The psychological challenge of paediatric organ transplantation : gift and incorporation

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Abstract

The specific feature of organ transplantation is the confrontation of the patient with a body part not being his own and coming from somebody else. Thus the psychological challenge of transplantation will be the *gift* and *incorporation* of the graft.

The given organ confronts the patients with mental manifestations related to emotions of grieving and guilt, most constantly directed to the donor himself. It can also cause a fantastical imagination related to the idea of having to some extent inherited the character of the donor. This very special *gift relationship* has to be questioned, as it can be interpreted in terms of a *tyranny of the dept*. A dept the recipient will never be able to reimburse.

In this context the contribution of sociological knowledge is determining. It makes it possible to reconsider the problem, and to discover that a gift relationship offers transplant patients much vaster possibilities than a materialistic conception of the gift, based on the dept, would do. (Acta gastroenterol. belg., **2004**, 67, **184-187**).

Key words : paediatric ; organ transplantation ; psychological ; psychiatric ; incorporation.

Introduction

The fact that the transplantation of an organ does mentally affect the recipient as well as his family has since long been known not only to psychologists and psychiatrists used to work in this field, but also to people of the medical sector. There is evidence for it in hundreds of articles bearing in their title key words such as "psychological" or "psychiatric". Nevertheless, a careful examination of these publications shows that they focus on the interest for the patients' psychiatric evaluation, particularly for selection purposes during pre-transplantation period. In addition, they show a major interest for the patients' quality of life regarding their psychosocial health during post-transplantation period. In other words, the patients' future on the socio-professional as well as family and scholastic level is still subject to numerous studies[1], whereas the intra-psychical effects of transplantation have given occasion to only a few publications[2]. This is the case for both, French-language[3] and English-language publications, whilst research work on children and transplantation is even sparser[4].

In the following, we will review these questions carefully, particularly the two most specific stakes of organ transplantation. According to us, these two are above all the problem of the *gift* and *incorporation* of the graft. Since the specific feature of transplantation is the confrontation of the patient with an organ not being his own, an organ that comes from somebody else. This is true especially when the organ is from a cadaveric donor. In the following we will deal with this specific problem, since our experience with living related donors is too restricted.

The mental incorporation of the transplant

The transplantation of an organ confronts patients with mental manifestations related to emotions of grieving and guilt. We must point out that when the patient is a child, the parents are the ones who on behalf of their child – being usually of very young age – experience these bewildering phenomena. At the same time, we have to make clear, that these phenomena are "normal" insofar as they arise in most cases. More important though is that they favour and even enable the necessary mental work of incorporation of the transplant.

The most constant manifestations of grief are directly linked to the donor himself. How can a person benefiting by someone's death actually not be affected by it and by the despair of his or her family ? Most of the time, the recipient's family shows a sincere solidarity with the anonymous family, though often tinged with feelings of guilt.

Those feelings of guilt linked to the donor often arise during the period of pre-transplantation. The promising waiting for a liver during this long period is actually equivalent to the waiting for the death of someone else.

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[1] Following is a selection of authors dealing with the psychosocial evaluation of patients : Kuhn W.F.. *et al.* (1988), Freeman A. *et al.* (1992), Leverson J.L. *et al.* (1993), Twillman R.K. *et al.* (1993), Olbrisch M.E. *et al.* (1995), Shapiro P.A. *et al.* (1995), Chacko R.C. *et al.* (1996).

[2] See particularly the pioneers, among which Muslin H.L. (1971), Basch S.H. (1973) and Castelnuovo-Tedesco P. (1973), as well as a French article by Crombez J.C., Lefèbvre P. (1973) regularly quoted.

[3] Besides the pioneers mentioned above, see also : Becker D. *et al.* (1978), Vaysse J. (1992), Consoli, S.M., Baudin M.L. (1994), Schwering K.L. (1999).

[4] Following are some characteristic references concerning psychological effects of organ transplantations with children and adolescents for the last 30 years : Bernstein D.M. (1971), Gold L.M. *et al.* (1986), Carton M., Defert P. (1987), Serrano J.A. *et al.* (1987), Bradford R. (1990), Stewart S.M. *et al.* (1991), Sexson S., Rubenow J. (1992), Raimbault G. (1992), Schwering K.L. (1993) and (2001).

