36 Communication with Transplantation Patients

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> What we perceive in the strangers with whom we live are "initially" neither "strange bodies", ... nor are they strange "selves" and "souls", but they are *unified wholes* that we look at.
>
> Scheler, 1926: 255 (transl. by KM & ML)

Abstract: The specific aspects of communication with transplantation candidates and patients are introduced and possible communication competencies and strategies are presented. When dealing with (potential) transplantation patients, many different developments can arise that pose particular challenges to the communicative competence of medical staff. In the transplantation process, the doctor's communication should also be characterised by an attitude of respect for the individual uniqueness of each patient and recognition of their autonomous decision-making competence. Communication with patients is not primarily about conveying technical information, but about a holistic perspective on a person with a life-threatening illness, whose questions and emotional reactions must be taken into account. It is advisable to involve family members in the discussions and decision-making processes in the transplantation process at an early stage.

36.1 Attitudes and competencies of medical staff in consultation with Transplantation patients

Communication with patients before and after organ transplantation is a special case of communication with seriously ill patients. Specific aspects arise in consultation with these patients that justify a separate presentation. Basic skills such as active listening and empathy are particularly important when dealing with transplantation candidates and patients.

General practitioners are rarely confronted with this special case of communication, but in special settings such as specialist outpatient clinics for seriously ill patients, transplantation centers or dialysis units, it can make up a considerable part of everyday professional life. More than 34,285 solid organ transplantations were performed in the EU in 2019; by the end of 2019, more than 58,000 patients were waiting for an organ transplant in the EU (Vanholder et al. 2021).

These waitlisted patients endure the uncertainty of whether they will be considered for a transplantation in time, i.e. before further serious damage and death. Yearly, 3–4% of those on the waiting list die before being transplanted. The waiting list manipulation scandals that have become increasingly publicised in the world in recent years highlight the great dependence of these patients on the medical system (meaning all decision-makers in the healthcare system such as doctors, health insurance companies and healthcare institutions). They also show the great importance of the trust that transplantation patients have to place in the transplantation teams: they entrust themselves and their recovery process completely to them.

A patient's trust in his doctor has many prerequisites. There are at least two basic expectations that patients have of a good doctor, as described by Talcott Parsons as early as 1951: firstly, the expectation of his affective neutrality (i.e. the expectation that he will treat all patients equally, regardless of person and regardless of sympathy or antipathy) and secondly, the expectation of his altruistic (collective) orientation (i.e. the expectation that he will put his own - scientific or financial - interests to one side) (Parsons 1951).

Due to the particular existential dimension of the situation in which transplantation candidates and patients find themselves (transplantation directly addresses questions of physical identity and the finite nature of life), medical communication with such patients is always a "special encounter". The doctor must reflect on how the relationship between himself and a person who is confronted with his finiteness at the very moment he is talking to him will develop. The patient may be struck by the fear that he will not receive help in time or that his transplanted organ could be rejected. The doctor must ask himself what he can do to ensure a respectful, successful consultation. In the temporal and economic constraints of a medical business, organized predominantly around medical technology and apparatuses, the fundamental importance of the relationship between doctor and patient threatens to fade into the background, so that it can no longer sufficiently develop its healing and containing function.

In contact with transplantation patients, it can happen time and again that the doctor himself is confronted with his own fears about finiteness and vulnerability. He must recognise and endure these feelings and can even usefully incorporate them into a compassionate attitude in the communication with the patient.

