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# Psychological Aspects of Kidney Transplantation

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## 1. Introduction

The currently promoted holistic health care model assumes a close interaction between the somatic and mental aspects (Sheridan, Radmacher, 1998). The past few years have recorded a considerable progress in the study into the psychological determinants of somatic illnesses. The domains representing the so-called behavioural sciences show, at different levels, the relationships between the physical and mental health. Such approach, in practice, assumes that there is no illness which would be unconditioned by psychological factors (Salmon, 2002).

The mental psychological factors can be the cause of the disease, they can maintain the occurrence of pathological symptoms or they can constitute the result of the pathological process. Interestingly, the psychological knowledge does not only account for the origin of the psychopathological symptoms found in somatic disorders but it also provides constantly improved and scientifically-verified methods of their treatment.

Similarly the transplantation is a treatment method connected with numerous psychological implications for the patient and the family (Kidney Transplantation, 2000). The transplantation ward patients face psychological problems, e.g. concerning the autonomy and the responsibility for the health decisions, managing the chronic disease stress, operative procedure and the uncertainty after the transplantation. These problems often overlap with changes in behaviour, emotions and cognitive functions being a result of organic changes in the central nervous system (CNS) triggered by dialyses (Griva et al. 2002; Griva et al. 2003).

For that reason the cooperation between transplant surgeons and clinical psychologists seems to be a natural consequence of the holistic understanding of the patient, taking into account the interactions between physical and mental health. The personnel of the transplantation clinics should form interdisciplinary teams of transplant surgeons, nephrologists, qualified nurse, transplant coordinator, dietician and the clinical psychologist.

The present paper is an attempt at providing characteristics of the most essential psychological problems found in patients before and after the renal transplantation. Psychological aspects of the qualification process of potential living donors are also presented.

## **2. Transplantation from a living donor who is a relative: psychological aspects of the potential kidney donor's qualification process. The goal of psychological assessment**

The psychological evaluation is an essential component considered in the process of qualifying a person who wants to donate a kidney to a person of immediate family. The decision on donating a kidney is difficult, conditioned by many factors and, as such, it calls for thorough consideration. It should be taken with full awareness, voluntarily, having the sense of freedom and respect for the donor. With that in mind, a potential donor should be informed by the transplant surgeon of all the facts connected with potential problems and possible complications. It is noteworthy that the decision on donating a kidney is most often taken as triggered by powerful emotions, an impulse. It is extremely rarely the case that a potential donor taking the decision has been provided with all the indispensable information on the transplantation process and thus the donor's expectations from the treatment can be unrealistic (Nolan et al., 2004, Włodarczyk et al. 1997).

The basic objective of a talk with the psychologist is to determine the nature of motivation of the potential donor as it is the aspect which creates the space for the development of potential psychopathological reactions later in time.

The opinion issued by the psychologist concerns mostly the potential donor of the organ, however, frequently it is not possible to make a psychological profile of the donor without determining the conditions and social relations the person operates in. A special attention is paid to accurate characteristics of the relationships between the donor and the kidney receiver. Initially the talk concerns mostly the kidney donor, later also the receiver; in practice, the consultation often ends up with a talk with both persons present at the same time.

The consultation aims at getting a grasp of the psychological atmosphere in which the decision on donating the kidney was finally made and excluding the presence of any kind of pressure on the donor and, as such, it refers to motivation. The research results show that despite the fact that the decision taken by most of the potential donors is independent and spontaneous, at the same time almost all the potential donors experience some kind of pressure, which can be generated by the behaviour of the receiver, other family members but also a specific system of beliefs of the donor himself. Although taking the decision on donating the kidney to a person the donor is a member of the immediate family with is mostly motivated by the sense of moral obligation and altruist aspects, from a psychological perspective, they are not sufficient to meet the requirements of the informed consent.

For the psychologist participating in the qualification process as well as for the entire transplantation team, it must be absolutely clear why the potential donor has decided to donate a kidney to a specific person. Recognizing hidden motivation behind the declared knowingly altruist motivation is the role of the psychologist. Such information is acquired applying neither standardized psychometric tests nor structured interview; therefore the basic tool here is free interview, observation data and clinical evaluation.

