The more organs you report, the greater donor consultant you are

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The greatest problem for Czech transplantations is the lack of organs. There is the suspicion that not all doctors report suitable deceased donors to the procurement and transplantation centre, even though they are required to under law.

Caption: "The fact that patients wait a year for a kidney cannot be termed a success, when only 11% of the sick are on the waiting list," says the Head Physician of the IKEM Transplant Surgery Clinic, Dr. Jiří Froněk.

Photo: Koalice pro zdraví archive

Compared to other European countries there is also a lack of organs from live donors, who are not motivated to donate by anyone or anything. In addition, the whole system of financing transplantations does not function. The number of organ donors stays about the same each year, while the number of patients waiting for a new organ rises.

Involving the medical personnel who are closest to the organ donor (i.e. doctors at the Anaesthesia and Resuscitation Department - ARD - and Intensive Care Unit - ICU) is the key to more effective management of organs. The Transplant Coordination Centre ("TCC") has now trained 20 "donor consultants" in collaboration with the Health Ministry and a further 50 will undergo training over the next few months. Under the training courses, doctors are familiarised in detail with the legislation in force and current and future practices. The coordinators are involved not only in increasing the donor potential; they also check that all statutory rules associated with donorship are observed.

A donor consultant is directly subordinate to the assistant for therapeutic preventive care. In a range of situations he must actually go against the interests of other departments at the hospital. For example, he carries out examinations which delay work on other examination processes or block the operating theatre for the collection of organs, which are then not available to other patients. These activities are difficult to coordinate by the Transplant Coordination Centre and transplantation centres, therefore coordinators are essential.

Increasing the collection of organs

"Now we are mainly training doctors at ARD and ICU, particularly from small hospitals. We teach doctors to identify clinical death occurring in an intubated patient with instrument substitution of heart activity. There aren't many such patients. They represent about 10% of those hospitalised at ARD and ICU, only one of which is suitable for organ collection," as Dr. Pavel Březovský MBA, Director of the Transplant Coordination Centre, who believes that hospitals often do not meet the obligation to report clinical death due to economic and administrative obstacles, describes the start of the transplantation process. "If we know that 1% of patients from ARD and ICU is suitable for organ collection and only 0.4 to 0.5 percent of those patients are used for transplants in the Czech Republic, it is clear that clinical death is not diagnosed in some hospitals," he adds saying that if cooperation between hospitals, transplantation centres and the TCC was improved by 100%, we could conservatively estimate an increase in organ collection by 30 to 40 %. By checking the correct and timely diagnostics of death the programme could be used successfully, for example in France, when every death at the ARD of individual hospitals is checked and procedures relating to collecting organs are evaluated. Hospitals will no longer be able to just stop taking care of the patient and his organs by turning off the machines and stating death.

Sudden clinical death

Identification of clinical death is a relatively difficult process. The neurological symptoms of clinical death are determined by a neurologist by clinical examination; they are proven with instruments according to the Act on donations, collection and transplantation of tissues and organs by examination of blood flow through the brain by arteriography or scintigraphy. If it is possible to make an examination on the spot, it is unnecessary to take the patient to a better equipped work station, since it is necessary to prove with the initial examination that the flow through the brain is sufficient and further intensive treatment is taking place. The examination is then repeated at the "better" work station based on the development of the patient's situation. The procurement transplantation

centre then decides whether the cause of death will prevent organ collection. In a range of diagnoses, such as the final stages of neoplasia, dissemination of metastases or crushing of organs, transplantation is not possible, although collection of organs cannot be clearly ruled out in the case of some diagnoses even among oncology patients.

If a patient is in a coma on a ventilated bed, the doctor should inform the procurement transplantation centre as soon as the Glasgow Coma Scale (GCS) drops to 8, therefore about 72 hours before the GCS drops to 3. The buffers should also be removed from the patient for 12 to 24 hours to prevent distortion of the neurological finding and an erroneous evaluation of the situation. "With clinical death the situation develops very quickly. Everything that the brain integrated up to that point stops functioning and everything runs by itself. Hypothermia begins, circulation is centralised and the patient immediately begins to lose a vast amount of liquids because the vasopressin stops working. At this moment somebody needs to be with the patient to apply medicaments and react to biochemical changes, that means a highly trained doctor," describes Dr. Březovský.

Few smaller hospitals are able to provide the two neurologists who have to repeatedly examine the patient. The TCC has created a system with a model inspired by Spain, under which transplantation centres collect these types of patients, which removes the burden from small hospitals.

In Ostrava they benefit from historical experience

Ostrava Teaching Hospital is home to the second oldest Czech transplantation centre. Its links to the local ARD and ICU are described by the senior consultant of the anaesthesia and resuscitation clinic there, Dr. Jan Jahoda: "Thanks to our long-term experience, the organisation of the transplantation programme is fixed and transparent. A failed transplantation case induced us to rigidly define practices. In addition to the regular rules for transplantology, we have JCI (Joint Commission International) accreditation and therefore designated management acts which define each step. In the methodology for determining clinical death each step is described to the letter."