When conferring with the chronically ill patient, the doctor must also remain aware of Thure v. Uexküll's fundamental observation that in the course of the increasing permeation of medicine by science two "models for the body" and its diseases have developed, as a result of which "two different images of the human being" have also emerged, the "official" and the "unofficial" model. The "official model", which according to von Uexküll is taught at universities, conceptualises the body as a "highly complex system of physical and biochemical processes, whose nature and functions we are getting to know more and more precisely, right down to the molecular level". The "unofficial model" is a completely subjective and individualised image that people have of their bodies. Although this model is not taught to doctors during their studies, it is essential for them to understand "what their patients are talking about when they complain of pain, nausea and other physical problems" (v. Uexküll 2001: 129, transl. by KM & ML). Particularly when complex biological and technical-physical connections are involved, such as in the transplantation of a solid organ, the doctor must maintain a holistic approach to the person with whom he is dealing. In consultation with his patient, he should try to understand his patient's subjective body image and his understanding of illness and healing. In order to successfully communicate with the patient, both images and models of the body and their corresponding images of the person must be integrated. In addition to focusing on the diseased organ, the doctor must never lose sight of the whole person and their existential threat.

36.2 Communication with transplantation patients and candidates during the process of treatment

36.2.1 Notification of the need for a transplantation

The announcement that a transplantation is necessary in order to continue living is similar in its emotional power to the announcement of a life-threatening diagnosis. The patient perceives a dual sense of finiteness in this message: his body is life-threateningly ill, but the supply of a life-saving transplantable organ is a finite resource. It is not certain that he will receive a life-saving organ in time. In this situation, the patient needs someone to talk to about their emotions and sufficient time to understand and digest such a message.

The patient's emotional reaction to this information can vary greatly and range from hopeful anticipation of a possible life-saving intervention to "diagnostic shock" with a feeling of rigidity and being at the mercy of others. The patient can express various types of experience: "I feel like I'm watching a film", "I am shaken to the core", "I've already thought something similar" or "Wow, I don't even know if I want this yet". Feelings of helplessness, anger, despair and hopelessness can arise. These reactions are all completely appropriate to the patient's existential state of emergency and require an empathetic response from the doctor.

During the discussions with the patient about the next steps, the medical procedure and the stresses and strains that the patient will face should be explained in understandable language, and the patient's emotional reactions (fear, uncertainty, anxiety) should be closely observed and taken into account. Sufficient time must be allowed for questions. The patient's dignity, self-determination and ability to act independently should be strengthened - the patient will need a great deal of self-motivation and perseverance during the process of transplantation.

When communicating the medical necessity of the transplantation, it is essential that the doctor also recognises the patient's history of suffering and coping with his illness. He should address the fact that the patient has already travelled a long road of illness and coping with it. The fact that a transplantation has become necessary in no way means that the patient has failed in his or her health endeavours. Otherwise, there is a risk of a situation in which the patient is degraded to a passive recipient of an organ who has to endure the entire transplantation process. In fact, the transplantation process actually requires a great deal of active co-operation from the patient. It is therefore very helpful to address the patient as an actor in the process from the outset and to take their opinions and needs seriously.

The doctor should not overwhelm the patient with too much information or pressure to make a quick decision in favour of an operation. After providing important information, the doctor should regularly ask whether the patient has understood it or has any questions. The patient's emotional state should be recognised and their anxiety addressed. Particular attention should be paid to specific anxiety-related ideas about the transplantation, e.g., the patient's possible fear of having their personality changed by the loss of their own organ and the "incorporation" of a foreign organ ("Will I lose my warmth along with my heart?"). When communicating with the patient, the aim should be to support and inform them and to explore and strengthen their mechanisms of coping with the situation. The conversation should not be too "technical“ but should take the human and existential side into account. The patient should always be given the opportunity to ask questions. In their excitement or tension, patients often forget to ask about aspects of the transplantation process that are important to them. It is therefore important to signal that they will continue to have the opportunity to do so. Sometimes patients also summarise their last consultation in writing and bring their questions with them to the next appointment. Giving them the opportunity to ask questions can greatly relieve the atmosphere of the consultation, as the patient realises that they do not have to "fit everything in" in the short time available and that it is okay to forget aspects.

