particular:

1. *Is this therapy or research?* The "defence" claimed that limb transplants are research, not therapy, and that they should be allowed because research pushes the boundaries of scientific knowledge forward. The fact that limb transplant is not (yet) a treatment of proven efficacy, however, does not make it research. So this objection still stands.

2. *Do the costs outweigh the benefits?* Even if limb transplants are not *prima facie* wrong to perform, they could be proven wrong with more extensive argumentation, most obviously cost-benefit analysis. In therapeutic treatment, the benefits to the patients should outweigh the possible risks and harms (which would not necessarily be true in research). However, limb transplant is not a life-saving therapy. This is the calculus on the benefit side; on the harm side we have lifelong immunosuppressive medication, which also carries heavy resource implications. In the view of our clinical ethics committee, the degree of function regained did not counterbalance the costs.
3. *Should the patient be the one to decide on the risk-benefit equation?* We might want to argue that it is the patient who should decide what risks are acceptable. If this is so, it is not so because patients straightforwardly own their bodies. The law has traditionally been concerned with protecting patients from unauthorised trespass to the person, but has been unwilling to say that doctors must go along with whatever trespass patients do authorise. There are some procedures which we want to view as outside the goals of medicine, whether the doctor or the patient proposes them. So we come back again to the question of whether limb transplants are among those procedures.

On balance, so far, drawing on all three of the "standard" arguments from bioethics, we have yet to show positive reasons why limb transplants should be performed. Can more unconventional arguments take us beyond this impasse?

## BODILY INTEGRITY AND PERSONAL IDENTITY

Our first set of considerations was fairly standard bioethical fare, although the application to limb transplants is new. The second set is more speculative, but possibly more powerful. So far, we have two "no" results against limb transplants, and one "not proven." The more speculative arguments, in our view, actually favour limb transplants more than the standard ones; but they also require the clinician to take into account some new and unusual factors.

First, bodily integrity: an obvious issue in physiological terms is that invasion of bodily integrity precipitates the immune system's natural reaction, and the consequent need for lifelong immunosuppressive therapy. But the issue is not only biological; it is also symbolic, as is clear from the Lyon team's decision to attempt to restore the normal appearance of the dead donor through a prosthesis—in order, as they put it, to restore the dignity of the donor. That the surgical team felt such a need itself suggests that they felt all was not right. But what exactly is the ethical importance of bodily



integrity, and how does it bear on the rightness or wrongness of limb transplants?

The symbolic importance of bodily integrity may explain the emphasis put upon obtaining consent of family members for organ transplants, contrary to the general principle in English law that no one, not even a relative, can give or withhold consent on behalf of an adult patient.<sup>29</sup> In the absence of consent from the patient, bodily integrity is normally sacrosanct. However, the Human Tissue Act 1961 requires doctors to consult relatives about organ donation if there was no previous consent from the deceased person. French law in relation to organ donation is based on the "opt-out" principle; but in the UK, where the "opt-in" system applies, consent must have been obtained from donors before their death. The position is complex in law, but essentially a spouse or relative has the power of veto.<sup>30</sup> In countries with the "opt-out" system, it is also customary to request the relatives' permission, although this too carries no legal weight.<sup>31</sup> Since 1987, U.S. doctors have been required by law to request relatives' permission for "harvesting" organs of deceased patients who had not given a consent before death. Similarly in the Netherlands, a law has recently been enacted which gives patients the option of consenting or refusing donation of their own accord, or of leaving the decision to surviving relatives.

In passing, it is also important to note that the current donor card system in the UK may not cover limb transplants. The card reads:

- I request that after my death
- A. any part of my body be used for the treatment of others [tick box], or
  - B. my kidneys [tick box], corneas [tick box], heart [tick box], lungs [tick box], liver [tick box], pancreas [tick box] be used for transplantation.

The donor could be excused for thinking that the list under B covers all parts of the body which can be donated. If so, then ticking A would not imply consent to donating limbs.

We have seen that the law gives an unusual level of power to relatives of organ donors, and that this may be linked to feelings about bodily integrity of the deceased. But there is another possibility, which raises an argument from unnaturalness. Is there a lingering sense among the Western general public that transplantation is somehow unnatural and wrong? This is a view which certainly persists in other cultures such as Japan.<sup>32</sup>

All medical intervention is unnatural in that it constitutes interference with the natural order, although it is perfectly natural in the sense that we are ourselves part of that order.<sup>33</sup> (It may be that the argument from unnaturalness fulfills our need to maintain boundaries against which our choices have value;<sup>34</sup> but this says nothing about where the boundaries should be set.) One argument in favour of xenotransplants has been that all transplants are unnatural, and may affect our sense of bodily integrity, but that our hu-

man identity is not wrapped up in any of our organs. "If the essence of humanity is seen as a capacity to transcend their level of organic existence, then a person's sense of identity should not, in theory, be threatened by a transfer of organs across species boundaries," the Nuffield Council Working Party on Xenografts argued.<sup>35</sup>

If this is true of non-human organs, then *a fortiori* it should be true of any human transplant, whether of kidney, limb, or brain tissue. Yet there are two grounds for doubting whether it is true of human transplants. The first is the empirical evidence from transplant recipients, many of whom do report feeling disturbed at the sense of "otherness" of part of a dead person's body in their own.<sup>36</sup> In principle, at least, this could be controlled through psychiatric testing and counseling of recipients. The more challenging question is philosophical: whether some organs, such as the hand, represent personal identity in a way that other organs do not. This leads into a third set of considerations, concerning personal identity.