One shall also remember that the very qualification process also triggers emotional anxiety in the potential donor and the intensity of the anxiety depends on how close the relationship with the kidney receiver is, his or her health condition, expectations of other family members and on many other factors. Tension affects all the persons involved in the qualification process: the donor, the patient, the other family members and the people around them. It can trigger changing moods in the donor, anxiety and increased excitability.

Anxiety in the potential donor can be connected with the anxiousness of discovering real emotions about kidney donation and present but unexpressed doubts of the donor. As already mentioned, the willingness to donate the kidney is often declared as triggered by an impulse. Such declaration is often welcomed with enthusiasm and recognition by the other family members, including the receiver himself, which makes the atmosphere impossible for the potential donor to change his or her decision. Withdrawing from the initial declaration would involve the need to confront the disappointment and the feeling of being let down by the receiver as well as fear of a negative feedback from the other family members. Besides, donating a kidney to a person of immediate family triggers a lot of gratifications and rewarding in nature: it enhances the position of the potential donor in the family, it puts the donor in the centre of attention, enhances the respect towards the donor and thus the donor's self-esteem. All that can make, despite inner doubts, the donor trigger his or her defence mechanisms which will make the donor rationalise things and become sure that the decision taken is the right one, making the penetration of and thinking over the real feelings difficult. The behaviour of donors experiencing the ambivalence towards the decision they have taken up often demonstrates a discrepancy between the declared and strong desire to donate the kidney and the focus on minor health problems, presenting excessively pessimistic forecasts concerning the transplantation or a strong, sometimes even exaggerated, glorification and idealization of the recipient and their relationship, which expresses the mechanism of reactive formation, masking real but unconscious negative feelings towards the recipient or the decision being taken. The applicable literature describes cases of potential donors who, suddenly, informed of the fact of unexpected pregnancy, a necessity to take care of their own neglected health problems first or of a longer leave, giving 'reasonable' reasons.

Yet another serious factor is also the evaluation of the family dynamics, considering the distribution of family roles; who takes essential decisions, what has been the position of the donor in the family so far. It so happens that potential family donors are the people who are lonely, neglected, kept away from taking up decisions important for the entire family or the people who have not been in the centre of attention in the family. In such persons an undisclosed motivation being the springboard for the desire to donate the kidney is the desire to enhance self-esteem, self-image, strengthening the position in the family and winning the family's respect. The risk while facing this kind of motivation involves the fact that, with time, the attention of the family refocuses on the diseased (the recipient), making the disappointment and the sense of underestimation of the donor's sacrifice in the donor greater.

Another source of motivation is the sense of guilt in healthy family members towards the diseased one, where the driving force of the decision on donating the kidney is better or worse realised desire of compensation, which refers especially to women who wish to donate the kidney to their child. Mother-donors often perceive it as a form of life-giving for the second time, which, on the one hand, can enhance the emotional bond between the mother and the child yet, on the other hand, can release the mother from unconscious or unexpressed sense of guilt connected with having given birth to a diseased child, being a defected child.

Obviously, the decision on donating the kidney often reflects the real profound bond between the donor and the receiver, however, also the situation of that kind, although seemingly not triggering any doubt, should be exposed to thorough analysis by the

psychologist since the opposite is possible; a healthy family member who wishes to be the donor is the person in the centre of attention in the family, attracting all the family admiration and recognition, whereas the person's decision on donating the kidney additionally strengthens his or her position, decreasing the importance of the receiver and deepening the receiver's dependence. The receiver is 'forced' to be thankful to the donor, which helps the development of the pathological relationship, hostility and, finally, also the difficulty of the receiver himself to accept the graft. There have been recorded cases where the receiver not being able to express his or her real feelings, after the transplantation, demonstrated the passive-aggressive approach, apparently declaring his or her care for the graft and, in fact, not following the doctor's guidelines, which was the expression of the receiver's resentment, bottled-up aggression or hostility to the donor, the symbol of which was the graft.