The following is a short excerpt from a conversation with 57-year-old Mr Peter, whose heart function has increasingly deteriorated, so that there is a medical indication for a heart transplantation (E 36.1):

E 36.1		Notification of the necessity of a transplantation (consultation in a cardiological ward)
01	D	Mr Peter, we discussed yesterday that the condition of your heart has deteriorated. It is no longer pumping as well as it did six months ago.
02	P	Hm. I felt that myself.
03	D	Yes, you have told me in the last few days that you often had shortness of breath and were no longer in the best of health.
04	P	Yes, I've even often thought, now that was it .....
05	D	hmhm
06	P	It was that bad.
07	D	That obviously really affected you... and frightened you.
08	P	oah
09	D	hmhm. Yes=and now we can also see in our examinations that the heart function has deteriorated.
10	P	... hm
11	D	In other words, as doctors we can see with our methods, as you yourself have noticed, that your heart function is deteriorating. And we can perhaps stabilise this a little with medication ... but ... the heart will not get any better.
12	P	oah... uh

13	D	hmhm
14	P	Is there nothing you can do?
15	D	Yes, something can be done. Ultimately, a transplantation would be an option. Can you imagine what that would be like?
16	P	Jo ... Old heart out, new heart in.
17	D	Yes, it's not quite that simple. You're right in principle, but it's actually a bit more complicated=
18	P	Oah, er [groans] ... a transplantation [gaze wanders away from the doctor across the room]...
19	D	I realise that this might be a kind of shock for you and is still completely new and unsettling.
20	P	Joa, I don't know what...
21	D	It is quite clear that in a situation like this and after receiving such information, you first will need time to understand the situation and digest the information. We don't need to discuss everything right away. I think it would be best if we sat down together again tomorrow and I explained to you at your leisure what would be involved in a transplantation, what the procedure would be like and what else needs to be considered, do you agree? And, of course, what you would think of such a procedure, right?
22	P	Jo. Hm.

Over the next few days, the doctor discusses the procedure for a heart transplantation in several consultations, each lasting around fifteen minutes, and repeatedly asks in detail what Mr. Peter has understood about the procedure, what he thinks about it, how he reacts emotionally to it and how he assesses his own ability to cope with it. He also asks Mr. Peter's wife to join the consultation several times.

It may be useful to supplement the interviews with potential transplantation candidates with questionnaires in order to obtain information. At Stanford, Maldonado developed a standardised psychosomatic assessment (SIPAT), which apparently also has predictive value for assessing the psychosocial and possibly also medical consequences of a transplantation (Maldonado 2015). Such standard procedures can help to obtain information, but are always only supplements to direct, sympathetic contact with the patient.

36.2.2 How much longer? The waiting time between inclusion on the transplantation list and transplantation

The time between being placed on the waiting list and the actual transplantation can take many months, sometimes years. It is not uncommon that a transplantable organ will not be found in time, resulting in the death of the patient. During the waiting period, many patients consequently develop a fear of not being provided with the needed organ in time. They often need a lot of support and reassurance that they will not be forgotten during the waiting period.

Patients often experience a rollercoaster of emotions during this phase of the transplantation process: hope for an early transplantation can alternate with intense fear of the procedure or the fear that a saving organ may not be available in time. Sometimes patients are irritated by their own changes of mood and "do not recognise themselves". The doctor should always give special recognition to the emotional strains during the waiting period and the patient's efforts to cope with them. They should point out that changes of mood during the waiting period are by no means unusual and are entirely appropriate to the emotional "stress" of the situation. In cases of deterioration of the patient’s condition, sensitive requests for patience and emotional support are extremely important for patients and their family members.

The following excerpt (E 36.2) shows how Mr. Bernhard, a 60-year-old patient with terminal heart failure who is waiting for a transplantable heart, describes his current condition to the doctor at the transplantation center:

E 36.2		Patient well-being before a transplantation (discussion at the transplant center)
01	P	At the moment - let's put it this way: the main problem is my head.
02	D	What do you mean?
03	P	My head!
04	D	Head! Hmm.
05	P	Yes, in the sense that I can see in many things that I could die, now …..
06	D	Hmhm
07	P	Yes.//I walked here, but it took more of a toll on me … er …

