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## Psychopathological aspects of kidney transplantation: Efficacy of a multidisciplinary team

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### Abstract

Renal transplantation is a well established treatment for end-stage renal disease, allowing most patients to return to a satisfactory quality of life. Studies have identified many problems that may affect adaptation to the transplanted condition and post-operative compliance. The psychological implications of transplantation have important consequences even on strictly physical aspects. Organ transplantation is very challenging for the patient and acts as an intense stressor stimulus to which the patient reacts with neurotransmitter and endocrine-metabolic changes. Transplantation can result in a psychosomatic crisis that requires the patient to mobilize all bio-psychosocial resources during the process of adaptation to the new foreign organ which may result in an alteration in self-representation and identity, with possible psychopathologic repercussions. These reactions are feasible in mental disorders, *e.g.*, post-

traumatic stress disorder, adjustment disorder, and psychosomatic disorders. In organ transplantation, the fruitful collaboration between professionals with diverse scientific expertise, calls for both a guarantee for mental health and greater effectiveness in challenging treatments for a viable association between patients, family members and doctors. Integrated and multidisciplinary care should include uniform criteria and procedures for standard assessments, for patient autonomy, adherence to therapy, new coping strategies and the adoption of more appropriate lifestyles.

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**Key words:** Psychiatric consultation; Psychological care; Kidney transplantation; Therapeutic compliance; Social and family support

**Core tip:** Kidney transplantation is now an established clinical technique, although the emotional experiences and the psychological and psychopathological complications related to organ donation and transplantation should not be underestimated. Following transplantation, problems related to the physical integration of a foreign body can arise. On the one hand, the "Life-Extending" process creates a kind of symbolic rebirth with euphoric aspects, and on the other hand, the patient can develop a kind of emotional vulnerability with body image and self-representation disorders, or paranoid reactions to a panic crisis due to the presence of a foreign object (transplanted organ). In fact, the transplanted patient may experience a reactive psychopathologic process (depression, anxiety, dissociative disorder) both due to transplanted organ acceptance difficulties and immunosuppressive therapy complications. The study of psychological aspects and their evaluation using a multidisciplinary approach are important to avoid issues not adequately recognized, which can undermine the transplant success, and/or lead to psychological

distress and psychological suffering in the patient. Transplanted patient re-employment and social and family reintegration requires psychotherapeutic support to implement new coping strategies.

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## INTRODUCTION

Renal transplantation is a well-established treatment for end-stage renal disease, allowing most patients to return to a satisfactory quality of life. Advances in medical science and technology in this field are impressive. However, there are still some difficulties that limit the number of transplants performed and the positive outcomes of the interventions. In addition to the insufficient number of donated organs from deceased and living donors, a major difficulty is the result of transplant course management often exclusively medical-surgical, ignoring the close interaction between mind and body.

In recent years there has been a gradual increase in integration between medical and psychological disciplines and psychological support to patients at all stages of the transplantation and to the donor's family, which is now a fairly well-established method of intervention<sup>[1-6]</sup>. In the case of deceased organ donation, the medical-surgical process is conditioned by the death of another human being, and this raises biological, moral, religious, psychological and social questions.

On the one hand, the donation and removal of organs bring out strong feelings in the relatives of donors, such as demoralization, loneliness, pain and anguish. On the other hand, the person receiving the transplant has feelings of hope, joy, desire for life and rebirth. The inability to mourn and to accept the loss in donor relatives (usually mothers) may result in the so-called "syndrome of the hound". This is a state of mental suffering that involves some people who remain in a state of denial and in mourning, and who show an irresistible desire to know the identity of the transplanted person<sup>[7]</sup>.

In the case of a living donor, the family takes on the responsibility of donation. Feelings of guilt, any need of repair and symbiotic relationships between family members are sometimes reasons that prevent the specialist from granting suitability for transplantation. Psychotherapy has a very important function as it helps the patient to deal with reality, giving a different meaning to the motivations that lead to transplantation.