Opponents of brain tissue transplants often fear that the procedure alters the recipient's identity in a profoundly problematic way—so that the person who gave consent to receiving the tissue is no longer the same person after the transplant.<sup>37,38</sup> Similarly, we need to consider the wider function of the hand in relation to identity, as an instrument of physical intimacy, of contact with others, of consummate skill in artists and musicians, of agency itself—as witness the use of "hand" to represent agency in such phrases as "the hand of Fate," "by his own hand," "the hand of God." The hand plays an unrivaled part in both shaping and standing for the story of both the recipient and the donor, in representing agency, and our language reflects this role.

It might be argued that hand allografts entail the transposition of an organ with personal qualities from one person to another. This goes beyond the issue of the hand's visibility, though that too is an issue. "It may not be easy to live with a transplanted hand, which, unlike other common transplants, remains constantly in full view"<sup>39</sup>—a constant threat to the recipient's sense of his or her own psychological wholeness, arguably outweighing the physical wholeness for which the transplant was sought in the first place. An artificial hand or limb might arguably have the same effect, but on the other hand, there may be a crucial psychological difference. The recipient is not expected to believe that the artificial limb is his or her own, or another person's. There are no personal qualities to be transposed from one to another.

Personal identity, like bodily integrity, has a symbolic character: a person is not only a physical unity, but also a symbolic unity, presented towards others. The French philosopher Ricoeur calls this second notion of identity *ipse*, distinguishing it from the spatiotemporal *idem*.<sup>40</sup> Personal identity as *ipse* is created through interpersonal relations, built upon social practices and shared Stories.<sup>41</sup> This kind of identity is not spiritual: it is embodied. Emotively expressive parts of the body, like the face and hand, represent this identity and the relationships with others which are implied in it. If such



body parts are inserted into a completely different context, personal identity is at stake, and so are the interpersonal relationships connected with it.

Likewise, it may be conceivable that the intimacy which the hand can express is transformed as a result of transplantation, necessarily having an emotional impact on those who are intimately related to both donor and recipient. It is indeed unsettling to think that the hand with which one has once been intimate may now stroke another body. Even more than the issue of bodily integrity, the issue of personal identity seems to require extensive communication with close relatives in the case of limb transplantation. But is this enough? Perhaps what we really want to say is that the strangeness of hand transplants has nothing to do with their "experimental" status, or with the "yuck" factor, but with all that the hand represents. The hand occupies a privileged position, as the expression of both agency and intimacy—of our self and our relation to others.

Yet what is so morally special about intimacy? After all, someone like John Harris might argue, having someone to be intimate with is just a form of privilege, like having children. (Harris does not think we should give preference in allocating scarce resources of organs to those who have dependent children.)<sup>42</sup> One of us has argued elsewhere<sup>43</sup> that this is to view children merely as a consumer good, as a possession; the similar point here is that a view like Harris's is impoverished, and an inaccurate representation of how we come to be agents in the first place. It is through social contact, including the contacts of intimacy, that we become moral agents, on accounts which range from Aristotle's to Hegel's, and on into modern narrative, communitarian, feminist, and hermeneutic perspectives. This gives intimacy a claim of precedence on our moral judgment. To the extent that the hand symbolises intimacy, it also gives the hand a special status.

The issues raised in this second section have been less standard and more speculative; or perhaps it is more accurate to say that they have less to do with principlist bioethics and more to do with a narrative or hermeneutic style of ethics, which focuses on the construction and symbolic representation of identity. What conclusions do they suggest?

1. *Symbolic importance of the donor's bodily integrity*: It is difficult to see that limb donation offends against the symbolic importance of bodily integrity any more than does soft tissue donation; the only difference is that it is more visible. However, it is by no means clear that the donor card system includes limbs, and there might be a valid challenge to any presumed consent from relatives. In law, at least, limb transplants might in fact be wrong to perform, without clear and unambiguous consent from the donor.
2. *The argument from unnaturalness*: This, too, appears to fail. All transplants are unnatural; and what is unnatural is neither good nor bad, merely unnatural. So there is no objection to limb transplants on grounds of unnat-

uralness. The effect of this, however, is merely to confirm our initial hypothesis that limb transplants are not *prima facie* wrong to perform, rather than to provide a positive justification for them.

3. *Personal identity and intimacy*: Although these are the most abstract and perhaps speculative grounds for doubting the rightness of hand transplants, they are rooted in a view of human agency which has long historical roots and active current offshoots. The hand, as an expression of both agency and intimacy, occupies a different place in our moral sensibility than internal organs. Again, this is not a reason for absolutely prohibiting hand transplants, if those intimate with both donor and recipient consent, but it is a reason for thinking that the decision is not down to the individual donor or recipient alone.

## CONCLUSION

Is it right to perform limb transplants, and in particular hand allografts? Several of our six criteria merely ratify our initial hypothesis that it is at least not wrong to do so. Two—bodily integrity and intimacy—cast rather more doubt on our hypothesis that limb transplant is not forbidden. Overall, we do not rule out hand allograft *a priori*: transplantation may be consistent with respect for the bodily integrity of both donor and recipient, and the recipient may be able to integrate the new limb into his or her personal identity in a satisfactory way. This will, however, require a great deal of effort from all involved, including family members of both donor and recipient. Our discussion shows that limb transplants are not ethically straightforward: rather, they pose deep ethical dilemmas about autonomy and identity, which certainly cannot be solved by concentrating only on professional standards of competence.

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