I'll say now, than I thought it would. I ... er ... it's like when I'm lying down and something goes through my head, I always relate it to my illness.
08 D Yes=
09 P And er, as soon as something doesn’t let me feel totally comfortable ....
10 D Hmhm
11 P Then I am afraid that it would get worse again, that is, I had a defibrillator implanted and it went off several times on *[date], I was alone at home, then I was here in the clinic because of that, twelve times in total ...
12 D Hmhm
13 P And 24 hours later in the intensive care unit four more times
14 D Hmhm
15 P But they wanted to; they intercepted it well, I guess I can say that I didn't notice much of it

Mr Bernhard vividly describes his fears when he is constantly checking his physical condition to see if something is "getting worse". This patient is tormented by the idea that the "defibrillator" (pacemaker with built-in electric shock unit that is triggered in the event of life-threatening ventricular fibrillation), implanted due to his severe heart failure, could "go off" and cause very unpleasant physical sensations, such as he has already experienced. It is important that the doctor listens to and recognises his fears and allays them if necessary.

It is also not uncommon for information given to the patient to be forgotten during this waiting period and for the patient to ask the doctor the same questions several times; the doctor should be aware that the patient's cognitive functions may be impaired in the exceptional emotional situation of waiting for a transplantable organ and should patiently provide information again and again.

36.2.3 An organ has been found - we can operate on you

The notification (usually by telephone) that a transplantable organ is available and that the operation for which the patient has waited so long can therefore "go ahead" often triggers a shock reaction. Mr. Heinrich, a patient who underwent a liver transplantation a few months ago, recalls the situation in which he was informed that an organ was available (E 36.3):

E 36.3		Time to process a surprising information
01	D	What was it like when the organ was there?
02	P	I was operated on from the 27th to the 28th. That was our 30th wedding anniversary. And the Mr Heinrich left..., I was in the garden with my wife..., the phone rang..., I knew straight away that this was it. Because nobody else knew the number except the transplantation center. ... Yes, and then my knees were rubber. The bra:ve guy was..., not afraid..., so now..., well..., I was at the moment..., [makes himself small and bends forward looking down] this is how I must have been sitting there... then I first said to him on the phone: that's not possible, I can't now...
03	D	What did you feel then? So what was that?
04	P	I said goodbye to everything. I stroked my fir trees one more time... and my trees one more time. And I said: Bye, take care, if I don't come back, then... Then they called again, ... after 20 minutes... Yes, and then home and off we went.
05	D	You've reckoned with everything, so to speak?
06	P	Yes, yes. Sure. 65 years. And how quickly can something happen.

The first moment after being informed by telephone that an organ was available for him, Mr. Heinrich refused the transplantation operation; the doctor who called gives him some time and calls him again a few minutes later; only then does the patient agree. It is very important for the doctor giving the news to allow the patient some time to "digest the news" and adjust to the situation. This can be very difficult, as the doctor himself is under great pressure to organise the operation quickly and to have a patient sufficiently prepared for the upcoming operation. He may feel under great pressure to act and feel that he has little time to give the patient. In this situation, it may help the doctor to realise that the announcement that an organ is available can take patients by surprise and at first overwhelm them with their fears about the further procedure, so that they need a moment to collect themselves and consult with their family members.

36.2.4 Has it happened already? The immediate postoperative period

A few months after a heart transplantation, Mr. Jonas looks back on the immediate aftermath (E 36.4):

