## Section 9-k

# Quality of Life in Hand Transplant Patients

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## Introduction

The concept of quality of life is above all a subjective notion, even if it can be made objective using general or dependence scales such as those used in physical therapy. It is also possible to evaluate quality of life before hand transplantation using psychological interviews in order to identify and discuss important issues with the future recipient. The issues involved in hand transplantation are nonetheless quite different from those concerning internal organs: the hands are a part of the body that is always visible to the transplant patient; the hand (sor hands) of a cadaver at the end of the recipient's arm is permanent evidence of the presence of another person, of a "stranger"; the recipient only recovers use of the hand(s) after several months, according to the progress he made during reeducation and the regeneration of the nerves; and finally, the hands are important on both a narcissistic and a relational level. Moreover, hand transplantation is not really essential for the survival of the patient though, as we shall see, it might seem to be in the minds of certain patients.

The first hand transplant, involving only one hand, took place in 1998. The experiment ended in failure, after about 2 years following the operation because of the recipient's intolerance of certain risks linked to taking anti-rejection drugs for life, namely, increased susceptibility to infection and cancer. This first transplant recipient thus found a surgeon willing to amputate the transplanted hand, which in fact had been presenting signs of rejection for several months on account of the patient's refusal to take the immunosuppressive drugs.

At the conclusion of this first transplant, the French National Ethics Committee, after consulting several members of the operating team, decided in favour of hand transplantation but only in the case of bilateral transplants. In the case of a unilateral transplant, the improvement in quality of life did not seem sufficient when weighed against the drawbacks of immunosuppressive drugs and the amount of reeducation required in order to recover motor functions and sensitivity. It was in this context that the first bilateral hand transplant took place on January 12, 2000.

In order to better evaluate posttransplant quality of life, we conducted a number of open-ended or semi-directed interviews both before and after the operation. We have grouped together the topics explored in these those interviews under four major headings: motivation; the mourning of the lost hands; the patient's personality; the patient's and family circle.

## Motivation

What motivates the patient to seek a hand transplant, instead of making do with a prosthesis or the stumps? This question can be addressed in several ways.

### *Conscious Versus Unconscious Motivation*

The patient's spontaneous discourse gives easy access to his conscious motivation. The following elements are typically mentioned: the desire to recover motor functions beyond the plierpliers function of the thumb and index finger; the wish to be able to modulate the force that is developed in the hands and fingers, which can be quite difficult with prostheses; the desire to perform ordinary daily activities without help (bathing, for example); recovering sensitivity for physical contact with family members; and driving a car, and working, etc. Yet despite all these good reasons advanced by the patient, we must not lose sight of certain ambiguities which that point to a darker component of the desire to undergo hand transplantation. Hence one candidate, for example, a well-known former mine clearer who had lost his hands while on assignment, complained that now he could only work as an instructor of younger mine clearers, and wished to have hands in order to come back to the service in a more concrete way! We can assume in this example that the destructive impulse is very much at work in the request the patient had formulated in a rather naïve way, but which that nonetheless attests to his attraction for situations of repeated risk.

### *Narcissistic and Functional Dimensions*

The motivations mentioned in the preceding section refer to the functional dimension. Despite the improvement in prostheses, they cannot for the time being offer the same benefits as those of transplanted hands brought back to life by nerve regeneration. The possibilities offered by prostheses seem inferior in matters of motility, particularly in precise movements but also in the perception of muscular force, which is partly related to sensitivity: patients with both hands amputated of both hands regularly break glasses when getting themselves something to drink; they risk hurting their children at moments of everyday physical contact; they cannot perform certain movements related to bathing, particularly with regard to parts of the body which are hidden from sight. All these difficulties are part of the handicap experienced on a daily basis by these patients. Motivation may, however, be based on more narcissistic factors: the unbearable aspect of being seen by someone else, and of seeing one's own prostheses or stumps, which reactivate a feeling of incompleteness, or even of intense worthlessness. In this case, transplanted hands are wished for not to improve the quality of everyday life, but to restore a self-image damaged by the absence of hands. Here, the future transplant patient wants to become a complete person again.

The predominance of narcissistic over functional motivations, or even the near exclusivity of narcissistic motivations in the case of a moderate handicap (when the patient has the use of one hand, or has developed a great deal of skill with prostheses or the stumps), suggest that the improvement in quality of life brought about by the transplant will be minimal, and that the risks and drawbacks of taking immunosuppressive drugs are likely to take center centre stage after the operation.

