



## Kidney transplantation and its psychological effects on patients

Organ transplants are by far among medicine’s most technologically advanced procedures. In 2012, 252 people in Quebec received a kidney transplant, while another 923 were awaiting one. The average wait time for a kidney transplant is now over three years.

These statistics clearly demonstrate the current lack of donor organs, a source of a number of transplant-related stresses. They also explain the need to carefully select potential recipients. Originally, recipients were selected according to medical criteria alone, such as tissue typing, candidate health and organ availability. Those in the medical field recognize the impact various psychosocial factors can have on a person’s ability to deal with the issues surrounding the various stages of the transplantation process: pre-transplant, immediate post-transplant and long-term post-transplant.

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## Post-transplant psychiatric complications

In the month following the transplant, recipients can obtain psychological support from psychologists who specialize in organ transplantation. The mixed and poorly understood emotions that follow the transplant, such as feelings of indebtedness, guilt and being beholden to the donor, are completely normal. It is also possible to seek this psychological support during the pre-transplant period.

Psychologists who are integral members of the transplantation team must have four specific competencies: expertise in evaluating psychological states and behaviours; expertise in dealing with therapeutic adherence, depression and anxiety; the flexibility to work with individuals, couples, families and groups; and research skills. As a result of their professional training, of the personal qualities that make them competent psychologists, and of their ability to work in a multidisciplinary setting, psychologists play an essential role in optimizing both patient care and the medical and scientific progress of transplants.

“It is important to understand that transplants are not a cure; however, they are the only alternative to dialysis, and they can involve a difficult adjustment. Many patients, especially young ones, expect their transplant to be a cure that will restore the life they once led. This, despite doctors’ insistence on both the importance of preparation and the fact that the transplant will not be a long and smooth road. But for patients awaiting a transplant, these words often fall on deaf ears. We have also noted that many patients have a *blasé* attitude toward kidney transplantation because

transplants are now so widely available in our society. As a result, potential organ recipients rarely consider the negative effects they may experience and often feel depressed in the six months that follow the transplant, especially young patients and those on peritoneal dialysis.” **Dr. Marie-Josée Hébert, researcher at the CHUM Research Centre (CRCHUM) and Director of the Organ Transplant Program at Université de Montréal.**

## The psychological consequences of kidney transplantation include:

- An episode of depression in those who idealize the transplant. Often they mourn their unrealized dreams, such as that of regaining their full health after the transplant. They also feel guilty for not being able to contribute to society, a feeling patients often have trouble expressing.
- Difficulty accepting the transplanted organ as a natural part of themselves, seeing it instead as a foreign body.
- Anxiety about the potential rejection of the transplanted organ and the return to dialysis the rejection would entail.
- Potential mood disorders linked to the transition from dialysis patient to transplant recipient. Some patients mourn their former life and the relationships they had developed at the hospital. In the case of deceased-donor kidneys, transplant recipients may also mourn the donor.
- However, positive psychological outcomes are also possible, such as feelings of accomplishment, the ability to maintain a sense of self into the future, the quality of the social support system and a sense of independence.



## Issues and psychological effects occurring during the various transplant phases

PHASE	ISSUE	PSYCHOLOGICAL EFFECTS
<b>Pre-transplant phase</b>	<ul style="list-style-type: none"> <li>Shock, certainty regarding the seriousness of the condition</li> <li>Uncertainty regarding meeting eligibility criteria</li> <li>Availability of an organ (or lack thereof)</li> <li>Awareness of the seriousness of the condition and complications</li> </ul>	<ul style="list-style-type: none"> <li>Acceptance or refusal/denial</li> <li>Anxiety, fear</li> <li>Depression</li> <li>Feelings of guilt</li> <li>Grief</li> </ul>
Diagnosis of kidney failure		
Selection	<ul style="list-style-type: none"> <li>Competition with other candidates on the list</li> <li>Confronting death, death of other candidates</li> <li>Awareness of the donor's death</li> <li>Shrinking of and alienation from social circle, marital tension</li> <li>Extended wait</li> </ul>	<ul style="list-style-type: none"> <li>Isolation</li> <li>Interpersonal problems</li> <li>Discouragement, hopelessness</li> </ul>
Placement on the waiting list		
<b>Pre-op phase</b>	<ul style="list-style-type: none"> <li>Awareness of the surgical procedure, anaesthesia, hospitalization</li> <li>Odds of success</li> </ul>	<ul style="list-style-type: none"> <li>Persistence and/or aggravation of previous reactions</li> </ul>
<b>Immediate post-transplant phase</b>	<ul style="list-style-type: none"> <li>Potential improvement of health and quality of life</li> <li>Lifestyle changes</li> <li>Use of immunosuppressants</li> <li>Wait for results</li> </ul>	<ul style="list-style-type: none"> <li>Awareness of a "second life"</li> <li>Relief, hope</li> <li>Reduced symptoms of distress</li> <li>Coping style</li> <li>Consistent treatment adherence or non-resurgence of anxiety</li> </ul>
Biopsies and follow-up		
<b>Post-transplant to long-term phase</b>	<ul style="list-style-type: none"> <li>Social reintegration</li> <li>Readjustment to previous roles</li> <li>Family support</li> <li>Acceptance of the organ</li> <li>Acceptance of body image</li> <li>Potential complications</li> </ul>	<ul style="list-style-type: none"> <li>Impact on self-image</li> <li>Abandonment of "sick person" role</li> <li>Powerlessness</li> <li>Dependency/autonomy</li> <li>Resurgence or emergence of psychopathological disorders</li> </ul>