E 36.4		Conversation about the experience of a transitory psychotic episode
01	D	hmhm How did you feel during that time [immediately after the transplantation]? Can you still remember that?
02	P	Yes, yes. So well that I can describe that to you very, very precisely. The first time after the operation after I = came out of the coma? and practically only just had my eyes open again =
03	D	Yes
04	P	So when you saw me there, that was: ... uh? such a to:tal time; a time of total, - uh? ... persecution. - That may surprise you. I didn't even realise it at the time because I thought it was normal.
05	D	hmhm
06	P	It was a real persecution mania, which is how I see it now. I didn't eat anything back then - and I didn't drink anything, even though I was incredibly thirsty =
07	D	hmhm
08	P	And only hesitantly, because I couldn't stand it any other way, did I start drinking anything=
09	D	Yes?
10	P	And... one detail for example, never drank my tea completely =
11	D	hmhm
12	P	because I wanted to leave something behind - which could be used to check what I had been poisoned with =
13	D	hmhm
14	P	- It went that far: that's how crazy it was.
15	D	hmhm
16	P	That far. So I've always had the feeling ... but I've only now realised this in retrospect: I've had the feeling - I haven't even had the operation yet. That means I don't have a heart yet! I've had an operation: = but they've realised that it's no longer possible = that it's no longer worth it. - because I was just so weak, and everything. You've had an operation, but the heart is still the old one in there. And they're now waiting for you to die so that they can take your organs.

In this dialogue with a doctor of psychosomatic medicine, Mr. Jonas, a patient a few months after a heart transplantation, vividly describes his experience after waking up from a coma in the intensive care unit. Apparently, he suffered a post-operative delirium ("brief psychotic disorder") with hallucinations and delusions. During a post-operative delirium, the patient requires particularly intensive support with constant communication and informative references to his situation ("You have already undergone surgery and are recovering from the major operation"; "You are on the road to recovery"; "You are currently in the intensive care unit, things are improving").

As such delirious states are not uncommon, especially after cardiac surgery, it is advisable to prepare patients for the possibility of their occurrence before the operation. A visit to the intensive care unit can serve to alleviate patients' fears before the operation and enable them to realign after the operation, which supports patients' sense of orientation.

Even without the occurrence of delirium, the post-operative period demands a great deal of adaptation from the patient: they must familiarise themselves with their physical capabilities, gradually test and train them. They have to adapt to the new possibilities they have regained. They also have to realign in the family system: Patients who previously had terminal heart failure and needed a considerable amount of support from their relatives can now take on many tasks themselves again and redefine their limits. This often meets with resistance from family members and can lead to a variety of conflicts. It is advisable to offer the patient the opportunity to talk about such issues in the run-up to the transplantation and during the further course of recovery; a discussion with family members can be very helpful in some circumstances.

36.2.5 There has been a rejection

The announcement of a rejection reaction against the new organ is equivalent to the announcement of a life-threatening diagnosis. It very often triggers existential fears in the patient: How will the rejection be overcome? Will an effective antidote be found? Will I have to take strong medication with severe side effects? Will a re-transplantation be necessary? During this time, the patient's hope for effective therapeutic options will often be severely put to the test. The disappointment of "failure" can result in constant anxiety, bitterness and isolation from the therapeutic team. This is precisely when empathetic contact with the patient is essential.

A few weeks ago, Mr Konrad experienced the rejection of his transplanted heart (E 36.5):

E 36.5 Condition of a 57-year-old man 1/2 year after heart transplantation and 6 weeks after a rejection reaction

01 P I say to all the doctors, "Talk is cheap: - I'm case number so-and-so for you: that's not meant in a bad way: but = and if something goes wrong, then they say, "yes: and *[year], then we had =" eh = what do I know, "case number so-and-so;" and they think, "yes, and at first it looked so good: and then all of a sudden it went wrong," and I don't really have any desire for that. I'm my - what’s the saying? "Be your own chairman", right?
02 D hmhm. - Yes. --[7]-- Do you often think about possible complications = that could occur? -
03 P [sighs] Eh, I, I don't think about it = just the type three rejection = that burdened me = a lot, because = I didn't realise it myself. - so. Ya know? and eh = neither during the measuring…nor… just by eh subjective feeling. and that's one of those things that I think there's a bit of…how do you say? I didn't notice it at all and would have if it hadn't been discovered at that moment! I would have found myself on the best way to the village cemetery here…or to a new transplantation (takes a breath) an artificial heart…who in hell knows when another organ would have been found so that means if I had the thermome:ter…that, the thermometer would be somehow like this…there is somehow: [very loudly] something to go on.
06 D Hm. yes.
07 P but a type three straight away! and nothing: but nothing at all: nothing noticed = that's hard.
08 D hmhm.
09 P because with a type four I'd be down in intensive care.
10 D hmhm.

