

Transplantation okay – Psyche okay ? Reflections on psychosomatics in the field of organ transplantation

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Abstract

Transplantation puts a large burden on patients' psyche, before and after the operation. Psychosomatic care implicates helping patients to take a firm decision in favour of a new organ, of a new life. Incorporation of the graft, efficient doctor-patient-relations, pregnancy and sexuality, everything is possible but crucial to many patients. Psychosomatic knowledge and specified consulting help them and their families and even the doctors and nurses to cope with overwhelming emotions, fear and a lifelong danger of losing the organ. Transplantation means crossing borders, going into unknown psychic regions. And the recent rapid development of living liver transplantation does not facilitate things. (*Acta gastroenterol. belg.*, 2005, 68, 353-357).

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Congratulations, Cliniques Universitaires Saint-Luc – twenty years of liver transplantation is a long period for a rather young discipline of medicine. I do remember the day when Christian Barnard transplanted the first heart – I was then a young journalist and deeply touched – and shivered by the thrill of the idea, that man can extract a part of the body of someone and fill in another part of the body of another person – and it works ! We were terribly fascinated and I confess I still am – watching a transplantation, having a look in the empty abdomen, seeing all the parts of the surgical treatment you are so able to do and then see the new liver being put at the correct place, smooth, shiny, then being connected to the body vessels – and the miracle – the blood pouring into the vessels, giving that very moment of a liver full of stars.

Whenever I feel that a patient is very anxious I tell him or her this observation, and they keep back their breath and look at me with wide open eyes and something like consolation, comfort reaches their souls.

Of course – more than 30 years have gone by, I do not really know how many hearts and livers, not to talk about all the kidneys, have gone through transplant doctors hands. Transplantation certainly has become a routine treatment, and there are transplantation centers, where patients are treated like objects on an assembly line. But in spite of their will for adaptation, their obedience and their compliance – they are not objects on an assembly line and their behaviour just masks their fear, their feelings of guilt and shame. They certainly know much more about transplantation than Barnard's patients did, but they also know more about the dangers, they fol-

low the discussions about brain death, organ trafficking and might even know a lot about outcomes that were not as well as we always hoped they might be.

Prior to every transplantation is a human being that gets ill. Deadly ill. Somebody who appears on the transplant waiting list is aware that this is the last chance to some more life. And it sure does not minimize the individual uproar of the patients' feelings to inform them that there have been thousands of successful transplantations been done already, not even the personal record of the operating surgeon really calms. And, let us be honest, we all working in our little niche know about that.

I have been working in that niche for more than ten years now at the Munich Klinikum rechts der Isar, hospital of the Technische Universität, and the ambivalence still fascinates me. I am not up to pour the bitter drop into today's cheering champagne, but you asked me to ponder on the question whether psyche is okay when transplantation is done. So let me use my time to reflect some basic observations, that may get lost in the hectic everyday hospital life we are all living.

What does psyche okay mean ? Just functioning ? Committed, compliant, cooperative ? Able to do away with fear and all the emotions ? Keeping a confident exterior ? Delegate all the responsibility successfully to the doctors ?

Transplantation puts a large burden on patients. When they have survived the very strenuous waiting time for the new organ, they will never be healthy again, they have to be aware at any moment of their future lives that' no matter how much time elapses, rejection and sickness will always plague them. Transplantation is not a panacea but a disease that will remain with the recipient forever !". Thus Brian Reames is quoted, the founder of TRIO. "Transplantation is more a syndrome than a disease because it is actually many diseases. You are trading one disease, the one you had before transplantation, for many others".

All transplant patients will always remain dependent on medicine, on doctors' advice. Most of them live a so

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called honeymoon period after surgery, they are euphoric to be reborn, the gift of life makes them feel very deep happiness. They very quickly recover, get back a normal colour of their eyes and skin, and even tiny depressive episodes or a small psychotic or extended hallucinatory periods do not alarm anyone. We all know that the high doses of steroids mark them, and the reaching of a long awaited aim – to be transplanted – causes relief, that may feel and look like a depression and vanishes in a few days. Rejections are quickly detected and treated, complications of the healing process explained, the security of being in a highly specialized ward gives peace and the feeling to be sheltered.