## Mourning Lost Hands

This is an important dimension to take into consideration, with the knowledge that the process of mourning lost hands, that is to say, the acceptance of having lost them, can never be complete or total, particularly because of the significant limitations encountered in daily life. If the mourning process had been perfectly completed, there would be no reason to ask for a transplant. One patient who lost his hands in 1996, and thus well before the first actual transplant operation, was in such denial about the loss that he was sure that one day medical science would allow him to have hands again, and that he would not spend the rest of his life with prostheses. Though future events proved him right, his unshakable conviction, which could have appeared to be the sign of madness in 1996, attested to the unbearable aspect of a life without hands, and to an insurmountable kind of grief. In this respect, and for this particular patient, the hand transplant did not merely signify the recovery of a manual function, but was a life-or-death matter at a psychological level, even though hands are not as vital for example as, for example, the heart or the liver.

Having hands again is one thing; imagining that this will resolve all of life's problems is quite another. It thus becomes important to understand as fully as possible what the patient expects from having functioning hands again. If, in fact, expectations are too far from what is possible in reality (never having relational or professional problems again, after the transplant, when, in fact, the individual has always had these kinds of problems), the candidate runs the risk of a posttransplant disappointment which that no surgical procedure can prevent. We should, nonetheless, mention that currently, transplant patients, because of their small number, have obtained a narcissistic benefit related to the exceptional nature of their status, which has allowed them to change certain things in their lives which are not directly related to functional recovery. Yet, the transplantation of hands changes the patient's body in a radical way; he does not get his own hands back (we say "he" because all transplanted patients thus far have been men), nor does he return to a previous state. The recipient has to make the donor's hands his own, and, even with the recovery of motor functions and sensitivity, these hands are forever present before the patient's eyes, and they retain morphological characteristics which that are not necessarily similar to his own (skin color, a potentially different pilosity, finger shape). We have been able to observed the re-emergence at difficult points in the patient's life, of issues related to the donor's hands, which the patient was unable to process completely, and which reactivate a feeling of strangeness or of the incomplete integration of the transplants. This can take the form of anxiety, or dissatisfaction about a morphological detail; most of the time, these feelings are not evoked in the interviews.

### The Patient's Personality

In a more general way, the patient's personality impacts his posttransplant quality of life. Certain factors are favourable;, others are rather unfavourable. Thus, as in the case of organ transplants, compliance with the drug regimen is a predictor of the persistence of a satisfactory quality of life. This compliance is in part related to a kind of mental flexibility, which allows the patient to better accept the negative aspects of experiencing a high level of dependence during the first months. A rigid personality, on the other hand, is likely to have trouble tolerating the inevitable degree of uncertainty (the risk of rejecting the transplant rejection, for example) and the necessary period of regression during the first weeks following the transplant operation: not only are the transplanted hands not yet functional, but, moreover, all the skills acquired using the stumps or the prostheses have been lost. When it comes to eating, washing, or even scratching himself, the patient finds himself in a state of total dependence. It thus becomes quite important to talk with the preoperative patient about the period which that followed the loss of his hands, because the degree of dependence in the postoperative state is comparable. This, of course, revives the initial trauma, which the patient's psyche dealt with in a more or less satisfactory way.

### The Patient's Family Circle

The hands are also highly charged with meaning in the human being's imagination: this came across more or less clearly in the discourse of the patients or of their families. What, for example, did the donor's hands do before his death, during moments of intimacy? The patient's ability to integrate the transplants is also dependent on the reaction of the close family circle, which could display feelings of rejection, of disgust or worry, or, on the other hand, could be quite happy for the patient and give him vital support in accepting the transplant. Postoperative quality of life thus also depends on the family circle's ability to accept the transplant.

## Conclusion

In the end, as we have tried to show in this article, patients receiving hand transplants have a high level of satisfaction, once the critical period of dependence, with the initial absence of motor

functions and sensitivity, has passed. We must, nonetheless, keep in mind that these patients were particularly motivated for setting off on this kind of adventure. The deep feeling of satisfaction which that patients express several years after the transplant operation is not just that of having functioning hands again, but of having begun a new life.