The motivation to donate the kidney is rarely 'pure motivation' and it is mixed in nature, being a combination of a sincere desire to help, hidden motives and fears, which obviously does not make it less valuable. However, it is important that it is possible to discuss the doubts and fears of the potential donor in the presence of the psychologist since the transplantation assumes an earlier donor's consent which would be clearly expressed, voluntary and fully informed. The people who donated their kidney in the past express their definite conviction that discussing the topic of the transplantation with the psychologist made it possible for them to take a decision with the sense of complete freedom of the choice made. The reports show that a talk with the psychologist, who is perceived as 'an advocate of the donor' is the factor which facilitates an honest exploration of the donor's own motivation and emotions. Such a talk also alleviates fear from being evaluated by others. The contact with the psychologist is also important because the decision of the donor is embedded in the emotional context of chronic stress, namely an illness of a person of the immediate family. The psychological consultation is important especially when the idea of donating the kidney to the diseased person does not come directly from the potential donor. Especially in such situation the donor needs to be able to discuss the decision and to have a closer look at all its consequences. The psychologist, being a stranger, not involved in family relations, can help to see all the aspects of the situation in a way which would be possibly most neutral and objective.

During such talk it is essential to create the sense of absolute freedom of choice, to make it possible for the donor to have a real grasp of the situation the donor enters. Irrespective of the relationship with the receiver and dependence on the receiver, the donor must remember that he or she enjoys the right to change the decision. In fact, the psychologist's talk with the donor also serves the receiver since, by penetrating into the real motivation of the donor, it often helps the receiver to avoid the emotional dependence, protecting him or her from unrealistic expectations by the donor. The talk of the psychologist with patients eligible for the family transplantation is a process during which the psychologist gets to know not only the motivation and personality of the patients but also the mechanisms creating the dynamics of a given family. Here the studies of psychopathology, personality psychology, family psychology and psychotherapy are applicable.

The evaluation of the donor-receiver relationship is important. The decision on donating the organ to a member of the immediate family is a beautiful gesture; however, the role of the psychologist is to determine the nature of the basic motivation. Is it not the case, for example, that besides the altruism and selflessness declared, it is not about, for example, an attempt at involving the receiver into the dependence with no possibility to refuse,

'relegating' a person by the family to act as the donor, without considering the person's opinion, using the position of the fall-guy or manipulating him or her with the sense of guilt? Sometimes it is also the case that the donor can manipulate with his or her decision and expect different kinds of gratification from the receiver; those are the cases of emotional blackmail; how could one refuse later anything to the person who has donated the kidney? Yet another important aspect of the talk with the psychologist is to determine the level of knowledge of the patient on the kidney transplantation (potential donors, in fact, the same way as the receivers, often have information from informal sources). It is essential since it is the patient's image of the transplantation which determines the patient's expectations from the treatment.

While evaluating to what extent the decision on donating the kidney is an informed choice, taken with realistic consideration of not only the expected benefits but also a potential risk, it is also essential to make a thorough evaluation of the mental state of the donor. In the talk one shall consider the burden of mental diseases, and in the case of stating that the donor meets the diagnostic criteria of emotional disorder, one shall study in detail the case history. In justified cases, it can be necessary to assess the intellectual fitness of the potential donor to exclude the degree of mental retardation which makes full understanding and taking an informed decision impossible. The actions taken by the psychologist should be especially careful when the potential organ donor is, at the same time, a person directly dependent on the potential receiver.

Interestingly, besides the psychological mechanisms, also psychosocial factors are essential: socioeconomic and professional status of the donor, family situation, children, if any: the number of children, their age, attitude of the entire family (especially in the case of the transplantation between the siblings) to the idea of transplantation.

### **3. Psychological problems of the patients before and after kidney transplantation**

Organ transplantation is a specific treatment method which is connected with many implications of psychological nature (Jakubowska-Winiecka 1999, 2001; Trzcińska, 2002). Before the transplantation the biggest problem concerns the motivation connected with taking the decision to undergo transplantation. Even though the consent to kidney transplantation, being a procedure which is to enhance the quality of life of the patient, increasing the patient's independence and which aims at the normalization of the medical parameters, seems obvious and unequivocal from the medical perspective, it is not such from the psychological point of view (Rebollo et al. 2004; Griva et al. 2002; Eggeling, 2000). The decision to enter the list of patients waiting for transplantation is made by some patients exposed to the pressure of doctors and the family. Also frequently the reservations brought up by the patients do not meet with the understanding from those nearest and dearest or the attending physician, which makes the patients themselves stop talking about their fears or resentment, however, expressing them in action. Transplant surgeons as well as transplant coordinators report on the cases from their experience in which the fear, concerns or resentment to undergo the transplantation found in patients are strong enough to make them, upon receiving the call with the information on the possibility of transplantation, give various reasons which makes it impossible at the very moment to appear in the transplantation centre, being a form of rationalising more or less unaware impulses. There are many reasons of such kinds of behaviour; one is the fear of the operative procedure and