Liver transplant patients spend three to six weeks approximately in the hospital, if there are no major complications. And most of them then adapt to their new lives, trying to make them feel – and look – like they did before. Research shows that most of them enjoy a good quality of life. Though this is rewarding for the treating team we should not forget that our patients have an immense feeling of gratitude towards all of us, especially the head surgeon, who gave them a new life. And they compare their quality of life post TX with their quality of life before it – when most of them were in a rather deplorable state of health. And mind.

Psyche okay – well, I will leave it to you to judge upon the degree of “okayness” in the following cases.

Personal or biographic background does not necessarily ease the strain. I had a patient who is “Kopfmetzger”, one of those who kill cattle with a shot in their heads at the slaughter house. He told me he was free of fear because death came to him every day many times and he could handle it. Finally he could not – he had a very hard recovery time and it needed a lot of care from all of us to stabilize him. Death – or the miraculous avoidance of death – had occurred to him in a very different way.

A young person I am actually working with has had very special problems with the donor. It is not so much that she, a lesbian woman, was afraid of getting a mans liver, but she feared that the donor had had perverse ideas, because, she argued, how can someone with a sane brain decree that after his death he will be cut apart and distributed in clearly defined pieces to a bunch of unknown people ? You probably all feel the huge burden she was carrying. She finally managed to get over the assumption of perversity, which probably was an example of psychic repulse. She now visualizes her new liver as working like a source of warmth, giving comfort and life energy. And all of a sudden she figured herself as surrounded by a red shiny aura. Rays coming concentrically from out of the new organ gather in that aura – isn't that a bit the image of the Madonna giving shelter with her coat, a motive we find frequently in old altarpieces, in history of art ?

Bavaria, where I come from, is a catholic country with impressively many people who profoundly believe in god and his saints. After a successful transplantation

they are willingl to attribute a part of their gratitude to heavenly supplied shelter. And they are glad they can go to their parrish church and light lots of candles or have a mass celebrated in praise of the donor. This calms their – mostly unconscious – feelings of guilt. Guilt, that may mean in a very distant corner of their hearts that somebody had to die, while they may go on living. Why that selection ? Why did they survive ? Why did fellow-sufferers die waiting for the new liver ?

Nobody knows the answer, all we can do is to prepare every patient in time, which means before they are put on the waiting list, confront them with those thoughts we know from experience that may arise after surgery. Like a vaccination, make them think things that may emerge later und be threatening to their feeling okay.

Grief and mourning will also accompany them at low doses, if they are not psychiatrically ill. Their lives are combined with the death of another human being. A stranger, whom they will never know nor know anything about, which means for most of our patients, that they have to fight the wish to know.

Incorporation of a new organ is dependent on the ability of a person to handle psychic borders. Everybody sets up those borders, frontiers between self and others, this is part of the human development. Transplant patients get a bit confused sometimes – they lose their safe borders, go through a time of total dependence on help, medical personell and machines, and then have to readjust the borders – to the outer world and to the foreign part inside themselves.

Most humans have a very strong sense of survival, they use a kind of a narcissistic strategy adopting the part of the donor as part of themselves now, minimizing the liver to a piece of flesh, rationalizing it to a point of denying the strangeness, denying the donor and claim the new liver to be theirs. They give a name to their new liver, caress it sometimes and sometimes even allow it a sip of champagne.

But there are patients with less capacity to defence or mentally ill ones. They may have the phantasy that there is a strange person inside their abdomen. This person may influence their future enormously, if he or she is not friendly, a welcomed person. One of my patients talked of a roommate that moved in to share his life, another one really figured a grown up man folded into his intestins.