With regard to the psychological aspects of the recipient with chronic kidney disease, kidney transplantation, although it represents for many patients the "liberation" from

the restrictions imposed by the "dialysis addiction", it can also arouse doubts, anxiety and distress which can become, in the post-operative period, fear of infections, worries of rejection and of the unpredictable outcome. In fact, transplant patients can develop emotional distress and affective disorders, such as anxiety and depression, associated with a compromised quality of life<sup>[8-12]</sup>.

Transplantation can also result in a psychosomatic crisis that requires the patient to mobilize all their bio-psychosocial resources during the process of adaptation to the new foreign organ which may result in an alteration in self-representation and identity, with possible psychopathologic repercussions<sup>[13-15]</sup>.

This article will review relevant research on the psychopathological aspects of kidney transplantation. The topics analyzed include body image, personality, post-transplant psychopathological risk, and therapeutic compliance.

## BODY IMAGE IN KIDNEY TRANSPLANTATION

The human being has a mental representation of one's body. This, as only a small part is innate, is something that is formed in early childhood, which can change during a person's lifetime and varies in health and disease. The body, therefore, is also a mentally complex construct.

In Schilder's theory (1935), organic disease is a factor of fundamental importance in the evolution and organization of our body schema. Disease in an organ can facilitate a "psychosomatic crisis", a crisis in which the somatic and the psychic aspects are of equal importance, and influence each other<sup>[16,17]</sup>.

In transplantation, if surgery rapidly restores the anatomical and physiological function, cognitive and emotional integration is required: "psychic transplantation"<sup>[10,18-20]</sup>.

In this context, the contributions from psychosomatic aspects refer to the complex task of mind reconstruction which the transplanted subject must perform in their own image. This is a difficult process of reconstruction, which allows the acceptance and psychic integration of the new organ<sup>[21-23]</sup>.

During the course of transplantation, the wholeness and unity of the body image is broken. This "Life-Extending" process can develop a kind of emotional vulnerability with body image and self-representation disorders, or paranoid reactions to a panic crisis due to the presence of a foreign object (transplanted organ). This reconstruction process is long and difficult and requires psychic integration of the transplanted organ. According to Castelnuovo-Tedesco (1981), during the organ integration process there are three stages: (1) phase of the foreign body, in which the transplanted organ as foreign can cause persecutory anxieties, or on the contrary idealization; (2) phase of partial incorporation, in which the patient begins to integrate the organ; and (3) phase of total incorporation, in which the organ is acquired automatically, therefore, spontaneous consciousness of the same is absent<sup>[18]</sup>. Therefore, following

transplantation the “foreign” organ is integrated leading to good harmonization of body image in the recipient<sup>[24-26]</sup>.

## PERSONALITY AND RECIPIENT EMOTIONAL PATTERNS

The affective profile in transplanted patients should be more extensively examined to review all aspects of their mental and emotional assessment, as the emotional pattern constitutes a critical clinical feature of these patients<sup>[27]</sup>. Receiving an organ requires the death of the donor, or at best, living donor surgery, and even if voluntary, this may be the cause of guilt fantasies expressed by transplant subjects<sup>[28,29]</sup>.

Another important aspect to be taken into consideration concerns the psychological attitudes in the stages preceding the transplant, as the patient may have “unrealistic expectations” that will be an obstacle in dealing with transplant procedures and consequences<sup>[30-32]</sup>.

Equally disappointing may be the “traumatic” discovery that the transplant did not provide a good “restitutio ad integrum”, with the onset of depressive dynamics and difficulties in accepting the therapeutic post-transplant program<sup>[33-37]</sup>.

This lack of motivation must be identified and possibly corrected before transplantation, as it can lead to rejection resulting in a waste of resources and equipment. If the patient is motivated and understands all the implications of kidney disease in the terminal phase of uremia, the patient feels a responsibility to himself, his family and hopes to improve, following transplantation, his quality of life and his own mental and physical balance<sup>[38-42]</sup>.