of all its implications (pain, anaesthesia, etc.). In some patients what dominates is the fear of the unsuccessful treatment itself, while some fear giving up a stable lifestyle the routine of which is determined by the rhythm enforced by the dialysis dates. The cycle of hemodialyses, usually taking place three times a week is a time-burden, it limits the independence of the patient, it makes it difficult for the patient to execute many activities and excludes the patient from many domains of social operation, however, it still gives many people the sense of security and control, based on repeatability and predictability, while the decision to undergo transplantation ruins that secure reality and makes the patient take a risk and deal with the uncertainty. The justifiability of that hypothesis can, for example, be seen from the fact that many patients after their successful transplantation do not consent to arteriovenous fistula ligation. The decision on keeping the fistula active, although it can result in numerous inconveniences or complications of medical nature, for the patient it can be some kind of 'safety net' since it expresses a kind of unconscious defence mechanism. The present research demonstrates that many patients, with time following the transplantation, despite a stable concentration of creatinine, express their need to keep the arteriovenous fistula patent, which becomes, in a way, a symbol reminding that if the graft is rejected, it is still possible to come back to dialyses.

Before the operation the basic difficulty is the time spent waiting for the organ. The diseased person has no choice but to wait long, no choice but to experience uncertainty. The person must, in a way, operate all the time with mental alertness, at any moment the person can receive the information about the need to appear at the transplantation centre. The psychological mechanisms the patient undergoes are complex: on the one hand, a strong waiting-related tension and, on the other hand, the stressful urgency of the call, a stay in an often unknown centre, city, among strangers and, finally, the procedure itself. It is after the treatment that the period of the greatest tension starts; it is when it turns out whether or not the kidney has started its functions. The observation and the stay in hospital can take very long, with no guarantee of keeping the graft. Each day of the stay in hospital gets longer and longer since the only and the most important activity is waiting for the laboratory test result which indicates whether the kidney has started to work and whether it plays its functions. It should be remembered that the patient's mood depends not so much on his or her real medical state but on its subjective interpretation, namely the way the patient understands and perceives his or her own situation. Most frequently at that stage the patients are becoming extremely susceptible to different kinds of emotional disorders (most often depressive and anxiety disorders), which require work with the psychologist. Often the frustration caused by prolonging uncertainty makes them aggressive, showing a demanding attitude, or closed to cooperation with the personnel.

Some patients' fears concern the wound healing after the treatment (some patients recover quite long, in many patients there is still anxiety, and despite the encouragement from the doctors, they are afraid to leave their bed not to make the movement harm the wound), however, fears are mostly connected with the newly received kidney.

The worst tolerated psychological aspects of being the kidney receiver include a constant never-ending uncertainty about the future of the graft. The patients after the transplantation develop different types of strategies of dealing with such uncertainty. The type of such strategy depends on the patient's personality, his or her earlier ways of managing stressful situations, locus of control, high self-esteem, as well as social support and the skills of benefiting from such support.

Those who manage definitely worse are anxious patients, dependent, demonstrating incapacity for tolerating negative emotions: distrust, excessive alertness, and showing the tendency to focus on negative aspects of the situation and the tendency to somatization. As for such people the transplantation seems not to meet its basic objective, namely the enhancement of the quality of life and increased independence and dealing with the disease more effectively; just the opposite: those people live with a constant sense of threat. They subordinate their life, and often also the life of their nearest and dearest, to the dynamics of the kidney operation. They seem as if they could not break from the need to think of the graft. They keep on measuring the amount of urine produced, record the results, and make never-ending comparisons between the results recorded on respective days. They follow the recommendations of the doctors scrupulously, often deforming their contents, thus introducing an almost military regime into their lives. In fact, their life is never, even for a while, anxiety-free, and continuous focusing on the functioning of the body triggers a vicious-circle mechanism: focusing on the body symptoms makes each change in the mood, even the smallest one, intensify fear and cause depression, which, in turn, based on biofeedback, intensifies the need to monitor the functioning of the body. The tendency to aggravate the symptoms is becoming burdensome not only for the patient himself who cannot enjoy the advantages of the renal transplant but also for those nearest and dearest and the doctors.