Mr. Konrad has lost his "basic trust in his body" because he has not subjectively noticed anything about the rejection and the regular measurement of his body temperature has not provided any indication of a rejection reaction. Anxiety characterises his current state of mind: Will such an event happen again? Will it be recognised in time? Do I have to be under constant medical observation? Will there be a rejection of a higher degree ("type four" instead of "type three")? Here it is important to recognise his anger towards the doctors ("Talk is cheap"), to acknowledge and endure it as an expression of his fear of sudden death, and together with him to try to put this fear into perspective: What can happen? What needs to be considered? How can Mr Konrad take good care of himself? What changes in his body should he be aware of? It is important not to "dismiss" his anxious fears, but rather to recognise that he is fundamentally threatened and that an anxious state of mind is perfectly understandable. Together with him, one can consider what a good balance between anxious rigidity and carefree satisfaction with life might look like for him personally.

36.2.6 What happens next? Consultations during the future course

In the months and years following the transplantation, questions can repeatedly arise or problems occur. In these cases, it is important for the attending physician to patiently answer the patient's questions and discuss medical findings.

Difficulties experienced by patients in following medical rules and advice (compliance or adherence difficulties) should not be perceived by the attending physician as a personal imposition and rejection of his medical expertise and answered with moral reproaches to the patient but should be understood as questions from the patient about how to proceed, which require intensive support. It is important to "take patients along” as active subjects in the further process. They must always be informed transparently about the medical and personal consequences of their actions and addressed as subjects of the healing process. This implies the readiness of the physician to allow the patient to reject actions that appear medically sensible from the doctor's point of view.

36.3 Special dialogue situations in transplantation medicine

36.3.1 Living donation

In the case of the paired kidney organ and the large multi-lobed liver organ, where a partial organ donation is possible, there is the option of the living donation, i.e. relatives can donate an organ to the sick patient. In this case, a comprehensive preliminary diagnostic examination of donors and recipients of the organ is carried out in order to assess the motivation and relationship between donor and recipient (LaPointe Rudow et al. 2015). It requires a great deal of sensitivity on the part of the examining physician to assess the motivation of the donor in a discussion with the donor and recipient (which should ideally take place at first separately and subsequently together) and at the same time to check whether there are any relationships of dependency that could be a burden on the transplantation process. Organ recipients and donors should also continue to be supported after the living donation in order to be able to support them in the event of complications.

In the case study (E 36.6) below, a mother who three years ago donated a kidney to her now 23-year-old daughter talks about how she is able to give her daughter, whom she had always seen as particularly vulnerable and susceptible, more freedom and independence. She realises that she is gradually less worried about her well-being, which has also led to a reduction in her own complaints.

E 36.6 How a mother feels 3 years after donating a kidney to her daughter (interview at the transplant centre)

01 P I mean, at that…., at my age, you do have aches and pains from time to time.
02 D What kind of aches and pains do you mean?
03 P I have to say that the whole thing [the living donation] has a pleasant side. I had more headaches before the operation, but now, after the operation, I have very few. Yes. I don't know why that is. But I've noticed that before… Maybe it was also the fear: for my daughter or something, that it was somehow psychological perhaps. I don't know. Now I occasionally feel, before my period… I feel a bit indisposed, unwell. But it's nothing serious. I just get a bit of… just a hint of a headache. But I used to have real attacks. Almost migraines. And I haven't had that for the

last three years.
04 D And you think that might have something to do with the operation?
05 P I don't know = perhaps. I don't know.
06 D That you worry less = you don't rack your brain -
07 P Yes, definitely, for sure. That's one less thing to worry about. Sure, I'm still worried about illnesses or the flu epidemic and stuff like that. Sure, one does worry about that.
08 D That [daughter's name] could catch something.
09 P But she takes care of herself. She dresses warmly. I don't need to tell her to put on warm underpants or anything. She does it all herself. That's how sensible she is.
10 D In this way, she also relieves you of another worry -
11 P Yes, yes. And she moved out in May. But just a few streets away. Yes. When she's ill, she comes to me, then she stays with me. Then I can look after her. And mother her a bit.

