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# Live Donor Kidney Transplants: Psychological Aspects of the Donor-Receiver Relationship

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## 1. Introduction

A live donor kidney transplant is a therapeutic option for treating chronic kidney diseases widely used in several countries, frequently due to the scarcity of donors who have died. As is the case in non-living donor kidney transplants, the patient who is submitted to this type of surgery has already undergone a long period of chronic illness and dialytic treatment, which causes both physical and emotional damage. Thus, the suffering produced by the irreversible chronic illness associated with the anguish of waiting for a donor for the transplant affects not only the patient, but also his or her family and all those involved.

The live donor is usually someone who is known to and emotionally involved with the receiver. The choice of the donor is a complex task, as it involves a series of clinical evaluations which include, besides the physical, laboratory, immunological and image examinations, the evaluation of the emotional conditions and motivation of the candidate to be a donor before undergoing the operation (Burroughs et al 2003; Dew, 1997).

Thus, in donating organs with a live donor there are apparent and latent psychological aspects which affect the decision to donate and that are closely related to the psychological dynamics of the donor and his or her relationship with the receiver (Lima et al., 2006). For the donor, the decision can be very difficult, as the obvious reasons for the donation are predominantly altruistic and aim at the receiver being able to stop having dialysis and have an improved condition of life. Nevertheless, the donation involves self-mutilation and evokes the fear of death, which occurs in the donor through the apprehension of not coming out of anesthesia or of being impaired after the donation (Jordan et al., 2004).

Thus, regarding the reality of the suffering caused by chronic kidney disease, the transplant is often the only possibility of having a life with greater quality. Therefore, the possibility of having a transplant generates expectations both in patients and all the family group. As a result, donating organs with a live donor can cause ambivalent and contradictory feelings in both the donor and the receiver. That is why being aware of the psychological aspects of the donor and receiver is important for the team to deal better with the patient and his or her family, and for planning the psychosocial interventions required throughout the transplant process (Santos & Massarollo, 2005).

Thus, the present chapter aims to present a review of the literature about the experience of live donor kidney transplants from the point of view of donors and receivers, seeking to understand some of the psychological aspects involved in the process of donating organs. Therefore, first the psychological effects of live donor kidney transplants will be looked at, and then the psychological aspects of the donation and donor-receiver relationship will be discussed.

## **2. Live donor transplants and their psychological effects**

Live donor transplants can be performed with blood relations and members of the same family up to the fourth degree, although the donors are usually close relatives. The operation is usually performed by choice with the donor available or, preferably, with the one with best compatibility concerning the antigens of the HLA complex (Manfro & Carvalhal, 2006).

The option for the transplant usually arises from the chronically ill person seeking a better quality of life. Upon opting for the transplant, the patient needs to enroll in a transplant center, where he or she undergoes a process of evaluation and preparation. The pre-transplant evaluation of both receivers and live donors is extensive and detailed. It aims to check the health conditions of both and the presence of any co-morbidity which might lead to an adverse result in the transplant. During this period, the patient undergoes several examinations and is sent to different specialists, which frequently also includes a psychological examination. At the end, and provided that there are no medical contraindications, the patient with the live donor has his or her operation scheduled and the patient with the dead donor is enrolled on the waiting list for the organ (Lage & Monteiro, 2007; Mendes & Shiratori, 2002).

Although the transplant process creates a series of emotions coming from the suffering of the patient who has a chronic disease, the doubts and fear related to the transplant and the apprehension of submitting a healthy person – possible donor – to a very large operation, on the other hand there is the hope that someone close can be the compatible donor. There is the euphoria and ecstasy because the disease can be treated - the transplant - and, simultaneously there is the despair and fear concerning the result of the procedure. Patients and those close to them are continually confronting finiteness and death, which launches them into an emotional spiral which causes accentuated psychological wear.

In the case of live donor organ transplants, the fact of injuring a physically healthy person to benefit another is an aspect which merits care and discussion among all those involved: patient, family and health team. Although it is small, there is a risk of death for the organ donor. He or she will also undergo a period of intense stress due to the operation, and will have to deal with the loss of a vital organ. The patient, on the other hand, can also undergo states of intense suffering and will have to adapt to his or her new condition of transplantee, which includes limitations in his or her daily life and care with food, medicaments, etc. In this context, reactive psychopathological states can appear in both the patient and the donor, which can be unleashed by the disease, the clinical examinations, the hospitalization and the transplant.