De Pasquale *et al.*<sup>[23]</sup> explored personality characteristics in patients undergoing renal transplantation and confirmed the hypothesis that transplantation can pose a potential risk to the patient’s psychological balance. The analyzed psychological variables showed a “hysterical personality” characterized by immaturity and self-centeredness, impulsive behavior, dependency, inferiority feelings, hypercontrol and superficial interpersonal relationships. This mental condition is well established in transplanted subjects who tend to be egocentric, dependent on caregivers and focus only on their own needs and the new physical condition, thus changing relationship quality, emotions and self-esteem.

In determining hysterical phenomenology, congenital factors as well as acquired factors related to the environment, suffering, stress and electrolyte changes (K/Ca) are important<sup>[43]</sup>. Organ transplantation is very challenging in patients and acts as an intense stressor stimulus to which the patient reacts with neurotransmitter and endocrine-metabolic changes. These reactions can result in mental disorders, *e.g.*, post-traumatic stress disorder, adjustment disorder, and psychosomatic disorders.

Pistorio *et al.*<sup>[30]</sup> investigated other personality traits which may emerge in transplant patients and found borderline personality and obsessive-compulsive personality, which are traits negatively correlated with good quality of life. They concluded that it is important to identify patients who have

shown pathologic personality traits in order to provide adequate psychologic-psychiatric support and follow-up.

## LIVING KIDNEY TRANSPLANTATION

Kidney donation from a living donor is the best solution for end-stage renal failure, both in terms of cost-effectiveness and quality of life, and has many advantages compared with cadaveric transplantation. However, medical practice has long been questioned on ethical, legal and psychological aspects related to living donation.

In this regard, it is important to remember altruistic or “Samaritan” organ donation, only allowed for kidney donation, which follows the National Bioethics Committee of April 23, 2010 and Board of Health of May 4, 2010 guidelines, in compliance with the law n. 458/67 and its implementing regulation n. 116 of April 16, 2010. The Samaritan donor’s clinical suitability evaluation follows the same procedures as recommended for standard living donation. Personality dimensions are an essential prerequisite for suitability assessment in transplantation<sup>[44,45]</sup>.

Both recipient and donor affective disorders diagnosed by diagnostic and statistical manual of mental disorders IV TR Axis I personality disorders, substance or benzodiazepine addiction and cognitive deficits should be excluded to avoid psychological and psychiatric post-donation complications<sup>[46,47]</sup>.

Studies have identified many issues which may affect adaptation to the transplanted condition and post-operative compliance<sup>[21,48]</sup>.

The decision to choose living donor transplantation is determined by a particular condition characterized by strong mental and emotional distress in the patient and his family, compounded by the fact that the donor is almost always a family member. Living kidney transplantation creates a particular donor-recipient relationship, characterized by mutual emotional support, which is useful in dealing with this delicate situation<sup>[49]</sup>.

Several authors point out that the reasons for living donation seem to be linked to the suffering of their relative due to progressive renal failure, dialysis and its side effects and long waiting times for deceased donor transplant. Attention should also be paid to the indirect benefits that donation brings to the donor in terms of improvements in self-esteem and self-image.

It is necessary to explore the development of motivation for living donation in order to achieve and maintain a harmonious relationship with the recipient, while respecting their individuality.

In the intra-family selection process for donor identification, the donor is most often the mother enforcing the “maternal privilege” of being the only one eligible for donation<sup>[50-52]</sup>.

In identifying the donor it is necessary to assess the risks of an “impulsive” or poorly cognitively and affectively processed decision, caused by excessive “moral obligation” feelings, “hypomania” and “megalomania” aspects<sup>[31,53,54]</sup>.

Several studies have shown the presence of reluctance on the part of the sick person to accept the donation from a relative. The reasons for this reluctance are different and vary

from one individual to another, and transplant failure can result in intense guilt feelings in the recipient<sup>[28,55-57]</sup>.

With regard to the couple (donor-recipient), some studies have reported an improvement in this relationship, while others have defined it as stable<sup>[58-62]</sup>.

According to a study conducted in 2006 in The Netherlands, the main factor leading to the increase in the number of consents in favor of living donation was being properly informed about the surgical procedures and any risks to themselves and to the donor through specific interviews and questionnaires<sup>[63,64]</sup>.