In some patients there is observed a negative effect of surrendering to excessive emotions. Those are the people who, often already before the transplantation, demonstrated a vivid emotional expression, poor impulse control, temperament showing a little balance between nervous processes and low tolerance to negative emotions: fear, anger, etc. Such patients, when exposed to prolonging uncertainty concerning the kidney functioning can react with an outburst of strong emotions, uncontrolled crying, sometimes anxiety attacks, psychomotor agitation. A low tolerance to prolonging stay in hospital is also observed in the patients with little insight into the emotions they are experiencing and in those who cannot verbalize their emotions. In some there is reported emotional changeability, sleeplessness, loss of appetite, sometimes apathy or other depressive or anxiety symptoms. There emerges yet another mechanism of vicious circle: living with the graft triggers tension, which becomes a springboard for creating anxious interpretations, while anxiety and other emotions affect, by means of feedback, the functioning of the kidney, e.g. by constant increase in blood pressure, while every single, even the smallest, deterioration in the somatic state in the patient deteriorates zwrotnie the patient's mental mood.

Yet another factor is the need of taking immunosuppressive drugs and its consequences in a form of side effects of those drugs which can affect the mental condition of the patient. It concerns mostly the effects connected with a change in physical appearance, which mostly affects the mood and mental well-being in women: an increase in the body weight, 'the moon face', hairiness which appears on arms and legs, deteriorated facial skin condition. Those factors can seem minor but, in fact, they determine the self-image of a given patient, affecting her self-esteem as a woman. With the change in the looks, there can appear depressive states, dejection, especially in those women whose self-esteem and the sense of identity depend on their looks considerably.

A specific problem observed in the patients being prepared for the kidney transplantation is the problem of their cognitive fitness. Many reports show an occurrence of different kinds of cognitive function deficits in dialysed patients. The applicable literature also uses the term of 'the dialysis encephalopathy', describing the dementia characteristics observed in the

patients after many-year dialyses. The aetiology of cognitive dysfunctions in the dialysed patients is conditioned by many factors. In the past researchers pointed to the accumulation of aluminium in the CNS structures, originated from dialysis fluids, whereas today the researchers suggest that the degradation of the cognitive fitness is an effect of uremic toxins on CNS, disturbing the operation of the sodium pump, they increase the permeability of the blood-brain barrier. Other hypotheses point to the role of GABA neurotransmission disorders, hypoxia of the brain as a result of frequent blood-pressure drops, metabolic disorders or a persisting increased level of calcium in the brain.

The results of neuropsychological studies point unequivocally to the post-transplantation improvement of cognitive functions, mostly memory and attention enhancement, which is yet another factor determining the improvement in the quality of life in patients, as well as yet another reason for which the patients before and after the kidney transplantation should undergo neuropsychological tests.

Quite often after grafting the patients' attention is focused on the issue of the origin of the kidney received; whether it belonged to a young or older person, a woman or a man, etc. For many patients it is very important to contact the person who has received the other kidney from the same donor and to observe that person's health condition, ('If her or his kidney works, it must work in me as well since they do come from the same person'). In such cases some patients say that they are 'twins'.

#### **4. The patient in the face of the graft rejection**

Unfortunately sometimes the patients' fears are justified. It is still impossible to prevent, with a hundred-percent effect, the process of the graft rejection.

From the psychological point of view, it seems that in the case of family transplantation and receiving the kidney from a related donor, the graft rejection has a slightly different significance than in the case of the transplantation from an unrelated dead donor.

In both situations there appears a feeling of disappointment, however, in the receiver of the kidney from a relative, there is an additional special kind of the sense of guilt towards the donor ('wasting' of the received organ), which can often affect also the donor himself ('there must have been something wrong with my kidney'). In many patients who were dialysed before the transplantation there appears a fear of coming back to that burdensome procedure. Frequently the struggle of the doctors with the rejection process gets so much longer and longer that the patient, mostly mentally tired, wishes any specific and final solution to the situation, even if that would mean returning to the dialyses.