[5] See among others Godbout J. (1992) as well as Caillé A. (2000).

The parents experience themselves as being the evil eye accelerating the death of an anonymous donor with their guilty hopes.

This guilt increases when it comes to the actual transplantation, since the pleasure caused by a successful surgery, though being legitimate, is mingled with shame and reproach : how can somebody actually feel relieved and be full of hope while the person to whom he or she owes all this just died.

An additional level of guilt consciousness is linked to the attempt of mentally incorporate the unfamiliar transplant. This process requires a progressive appropriation of the organ by the recipient, since it corresponds to an imaginary expropriation of the donor by eliminating him of one's memory. Now, should there be a way to free oneself of this guilt of oblivion, then it is by preserving the memory of the deceased person and to allow the organ to continue to be a kind of "living" representative. It is no wonder that some parents, even after years, consider that the donor is still surviving in their child and that the mourning parents would probably be happy to find out that the death of their child enabled another one to live.

The organ transplantation often causes a fantastical imagination relating to the donor and his family, although patients usually do not admit it because they fear to appear ridiculous. Those fantasies base on the snatches of information the patients have been able to glean with the medical staff. The nationality of the donor, the causes of the accident, the sex as well as the age of the donor are reference points likely to start a not always unproblematic process of identification. Because to identify oneself to a donor belonging possibly to the opposite sex, being of another age or another culture is not evident. This will in any case have a certain influence on the capacity to proceed to a satisfying mental incorporation.

Children asking questions about the donor are rare. The younger they are, the less they are concerned by this kind of questions, at least in a first time. The parents take over the job showing sometimes flights of fantasies, which are as impressive as those observed with adult transplant patients. Let us give the following example :

Michel, two years old at the time of his liver transplantion, came back to hospital two years later for a one-week post-transplant control. He is well ; the medical examination confirms a nice development as for his liver. A discussion with his mother, stemming from the middle-class, reveals no particular psychological elements. A couple of hours before they leave, we meet both in the corridor. At this point, the mother starts to report of strange sequences of gastro-oesophageal reflux recurring cyclically : they appear approximately every month. The doctors have found everything to be all right and do not seem worried. Michel's mother is reassured. However, a question pierces her : she was told that her son had received the liver of a young girl aged about 10 years at the time of the organ transplant. If the girl were still living, she would now be about 12 years old …. and in age to have her periods. Could it then be that her son's monthly reflux has anything to do with it ?

What an extraordinary story, so much it exceeds the limits of ratio ! Although spectacular, this little story is nevertheless representative for the mental work of fantasizing. From our point of view, this cannot simply be defined an odd behaviour. Fantasizing is the parents' mental work done in order to think the unthinkable, in order to honour the transplant's memory, which is a piece of a person's, of a family's history rather than merely a piece of flesh.

However, the imaginary survival of a donor can sometimes become an obsession and spoil the feelings for the real child. In this case, the giving child changes into an evil double, into a bad genius escaping from its "hepatic lamp" in order to possess the other child. These symptoms however are usually short-lived. They come up in connection with the changes transplant children experience during the post-transplant period. Relieved of the negative effects of the illness, the childs' behaviour after the operation sometimes changes suddenly : joie de vivre, vivacity, activity, all positive indications delighting the parents. Nevertheless, when it comes to claims of independence, to behaviour of opposition and even to aggressive outbursts, then a feeling of worrying oddness sometimes submerges the parents. The child they thought to know in details is suddenly perceived a different one. Independent of their socio-professional background, parents then start to question themselves by updating old animistic remains : and if the child had taken on the donor's personality ?

The following example shall illustrate the above mentioned. It occurred during a consultation with a mother and her six-year-old boy one year after his liver transplantation :

When it comes to mention Robert's every day life, his mother says : "he's fine, he is as he always used to be …though, he is much more nervous than he was before the transplant," she tells us. Actually, Robert is often choleric and even frankly tyrannical with his mother. If she does not satisfy his every whim, he goes wild, can hardly control himself, shouts, screams and tries to beat her.