## The psychological process of the transplant

Each step in the transplant process involves its own challenges. First, there's the shock that comes with receiving the diagnosis of end-stage organ failure requiring a transplant. During the selection process, patients may experience fear and anxiety about whether they meet the medical criteria governing acceptance as a potential recipient. Once on the organ waiting list, patients experience a range of emotions: fear that no compatible organ will become available; growing awareness of both the gravity of their illness and their own mortality;

decreased ability to function in all areas of life; alienation from their social circles; tension with spouse and family as a result of the omnipresent uncertainty; and an increasing sense of discouragement and hopelessness as the wait drags on. In this phase, patients also experience feelings of guilt, often because they perceive that they are competing with other potential transplant recipients, or because by hoping to receive an organ, they are indirectly hoping a potential donor will die.

As the surgery approaches, fears become more specific—the procedure, anaesthesia, hospitalization and the odds of success. During the period immediately following the transplant, recipients experience relief and hope, which often reduces anxiety; however, for some, the anxiety returns quickly as the first biopsies are conducted to assess the state of the transplanted organ. Over the longer term, the acknowledgment of this "second chance at life" leads to growing awareness of the need for treatment adherence, of the risks of various complications (episodes of rejection, readmission to hospital, side-effects from medication), of the lifestyle changes that need to be made, and of the challenges of reintegrating into society. As a result, all candidates are expected to experience some degree of psychological distress during the transplantation process.

In fact, some may even develop a psychiatric disorder. A number of factors determine the reactions patients may have: various forms of stress, as described above, which tend to be amplified in patients who are more ill; the psychopathological potential, i.e. individuals' current mental state and their personal and family history of psychiatric disorders; and the resources available to patients, especially the quality of available social support. In this respect, we use a biopsychosocial model to explain each patient's individual risk of developing a psychological reaction to the issues surrounding the transplant.



For decades, the line between mental health and physical health has been blurring. Psychologists have long been aware of the impact that physical health problems can have on mental health, and vice-versa. Through their perseverance, psychologists have succeeded in convincing the health sector of the importance of treating patients' physical and emotional selves, and patients are all the healthier for it.

## Working with donors

Living donor transplants are on the rise. In 2012 in Quebec, 53 living donors donated one of their kidneys. When interviewing these people, psychologists must first ensure that the person offering to donate an organ is doing so voluntarily



and not in response to real or perceived family or social pressure. Psychologists therefore help potential donors explore their motivations, the nature of their relationship with the recipient and the reactions they expect to have in the event that they are deemed ineligible as a donor or if the transplant fails.

Psychologists also ensure that donors know what to expect in terms of the transplant procedure and their own surgery. Paradoxically, in kidney donation, donors often experience the most post-operative pain—their surgery is considered more intrusive—while getting less attention and family support than the “stars” of the show, the recipients. This situation, exacerbated by the loss of an organ, can increase the risk of depression.

Psychologists must remain vigilant in identifying cases involving imbalances in family dynamics or personality issues, e.g. wanting to donate an organ to repair their reputation as the black sheep of the family or in the hope of filling a void. In this case, the psychologist's involvement stimulates dialogue that can help address any non-relevant expectations.

### Sources :

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**Transplant Québec**, 2012 statistics.