Partners, that really fit are hard to find in life, when you are just wanting to live side by side – how much more concerning must it be to wake up and discover that someone has moved inside of you without your checking him for concordance. Even with living transplantation doubts persists – a patient who had received one of his fathers kidneys asked me whether his new kidney would die when his father had died... magic thinking is frequently used as a coping effort against overwhelming fear after transplantation. But psychologically healthy people use positiv magic – and include the introject in the abdomen in their newly recovered power and readaptation. Two peoples power, doesn't that sound better ?

I observe that doctors often oversee a very important sadness, especially in liver, lung and heart transplantation. Our patients do not only mourn the dead donor but also the irreversible separation from their sick organ, which is an irreversible loss of a part of themselves. A part that had become something like a companion to them – fighting with them for the survival of the suffering liver, fighting against its destructiveness that may cost their life and betraying that liver that they are about to abandon. It seems to be important to strengthen the conviction that it is the patients right to survive even if that means loss of an important part of themselves. A part, that developed from the first cells and grew with each of our patients. Again animistic thinking, that not every patient produces, but something to take into consideration early in the preparatory process. It may cause undetected unconscious damage which may come out as diffuse depression or fright.

Those patients may be afraid of the fact, that the new liver may threaten their health just as well. The taming procedure of baptizing the new organ is something magic I think many people use in secret. We should be aware of this coping because if the psyche does not incorporate the new part, the body will not accept it for long.

For all of us transplantation has become a routine treatment of very ill patients. I am always glad that in my job I am often set back to the recognition, that it is a very tough experience, to decide, to accept that you will never be free of fear till the end of your life. The rejection, the terminal rejection, may come at any moment. The cicatrice on your abdomen will remind you of that fact already in the morning when you take your shower and the comforting warm greeting of the day is structured by the feelings of your, maybe shaking, fingers that something is different, even at your skin surface. Big scars massively disturb the bodily acceptance of the transplant organ. Often our patients' gums proliferate and their faces are blown up by pushing and they do not recognize themselves in the mirror.

This leads us to sexuality after transplantation. A very important, but in ambulance consultations heavily neglected part of every patients life. Before transplant the sexual rapports between patient and partner are mostly close to none, the physical weakness, impotence and the long stays in hospital make it impossible. After surgery arises the uncertainty what one can risk – “la petite mort” ? Will the suture keep tight ? May sexual intercourse lead to rejection ? And, much more basically, will the partner accept the poor maltreated body ? Women especially often refuse closeness they so much long for after that horror experience, all the solitude and lack of tenderness, they refuse it because they cannot imagine being attractive to their partner. If alcohol was the reason for the liver failure, they may see the withdrawal of sexual satisfaction as a justified punishment for their personal failure.

Pregnancy is a large area of thought and desire especially in young women. Although there are quite a lot of

successful pregnancies recorded and mothers and children seem to be well, many a woman feels, that she risks her life and, worse, that she risks a life without mother for her child, if mother does not survive the pregnancy and the act of birth. Here good medical information can add a lot of quality of life to our patient, especially to the young ones.

From my experience it is a huge obstacle to “psyche okay” when a patient could not take the decision pro or contra a new organ for him – or herself because of High Urgency surgery after falling into a liver coma. I consider the strong, individual positive decision for a transplantation is the basis for a well coordinated psyche after transplantation surgery.

One of my patients fell into a liver coma after he and the rest of his big family had eaten a meal of poisonous mushrooms, I gather they are called death caps. The twenty year old man got deeply depressive when he realized what had happened. He fought against this feeling of helplessness : non of the others had become as sick as he, although he was the only one without symptoms after the meal. An injury to his soul and his feeling of self value – he wanted to rather die than continue a way of life he had not chosen and it was hard work to get him to accept his new liver as a friend, as a life saver.