She further explains : "Robert is not the same anymore ; he has changed …strange. Before the transplantation he was shy, a child who wouldn't look at you when talking to him". I can feel how helpless this mother is towards her boy. She cannot make him out ; they drifted apart from each other. The mother finally tells me her point of view, shared with her husband and which explains everything to them : The donor was probably a nervous child and maybe aggressive as well.

The fantasy to have inherited the choleric character of the donor may sound extravagant, but it is far from being an isolated case. Other parents also told us about similar fantasies, independently from their socio-cultural level. We must nevertheless state that parents rarely pronounce

these thoughts during the first meetings. A deep confidence must first be build up, before they start expressing things they often are ashamed of.

The problem of gift relationship

Although having already pointed out to the challenges concerning the donor, we still have to question ourselves on the implication of a *gift relationship* within this context. Since, when skimming through the literature one can notice that for many authors this relation may present a serious obstacle on the way to a successful appropriation of the graft. Even if only imaginary, the relationship between the donor and the recipient would actually result in a dept, for the latter never reimbursable. In terms of transplantation this would explain the so-called "tyranny of the dept".

This somewhat pessimistic view is not only theory. We already have mentioned the patients' feelings of guilt with respect to the donor. Moreover, aren't the ritual commemorations of the donor on the anniversary of transplantation tangible signs for this insolvable and tyrannical dept ? The hypothesis should be taken seriously indeed. This however, requires understanding the hidden forces of a gift relationship, in fact far beyond any intuitive and spontaneous notion of the fact to "give". In order to do so and by referring to sociological knowledge, we will briefly evoke the concepts of gift as we have inherited them from our occidental societies.

Thus, the Christian tradition of gift is linked to qualities such as generosity, gratuity and unselfishness. In this concept, the donor is supposed to content himself with the action itself without expecting any return favour. Moreover, he is supposed not to feel any satisfaction to have acted altruistically. However, such a conception of a "pure gift" quickly ends to the idea of the impossible nature of the "real gift" which by definition could only be of divine essence. However, with the beginning of the modern age it is precisely the idea of the divine that is scrutinized, which among others coincides with the increase in power of economic values. The gift, also notion of relation, is progressively substituted by the market, again notion of the impersonal exchange. Accordingly, the difficulty of the "real" gift, already existing in the Christian tradition, has intensified ; this time however, due to the introduction of an economical term : the notion of dept, that we have already evoked. The gift – being in fact only a loan – would automatically remain a dept in front of the donor having to be settled somehow.

As for the gift, both the Christian tradition and the modern age are at a dead-end : the "real" gift seems impossible. Some sociologists[6] however, following the work of Marcel Mauss, suggest a modern concept of the gift and relaunch this problem in an interesting way. Their concept questions the materialistic interpretation of the gift. Stemming from the modern age, this materialistic interpretation too often reduces the gift to the *given object*, thus becoming purely an economic object, whilst the gift relationship and the social actors in its centre disappear.

The modern concept consists in promoting again the gift in its dimension of bond. In this context, the given object or item is not exempt from a utilitarian or economic value. But in the first place it has to be in service of a value of bond by which it is transcended. In other words, the gift arises from the fragile balance between the good and the bond, between the gift as an object and the gift relationship. The scales are constantly in danger to unbalance, particularly when they tip too much to the side of the object. The latter in fact risks suffocating the relationship by its materialistic omnipresence. Thus, a "huge present" worth a lot of money will be admired for its economical value and less for its symbolic one, whereas a "small present", carefully chosen, will symbolize the relationship's strength and authenticity.

As regards the transplantation, the weight of the object, that is to say the utilitarian and materialistic value of the graft is considerable. Without the latter, death would be unavoidable. It therefore is no wonder that it favours a materialistic conception of the gift, thus letting the "gift scales" tip to the received object, rather than to the relationship arising from it. Some aspects of this conception precisely reappear in the idea of a never-ending dept to the recipient. In fact, the notion of dept, in this case always linked to the organ and its value, is an invaluable "gift of life" remaining forever "reimbursable".