The risk of problems in recipient sexual identity may occur in people who show sexual identity problems or in adolescents. In these cases, kidney adaptation and integration processes may be more difficult if the donor is of the opposite sex<sup>[65]</sup>.

Therefore, the psychological coping process involved in living kidney donation demands a reconstitution of the body self<sup>[66]</sup>.

De Pasquale *et al.*<sup>[31]</sup> (2013) analyzed living kidney donor personality by examining a sample of 18 living kidney donors using the Millon Clinical Multiaxial Inventory-III; they found the presence of narcissistic, histrionic and obsessive-compulsive personality traits in living kidney donors.

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## POST-TRANSPLANT PSYCHOPATHOLOGICAL RISK

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The emotional impact of transplantation can be a traumatic event that interrupts the sense of continuity and personal integrity, eliciting strong emotions.

The experience of negative and disorganized contents makes the person unable to cope with the stressors, including hospitalization, surgery, and invasive treatments, which can be encoded in a distorted way and experienced as terrifying perceptions<sup>[67,68]</sup>.

The threat to the “physical integrity” can then turn into a threat to the “mind integrity”, giving rise to psychopathological reactions of different nature and gravity<sup>[69-72]</sup>.

Several international studies showed physical functions and overall post-transplant quality of life improvement: uremic symptoms, sleep disturbances and appetite disorders disappeared, and hematocrit and hemoglobin levels increased significantly, as well as improvements in cognitive function<sup>[73-80]</sup>. However, despite these improvements and a reduction in total symptom distress, many studies also found a risk of psychopathological and psychosocial malaise<sup>[75,81-83]</sup>.

In the period immediately following surgery, the patient may present a confusional psychosis with anxiety, restlessness, confusion, agitation, hallucinations, confabulation and emotional lability. The frequency of this confusional psychosis varies (20%-40%) and the use of steroids may prolong the psychotic state resulting in “steroid psychosis” with the prevalence of paranoid and hallucination reactions<sup>[65]</sup>.

In the subsequent post-transplant period, liberation

feelings, intense emotionalism, euphoria and a sense of rebirth may be prevalent. This phase, which is defined as the “honeymoon”, also presents negative symptoms including rejection fear, post-transplant complications, existential uncertainty and gratitude feelings, but also guilt feelings towards the donor<sup>[84,85]</sup>.

In the case where “healing” expectations are amplified, both for a lack of information and for a state of post-operative euphoria, anxious-depressive states may be present in the post-transplant phase<sup>[86,87]</sup>.

The hospital discharge, return to the family and social context require an adaptation process lasting 6 mo to a year, the “life by sick” and dependence on others waiver. The perception of loss of support from physicians can make readjustment to the outside world difficult for transplant patients. This experience is more noticeable in people with a weak perception of their personal abilities and autonomy, for example, after a long period of dialysis<sup>[88]</sup>.

The acceptance of transplant status change is often difficult for family members who have had to redefine roles within the family and recognize the effective autonomy skills of their relative. The process is complex and can present moments of opposition to change, with a need to recover the pre-transplant relations system<sup>[44]</sup>.

The state of post-transplant well-being may be hindered by the following factors: (1) late shock effects/surgery stress (6 mo-1 year), which can lead to cognitive disorders, insomnia, anxiety and depression; (2) anti-rejection therapy side effects: tremors and ataxia due to cyclosporine, changes in body image; (3) anxiety for regular medical checks; (4) emotional crises for complications or rejection episodes with fear, anguish, dejection and anger; and (5) organic or psychological sexual dysfunction<sup>[23,63,87-89]</sup>. In summary, for better post-transplant rehabilitation and given the obvious risks of psychopathology, the development of interdisciplinary interventions such as socio-medical and psychotherapeutic programs, without which adaptation after transplantation may be difficult and with inevitable repercussions on quality of life<sup>[90]</sup>.

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## THE ROLE OF A MULTIDISCIPLINARY TEAM ON ADHERENCE IN KIDNEY TRANSPLANTATION

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Transplantation results in a significant improvement in expectations and quality of life, even if possible adaptation difficulties may be present such as psychopathological disorders, problems with compliance and adherence to treatment protocols. Such non-adherence seems to predict morbidity and mortality<sup>[91-93]</sup>.