36.3.2 Dealing with family members

Family members are also very burdened by the terminal illness and the transplantation process and should be involved in the decisions and accompanying discussions from the outset. The time after the transplantation is also challenging for family members.

In a joint interview seven months after her husband's successful heart transplantation, Mrs. Horst reports how she often must "slow her husband down" so that he does not overexert himself (E 36.7):

E 36.7 Conversation with a patient and his wife 7 months after a heart transplantation

01 P I realise that I can do a lot more, that I don't get short of breath at all when, for example, I go for walks. The only time I was out of breath was on a strenuous hike in the [name of the landscape]. I was really panting then. I deliberately stopped in the middle because my heart rate was also very high. It was 120 and that was a bit too much for me.
02 W* I was also very pleased that he then stopped. But I had to slow you down, otherwise you would have kept going ... [W and P laugh]

03	D	[So do you ever get the feeling that your husband is doing too much of a good thing?
04	W	Yes, yes. I have to intervene once in a while [W laughs].
05	D	Hm=
06	P	[Yes, not because... Sorry.
07	W	[Sometimes you only realise afterwards that ... that was probably too much? But then, in exuberance! or something like that, he gets going. And now I know I have to get involved [W laughs]
08	D	The exuberance of the new heart. Where so much is possible...
09	W	Yes, my husband has so many ideas which he wants to realise straight away ...
10	D	hmhm [turned to P] And what's it like for you when your wife slows you down?
11	P	Yeah, I know that she is very concerned about me. I'm really a bit unbridled sometimes, so it's good that you're looking after me [turns to W] [smiles]

*Wife of patient

After a transplantation, the patient's friends and family are always affected and the immediate family members experience fear, hope and despair at first hand before and after the transplantation. They should therefore always be informed on the steps to be taken and the situations to be expected. The doctor should empathise with the suffering and emotional stress of the family members.

In the interview example, Mrs. Horst vividly reports how she still "looks after" her husband even after the successful transplantation (which in this case apparently does not lead to a conflict with her husband).

After the transplantation, a new balance often must be found among family members (Who can do what? Who is burdened? Who has which privileges?).

36.4 Summary: Listening and speaking in transplantation medicine

The above comments are intended to give an indication that in transplantation medicine patients are in an existentially demanding situation causing intense emotional reactions, to which the doctor must respond with much empathy in the discussions. Transplantation is not a purely technical-biological process in the course of which an organ is replaced but represents a holistic challenge for both patient and doctor, which they must overcome in their consultations.

References

Further references on doctor-patient communication can be found in other topic-specific chapters and in the complete bibliography of the handbook.

LaPointe Rudow D, Hays R, Baliga P, et al. (2015): Consensus conference on best practices in live kidney donation: Recommendations to optimize education, access, and care. American Journal of Transplantation 15, 914–922.

Maldonado J (2015): Predictive value of the SIPAT for post-transplantation outcomes. Journal of Psychosomatic Research 78, 613.

Parsons T (1951) The Social System. Glencoe, IL: The Free Press.

Scheler M (1926/2009): Wesen und Formen der Sympathie. Studienausgabe. Bonn: Bouvier. (2017: The nature of sympathy. New York: Routledge).

Uexküll T v (2001): Körper-Sein, Körper-Haben – Der Hintergrund des Dualismus in der Medizin. Psychotherapie Psychosomatik Medizinische Psychologie 51, 128-33.

Vanholder R, Domínguez-Gil B, Busic M, et al. (2021): Organ donation and transplantation: a multi-stakeholder call to action. Nature Reviews Nephrology 17, 554–568.

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