According to Garcia, Souza and Holanda (2005), in the psychological evaluation of the candidate to be a donor, it is important to check the feelings and beliefs related to the donation, provide clarification concerning the surgical process and recovery, and prepare him or her for a possible rejection of the graft by the receiver. The decision to be a donor

encompasses, besides the family pressures and expectations, emotional issues, ambivalence in wanting and not wanting to donate and the fears and conflicts unleashed by the situation (Quintana & Muller, 2006).

Frequently, in the pre-transplant period the patient expresses his or her desire to be cured of the disease (Walter et al. 2007). He or she often believes that the transplant is an opportunity to be reborn and have a life equal to the one enjoyed before falling ill. It is not rare, that upon being informed about the characteristics of the transplant and the limitations and care entailed for the rest of his or her life, the patient and family react with a selective shield, i.e., only storing some of the information provided by the team and thereby preserving the idea of a total cure for his or her problem. Together with this there is the great quantity of information which the patient and his or her family receive about the procedure. Sometimes, it is information which is difficult to be understood, technical names hitherto unknown, which makes understanding difficult because until then it was not part of their daily lives.

Some patients are proactive concerning the disease and seek information from the health team, in books, on the Internet and from other patients about the disease and the transplant. On the other hand, there are those who avoid asking about the disease or who use rationalization and simplification of the process to handle the anxiety generated by the situation. In any case, it is known that information is a key element for the patient to have a realistic perception of the disease and, consequently, be able to face the transplant in a suitable manner. Avoidance and flight are inappropriate strategies for dealing with these situations, as they defer being aware of the disease and can affect adhering to the medical treatment prescribed.

Regarding the selection of the donor, frequently the patient's family, upon arriving at the doctor to speak about the matter, has already chosen this person due to its dynamics of functioning and the roles which each of the members can assume. Upon other occasions, the potential donor is chosen in an arbitrary way, by means of the compatibility of the blood type discovered by several members undergoing the relevant examination. Frequently, nevertheless, the potential donor is a volunteer in this process, i.e., it is someone who is motivated to give his or her kidney to the person who is close that is suffering. This occurs regardless of the time of dialytic treatment of the receiver and the gravity of his or her situation. The patient rarely requests the organ from somebody who is close. The donor is usually one of the parents, children, spouses, or a person with a strong affective link with the receiver and attained indirectly by his or her disease (Ismael, 2005).

Some patients can come to show the team clearly their fear of bringing losses to the donor, and owing the donor something in exchange for the organ. The conflicts, doubts and even the pressures of which the donor can be the target are exposed in the psychological evaluation course (Fukunishi et al. 2002; Walter et al., 2002).

In recent years there has been much discussion about the ethical issues involved in using psychosocial criteria in evaluating candidates for transplants, especially of vital organs for the survival of the individual. If on one hand, the psychological evaluation is important for being aware of the emotional resources of the patient and family to face the process of the patient's transplant and rehabilitation, on the other hand, the identification of psychological or psychiatric disorders prior to the operation can be an indicator of risk for adhering to the ensuing treatment (Caiuby et al. 2004; Mendes & Shiratori, 2002).

Thus, there arises the conception that psychosocial factors can have a significant impact on the adaptation to the transplant and adhering to the treatment, but on the other hand it can be questioned up to what point these same criteria can be capable of preventing the indication of a patient for the procedure. It is agreed, however, that the psychological evaluation will be able to make an important contribution to helping the team to deal with the patient in the pre-, peri- and post-transplant phases, and also to viewing the patient's prognosis concerning caring for his or her health (Jordan et al., 2004).

### **3. Psychological aspects of the donation and the donor-receiver relationship**

The wait for an organ, often long, is an extremely stressing period owing to the anxiety and fear of the transplant and the possible worsening and death due to complications of the patient's state of health. The disease and its consequences, therefore, can unleash psychological disturbances and symptoms in the patient and in members of his or her family. That is why, when the receiver or donor – in the case of an organ transplant with a related live donor – is evaluated in the pre-transplant period by a mental health professional, this evaluation must include and examine some risk factors for their handling the situation and ensuing mental health, as the presence of psychiatric disorders (especially anxiety and depression), understanding and beliefs about the disease, level of schooling and socioeconomic level.

As the transplant of organs is a procedure which has great emotional impact, due to the receiver having to take as his or her own an organ which belonged to another person, some emotional conflicts can be observed in the receiver regardless of the type of donation – whether the donor is living or dead: guilt related to waiting for somebody to die to benefit, or the removal of the part of someone, in his or her benefit (Achille et al., 2007).