With the uncertainty getting longer and longer, bad mood, and a long stay in hospital create a sense of mental exhaustion, which often calls for a frequent contact and cooperation with the psychologist. The best is the situation of the patients hospitalized on the ward where the psychologist is a permanent treatment team member, thus ensuring a possibility of establishing a therapeutic relationship; otherwise all depends on the awareness and sensitivity of the doctors to the possibility of emerging psychological complications in the patient at different stages after the organ transplantation. It is also essential that the doctors themselves can recognise such mental states which would require consulting the psychologist or the psychiatrist, especially that many transplant patients demonstrate a strong tendency to bottle up emotions and to deny negative emotional states.

The job of the psychologist is to provide the patient with support, understanding and, mostly, an opportunity of discussing their current situation fully. In the first phase of the

contact, the patient should be given comfort of talking about his or her health, health-related fears and to be listened to, which clearly alleviates emotional tension.

At the next stage it is applicable to involve elements of supportive therapy which aims at developing a stable patient-psychologist relationship helping the patient get the sense of security. Very good effects are recorded for the techniques of cognitive therapy; here the work focuses on dysfunctional anxiety-triggering patient's convictions and rephrasing negative unrealistic expectations from the transplantation. The techniques clearly help the patients to increase the sense of control over their own emotions. They are especially useful for the clinical psychologist who is expected to be effective over a short time. Short-term cognitive therapy helps to help the patient with perceiving the feedback mechanisms which occur between focusing on the health condition, catastrophic interpretation of symptoms and the psychophysical mood. An excellent method used to alleviate the anxiety-related tension involves also relaxation techniques.

If the renal graft rejection is the fact stated by the doctors, the job of the psychologist is to prepare the patient mentally to come back to dialyses. The most difficult job is when the rejection process can neither be confirmed nor completely excluded. It is the so-called work 'in suspense'; it mostly involves teaching the patient how to deal with anxiety, tension and other emotions referred to as negative: anger, sense of guilt. In some situations, despite the contact with the psychologist, the patients are also provided with pharmacological treatment in a form of antidepressants, anxiolytics, tranquilisers or soporifics.

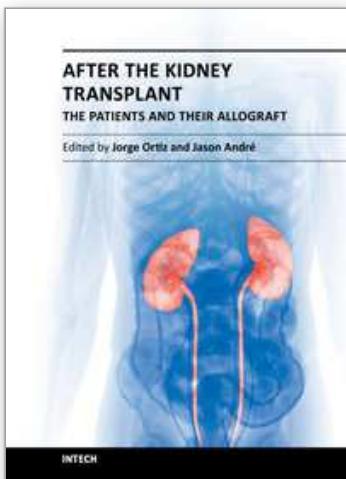
## 5. Conclusions

Transplantation is a therapeutic method which, although, at the end of the day, enhances the quality of life of the patients, triggers numerous implications which are psychological in nature. For the patients the kidney transplantation treatment is connected with long-term emotional tension, experiencing strong anxiety and with the need to confront and to deal with strong negative emotions. While transplantation decision-taking, directly after the transplantation and throughout the functioning of the graft, in the patients there can appear psychopathological symptoms, most frequently anxiety and depressive disorders. The functioning of the patients is also often affected by cognitive deficits, frequent in dialysed patients, which undergo regression after transplantation. A special attention and psychological help are required for the patients diagnosed with graft rejection. Frequently, they will require specialist psychological treatment (psychotherapy) and psychiatric treatment (pharmacological treatment). For that reason the transplant patient requires interdisciplinary care, with the psychologist also on the team.

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## After the Kidney Transplant - The Patients and Their Allograft

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There are many obstacles in kidney transplantation. For the transplant team, there is the balance between immunosuppression to aid in the recipient's tolerance of the allograft and the infection risk of a suppressed immune system. These potential long term complications of kidney transplantation are relatively well known, but there are many other complications that patients and families do not consider when preparing themselves for a kidney transplant. Although the benefits of attempting a kidney transplant far outweigh downfalls of the long term sequelae, kidney transplantation is by no means a benign procedure. It is the hope of these authors that the reader will leave with a sense of understanding towards the kidney recipients.

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