However, can we say that all patients experience it this way ? Do they endlessly suffer from the alleged dept ? Our clinical experience enables us to answer in the negative. This however is not the most important. What we are rather interested in is to analyse the characteristics of the gift relationship, in order to find out why the notion of dept in the economical sense of the word is not relevant in the patients' situation. The answer is that the patients' *gift scales*, as we called it earlier, tip resolutely to the side of *relationship* rather than to the side of *object*. They therefore do not perceive the organ at the first place as a precious *good* useful to their survival and the reliable functioning of their organism, as a pole of immanence where the object's worth lies chiefly in itself. It is perceived in its dimension of bond, pole of transcendence where the object has also a value as a symbol of another reality, in this case a relational reality.

Our experience with parents of transplant children enabled us to spot the facts mentioned above. As soon as the parents got over the post-surgical worries ("was the surgery successful ; does the liver function ; is my child recovering ?"), many of them started to desist from the object (the graft and its functioning, the body of their child, etc.) and to directing their thoughts to the donor. We have indeed quite often observed the parents' propensity to imagine the act of donation, in other words to construct a kind of *myth of the origins* concentrating

on the precise moment where the organ left its original owner.

The interest is focused here on the encounter of a donor and a recipient rather than on the exchange of the object. In this specific context, the organ in its materiality obviously wears off for the benefit of the relationship and the persons meeting each other – even if this remains in the sphere of the imaginary. Thus, this relationship is the total opposite of a trade relation – from our point of view a context specific to the dept – where only the object and its payment or restitution counts.

Therefore, our hypothesis is that the patients abusing the mechanisms of denial are more likely to develop a materialistic conception of the gift and to slip into the infernal spiral of dept. That is to say those patients who play down or even deny the psychological significance of the surgical treatment, making comments such as "everything is fine" or "I never think of the donor". Another typical manifestation of denial is the use of mechanical metaphors like "the liver is just a spare part like one for the car", or "I'm happy, I got a liver from the organ bank".

In order to clarify our hypothesis, we only need to draw conclusions from those metaphors, and see the results. That is : nobody can pay a spare-part with a grateful thank or a sincere interest for the mechanic's worries ; no need to say that this goes for the banker as well ! If the customer is unable to settle his dept, he will obviously be hounded by his creditors … and they will not cease to haunt his nights. Here starts the tyranny not of the gift but of a kind of relation where the gift precisely does not have his space. In other words, as from our point of view, these kinds of patients have not benefited of a gift relationship, they have kind of missed the encounter with the donor and have preferred the appointment with the banker or the mechanic.

In a gift relationship, on the contrary, the problem of dept is of a different nature. A gift relationship leads to a spiral of transformation where the initial gift is followed by another one, which will be different from the first one, perhaps even passed on to someone else. What happens with a present for example ? Nobody would imagine offering the same book or the same bottle of wine received a couple of months earlier. Understandably, the initial donor would have a hard time of it. With respect to the fact of giving to someone else instead of giving to the original donor, let us take the example of the master and his student. The latter will transmit the gift of knowledge to other students and by doing so will honour both, the memory and the initial gift of his master. Consequently, the notion of gift perfectly puts up with the idea of a community of donors and recipients, which interactions transcends the image of a relationship set in two persons, in such a way that the return of the gift can pass through a third party and even address it.

Consequently, like the student remembers his master, the transplant patients could feel an "I owe him so much" implying a serene gratitude rather than a torturing guilt. They could from then on act like the volunteers cited by the sociologists, and who estimated having received so much from their life, that they wished to give to others. That means, they could do without returning something to their initial benefactors. In other words, the gift relationship offers transplant patients much vaster possibilities and liberties than a too materialistic conception of the gift would do. However, the mental work resulting from organ transplantation would for both, the patients and their parents imply the achievement of a mental incorporation of the organ, of course, but one of a *given* organ *received as a gift*. This conclusion opens onto another debate related to the relevant legislation and methods of organ procurement. Some of them, considering the moment of gift an obstacle, try to eliminate it.

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