There I experienced how furious doctors must feel sometimes because of the lack of knowledge of some of their colleagues – this young man's practitioner gave him abundant quantities of antidepressives and pain relievers, so he became addicted and it really took great effort to free him. Another man, over fifty, successful manager, never came back to his feet – he tried to persuade everybody that he had died and that his salvation by transplantation was an error. He felt he was a dead man. Nobody could help him, in the long run he had to be taken to psychiatry.

This sad fate persuaded me once more, that the preparative talks are the most important predictor for a successful transplant. It is not that only the positive or the negative informations must be delivered, but that the requirements of the informed consent be met. Preliminary talks must open psyche for fight and mobilize the power of love for life. This means that a certain period of waiting and preparation is very good. Patients must know that they can choose the alternative to transplantation which is death. Our time that only seems to produce young, healthy, strong people and does negate death and suffrance creates the conviction that everything must be done for survival. But it may well be that physical survival is not equated by psychic survival.

Patients must get into a certain inner conflict to open resources and develop psychic stability. To cope with potential problems post surgery they must have taken the firm decision to want the transplant – to put up with it is not sufficient.

Of course you expect me to say something to alcohol induced liver failure. Alcohol is a huge subject. Certainly no one should drink too much, though there

must be a reason why the WHO claimed alcoholism an illness. But most patients with alcohol induced liver cirrhosis are treated by the majority of the health system like criminals, responsible for the cost and the trouble they cause. I once witnessed the chief of an intensive care unit yelling at a recently operated patient with alcohol induced cirrhosis that she had no right to cry or yell for pain medication – had not she herself ruined her liver ? So it was nothing but her duty to keep quiet and thankful. Did anybody give him the right to treat that person that way ? Is he free of stain ?

One of my first transplant patients, ten years ago, still is quite lively in the memories of all of our TX team. A man working as a construction worker in his forties who came to the ward yellow like a lemon, still actively drinking. He was not adjustable to any of the criteria we use to classify someone as transplantable : marriage broken, fighting for the beloved children, out of a job, looking for a flat, no friends, no real aims for the future – disaster on every aspect. A real loser.

But somehow he touched us. His will to live, his personal story of mischief and energy to put up with it, his obvious misery appealed to our hearts and brains and he got a new liver. He lived quite well with it, especially after some weeks of supportive treatment in our psychosomatic department where he worked out many of his former problems and made friends.

Then started the hunt for a job which, in his case, meant retraining for a new job. First blow : the medical officer wanted to send him into retirement. After our transplant resident intervened, it came out that she wanted to do him a favour.

Then he tried to be trained as an office worker. The authorities managed to make him wait for more than a year, only then he went to classes. Unfortunately he was assessed in a group of drunkards, who did not mean to really learn. His nerves went mad at exams, he had put the expectations in his own capabilities much to high, and finally he took up drinking when he failed.

He was so ashamed of the relapse because he felt very obliged to us, that he did not come to the ambulance appointments anymore. Then he was hospitalized. He was so very much deceived by himself, that he died not long after. His selfconfidence, his feeling of selfesteem had gone down to zero. Psyche okay ? Nothing to be done for him.

Also a long waiting time before transplantation seems to me not to be a test for abstinence but a very hard trial. We had a lady patient who waited bravely two and a half years – then she was too disappointed, too ill and discouraged by the endlessness of the wait that she took up the old way she had used as coping strategy in problematic life events – she went back to alcohol. As a relapse patient she was put n.t. for half a year and did not survive that extension.

So the cruelty of the endless waiting period without a real confirmation of transplantation, the actual bad working market situation and the broken family misfor-

tune may affect transplant patients psyche much more than their disease.

Let me come to my last point of consideration. The actual trend to living liver transplant does cause a lot of concern not only to me but also to my fellow colleagues from the psychosomatic departments. I am not speaking about the donation of a liver segment from parent to small child – I am talking about adult living liver transplant.