After transplantation, regular immunosuppressive drug administration is crucial, and even small deviations from the prescribed regimen are associated with an increased risk of rejection. The eventual resumption of dialysis replacement therapy after transplantation affects not only patient physical function, but especially his personal, daily and social life. Strong feelings of discomfort, especially

in females, with a “resignation to a life of eternal sick”, a reduction in self-esteem due to the change in their role in the family have been reported in the literature<sup>[94-101]</sup>.

A strong concern for the future of himself and of his family prevails, in addition to a strong psychological stress condition that leads to anger and depression. The sense of self-efficacy, coping with the disease and self-monitoring, fosters respect for prescriptions. Patients with a higher self-efficacy show a greater ability to self-manage their own health, with better physical health, a satisfactory quality of life and a decreased risk of complications<sup>[95,102-109]</sup>. Other studies have shown a positive correlation between self-efficacy and several indicators of health: better control of diabetes, fewer depressive symptoms, lower use of health care institutions and long-term adherence to prescribed drug therapy<sup>[110-113]</sup>. The beneficial effect of exercise on allograft function and its positive correlation with better health and quality of life were also demonstrated.

Another problem observed concerning psychiatric disorders prior to transplantation is related to non-optimal post-transplant therapeutic compliance<sup>[114-120]</sup>. Depression pre-or post-transplantation is associated with an increased risk of non-adherence to medical prescriptions, as well as high levels of anxiety and hostility and the presence of unstable personality traits. An excessive perception of “restored health” can lead to promiscuity, abuse of various substances and non-adherence to prescribed treatment in transplant patients, which has a significant impact on post-transplant recovery<sup>[65,121,122]</sup>.

The perceived consequences of living with a chronic medical condition (such as a renal transplant) likely affect adherence and psychological outcomes. Among investigations in adults with a chronic illness, more severe perceived consequences have been found to be associated with greater use of avoidance coping strategies, denial, and behavioral disengagement<sup>[123-125]</sup>. Medication non-adherence is a common problem in organ transplantation patients with severe consequences for the patients’ health<sup>[126]</sup>.

A better understanding of the perceived adversity associated with different aspects of living with a chronic illness may clarify possible interventions to improve illness outcomes. According to recent literature, patients who receive a protocol of psychological support before transplantation and during post-transplant follow-up, this leads to improved treatment compliance and quality of life with modifications related to the physical, emotional and psychological aspects<sup>[127]</sup>. In this context, consultation and liaison psychiatry has played, and continues to play, a role in stimulating research and fostering the integration between psychiatry and other medical and surgical disciplines.

In a hospital environment, there is a growing need for liaison between operators, and doctors and nurses from different specialties. More use should be made of the Consultation-Liaison Psychiatry facilities, particularly where there is a strong emotional impact on the relationship between operator and patient, such as the intensive care

unit, *etc.*, where psychiatrists and psychologists should encourage the involvement of the various stakeholders in patient management, and encourage the exchange of knowledge and experience in appropriate and useful liaison activities to prevent burn-out<sup>[128]</sup>.

It is also necessary to include discussions on clinical cases as part of the multidisciplinary team and to promote training sessions and supervision, which are useful in planning cognitive and psychosocial rehabilitation, and psychotherapy both for the patient and his family.

Assessment of quality of life is one of the key indicators for monitoring coping strategies acquired by the transplanted patient and/or the donor-recipient pair. In fact, although it constitutes a subjective variable, quality of life constantly changes in relation to the short- and long-term therapeutic results, and with recipient and donor expectations<sup>[119,129,130]</sup>.

Integrated and multidisciplinary care should also include uniform criteria and procedures for standard assessments, patient autonomy studies, adherence to therapy, new coping strategies and the adoption of more appropriate lifestyles. Only through a “working network” is it possible to monitor the re-employment, family and social reintegration of transplant patients, as health is the result of a number of social, environmental, psychological, economic and genetic determinants<sup>[1,48]</sup>.

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