The concern about possible losses to the donor's health is often reported by the patients. The donation involves self-mutilation and evokes the fear of death, which appears in the donor through the apprehension of not coming out of anesthesia or of having an impaired life after the donation.

It is common for there to be difficulties in the relationship between live donors and receivers. According to Walter et al.<sup>14</sup>, the introduction of the transplant with a live donor was responsible for new and important psychological conflicts emerging in the transplant process, as for example the debt for life felt by the receiver towards the donor.

The psychological disorders are more frequent in the receivers than in the donors of organ transplants. Nevertheless, there can be differences in the significance of donating an organ such as a kidney or a liver. Whereas the kidney donor will continue his or her life with only one kidney functioning and, therefore, loses a vital organ, in donating the liver the mutilation is only temporary, as this organ is regenerated. In this respect, the donation of the kidney has much more serious implications for the donor's physical health, which can also have greater psychological implications than in donating the liver.

Currently, reactive psychiatric disorders of several degrees have been found in both receivers and donors even when the transplant is successful, without rejection of the graft or any other medical complication. This paradoxical psychiatric syndrome is often found in adult receivers, especially in those where the transplant was a related live donor, and



includes major depression, somatization disorder, adjustment disorder and conversion disorder (Caiuby, 2004).

As in any large surgical procedure, the transplant may not have the functioning expected. In these cases, when the donation was made by a living donor, the failure of the kidney transplant can cause adverse emotional reactions in the donors due to the effort having been made in vain, as anxiety, regret, depression and reduced self-esteem. In spite of positive attitudes concerning the transplant predominating, in situations of the graft not functioning it is possible to observe regret and guilt in the donor-receiver pair. For the receiver, the immediate clinical interurrences regarding the loss of the graft do not weigh so heavily as the perspective of returning to the hemodialysis machine: in it the loss of hope and the meeting with death are projected. For the donor, frequently after the operation he or she becomes of secondary importance, as all the attention is turned towards the receiver and his or her kidney function, which can cause the donor to be resentful.

Generally speaking, the studies indicate that donating a liver allows wellbeing and an increased self-esteem of the donor<sup>19,20</sup>. Attention should be paid, nevertheless, to the fact that this situation does not necessarily lead to the relationship of the receiver-donor pair being strengthened. The receiver's attention reverts to the functioning of the graft, whereas the donor has already achieved his or her function and can be forgotten in this period.

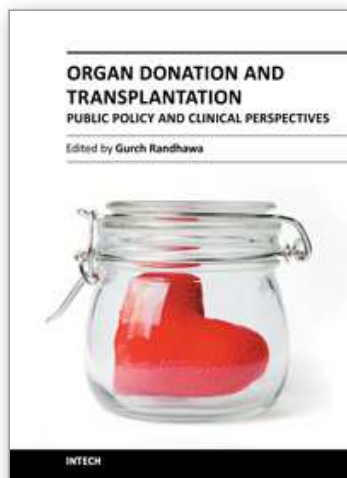
#### **4. Final considerations**

Due to that set out above, live donor kidney transplants generate great psychological impact on both the donor and the receiver, generating changes in the relationship established between them. The debt for life which the receiver will have for ever is a factor which, at the same time that it can bring him or her emotionally nearer to the donor, can also make him or her more distant owing to possible feelings of guilt for having interfered with the state of health of a healthy person.

In this respect, the evaluation of the mental health of the donor and receiver becomes of paramount importance within the pre-transplant evaluation in order to provide guidance about the aspects which interfere with the desire to donate and in the interference of the donation and transplant in the ensuing relationship of the donor-receiver pair. The psychosocial evaluation of donors (pre- and post transplant) is advocated; however, there is a paucity of data on the process and content of psychosocial evaluations (Hardeveld & Tong, 2010). There are no set standards regarding who should conduct psychosocial evaluations, whether evaluations should be mandatory, at what stage of the work-up evaluations should be conducted, at what time interval repeat evaluations should be performed and what criteria need to be met (Hardeveld & Tong, 2010). Also, there is no consensus about how the pre-transplant psychological evaluation should be done in donors and recipients. In all world, there is a lot of differences in the procedures used among different centers; in others, there is no psychological evaluation (Sajjad, Baines, Salifu & Jindal, 2007). In this sense, it is recommended that the psychosocial evaluation in kidney candidates, to examine the understanding of the candidates about the donation process, risk and benefits involved. Moreover, it will furnish greater awareness of them both, which will aid in future interventions which aim to help them in maintaining and adhering to the post-transplant treatment.

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