It all looks so easy. But is it easy ? And for whom ? Let me give you an example. A 50 year old mother of two children is in bad alcohol trouble, followed by liver failure. She would never survive the waiting period of about a year. Why not call in the children and tell them that they can save mother's life if they donate a part, just a part, of their own liver ! ?

The 50 year old got the liver segment of her daughter and died three months after – the daughter is my patient, she worked and works as a surgical nurse in the hospital where her mother was transplanted, is very well treated by everybody, but had to overcome a massive emotional crisis. There had been massive pressure on her, by the doctors, by her family, by her own superego. This was even strengthened, when the three members of the ethic committee, that is obligatory to be met pre living organ transplant in Germany, refused to accept her as a donor. They thought, she was not mature enough and under pressure. She then really got into trouble. She decided to fight and following the positive report of another psychiatrist consulted the transplantation started. This procedure, strange as it seems, was legal, because transplantation law leaves the ultimate decision to the doctor in charge.

Three months later her mother was dead. She is in good physical condition, but she says : "I will never really get over it – I did too much and too little". What she means is that she did too much for her own self, for her own power, she did overdo it, yet she could not save her mothers life, she did too little. I am very happy to see that she is about to change her life, get out of the reach of her family and the clinic, live a selfdetermined life following her own criteria of what she will do and what not.

Unfortunately it occurs to me that the will to help of some doctors – or is it the ambitious will to transplant ? – is major to their sensitivity for the potential donors and receivers. I asked one of the eminent transplant doctors of a huge German transplant centre about the contents of their psychological check up. He was dazzled and said, that he was not really sure but that it certainly had to do with quality of life. How is it possible that an excellent surgeon is so little concerned about the soul of his patients ? Maybe they are victims, like some of them think they are ? Some of our patients certainly become victims, those who die, because an organ, that might have fit them, will be implanted in a case of urgency in a donors or a receivers body. Reviews say this becomes necessary in 15% of the living liver transplants. Quite a

lot, says the pensive psychologist. And 3% mortality also is quite a price.

I was mentioning the ambivalences in the beginning. Transplantation is full of ambivalences. Look at this one : If your doctor in charge puts to you the alternative that either you give part of your liver to your mother or you will have to accept that she dies – how would you react ? I do not believe in voluntariness in coping with such a test.

The pressure that is put upon a healthy person loving his or her mother is immense, decision structures or the possibility of saying NO are paralyzed. The grip of a double burden cuts the breath : the impending death of a beloved person, the panic to be the murderer, the threat of social stigmatization, but also the frightful idea to be harmed yourself, to loose your own life physically, socially, professionally. I doubt the value of research that praises the value of “snap decisions”, i.e. the decisions that are made up in a second, even decisions concerning such vital items, and I hate the idea that some surgeons are proud that it is possible for a donor to take the decision and get ethic committee’s green light within 24 hours. Isn’t that a little too obedient to the urge of a technically highly advanced medicine that just does everything that seems possible to perform ?

But the fact that something can be made is not the justification that it is made. I am certainly not a person who thinks we should abandon high tech medical treatment in favour of herbal and witchcraft healing, but after ten years of engaged work as a psychologist in the transplant segment I see signs on the wall that the ethical and other limiting components may vanish in favour of feasibility and opportunistic short sightedness. It is not only the medication that causes major depression and fear in so many patients. It also is the lack of worry about psychic stability.

So to say that psyche is okay also implies that the transplant patient really got it clear, that the donation of the liver, certainly also the postmortal organ donation, is a gift, that gives at least a touch of sense to a death that seems so senseless und illogical.

Well, I became very serious. But there again you catch me at an ambivalence. Of course with most of our patients we can state : transplant okay, psyche okay. I do wish you many, many successful years – may transplant medicine and transplant patients benefit from the wonderful and conscious efforts of all the human beings who run Cliniques Universitaires Saint-Luc – doctors, nurses, scientists, administrators. Thank you.