In Ostrava all donors go through the anaesthesia and resuscitation department. If there is no space, the ARD carries out the work outside the department. According to senior consultant Jahoda, communication with the family is open and, in addition to the coordinator, the chief physician of the ICU also talks to the relatives. Last year there were 15 donors at Ostrava Hospital, this year 11.

Last year just one patient was transported from Prostějov ARD to Olomouc Teaching Hospital for organ collection. Despite this, the approach of Prostějov ARD, which is about 15 km from Olomouc Hospital, can serve as a model of good cooperation. "The proximity of Olomouc Hospital and the direct routing of heavily traumatised patients from the field to the trauma centre is a reason why there are few patients suitable for organ donations who meet the donor conditions. On the other hand, we have good relations and collaborate with the Anaesthesia, Resuscitation and Intensive Medicine Department of the Palacký University Medical Faculty in Olomouc, and Olomouc Teaching Hospital and their doctors coordinating donor care procedures," remarks the chief consultant of the ARD Dr. Martin Pomajbík, at whose work station one doctor is delegated with responsibility for this coordination inside the hospital and communication with the superordinate centre.

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International activities of the Transplant Coordination Centre

- 1) The MODE project is based on transfer of best practice in the whole process, from identification of the donor to successful transplantation. In this project the Czech Republic impressed the other EU members with its system of verifying data on donors from the medical registers, which is intended to increase the safety of transplantation. Experts from the European Commission are even considering making the Czech system obligatory for other Member States from 2013.
- 2) Under the COORENOR project the Czech Republic is leading a group organising an internet portal for exchange of organs between EU Member States. The portal should be launched by the end of 2013 at latest.
- 3) Transplant Coordination Centre representatives are also involved in the BSA (Black Sea Area) project, where transplantation legislation and the practical implementation of transplantation in countries of the Black Sea area are under review. TCC representatives are working on this project together with France and Italy as supervisors and advisors experienced with centrally managed health care and the transition to market conditions.

Money or a kidney?

"The general obstacle to transplantation is the method of financing intensive care and organ donors are no exception. Once again a DRG payment is involved, which is significantly generalised and does not reflect the

actual costs. Just like everyone else we are financed continuously by way of advance payments according to economic results in the previous year, or in the year before with VZP," senior consultant Jahoda describes the situation.

In this case even VZP agrees. "It's true that the blanket method of payment this year does not support the collection or transplanting of organs. The situation should improve in 2012, when the chief method of payment for inpatient care will be payment per case," says its spokesman Jiří Rod.

Chief consultant Pomajbik draws attention to the ethical aspects of organ management: "Though, like any other medical facility, we are under a certain economic pressure aimed at maximum savings, while maintaining quality care we believe that participation in the transplant care programme is so important that the indications or contraindications of a patient for organ donorship are medical only, not economic."

In the words of its spokesman VZP wants to support the donor activity of hospitals by changing the financing of some operations. "The cause of the low collection activity is not chiefly financial, but lies more in the unwillingness to organise the actual collection. For this reason the activity of transplantation coordinators, who are supposed to help in securing collections, will also be paid from insurance," adds Jiří Rod.

Codes not accepted in the list of operations

Dr. Eva Pokorná, CSc. (Chairperson of the Czech Transplantation Society and Chief Physician of the IKEM Organ Collection and Transplantation Database Department) says that the main limit in the field is the lack of organs. But she is also bothered by the long-term failure of the point system. "The professional Transplantation Society has proposed codes for the list of operations to insurers several times, but they have never been accepted. Some codes have never been in the rate table. Health insurers do not pay operations in cases of ABO incompatibility or administrative coordination of transplantation, which in many cases means several tens of hours work for coordinators. In the operations rate table a kidney transplantation has 6000 points, which represents about 5000 crowns, which is laughable. What is important is to clearly define tasks. Transplantation has a positive economic effect, in addition, it can't be overused – it's controllable and can be documented. There's a clear economic saving," emphasises Dr. Pokorná.

Now each transplantation is financed ad hoc according to individual contracts with insurance companies, for example, costs for heart transplants are partially paid from the Kardioprogram. According to Eva Pokorná a solution would be a "transplant package", which could include enumeration of work, administration, use of the theatre and transfer of the patient. For example, a lung transplant was enumerated here at 2 million crowns.

Before and after transplantation - incomparable costs

The savings that transplantation brings are significant. According to the TCC Director Pavel Březovský a single patient for whom the donor coordinator successfully surmises clinical death contributes to an annual saving of CZK 300 million in costs for maintenance treatment of patients on waiting lists for a kidney transplant. The costs for the health care of a patient with a transplanted kidney approach zero after five years, as opposed to a dialysis patient, who costs the insurer more than one million crowns annually.

"Kidney transplants significantly prolong a patient's life and improve its quality. Life with dialysis is not good, the patient spends three days a week in the hospital, and in addition he usually can't work either. The quality of life after transplantation is diametrically different. Most patients return to work, they are economically active and pay taxes," says the Senior Consultant at the IKEM Transplantation Surgery Department Dr. Jiří Froněk, Ph. D.

Caption: Director of a transplantation company Dr. Eva Pokorná: "Transplantation means a significant saving."

Photo: Koalice pro zdraví archive

There are not enough patients on the waiting list

Despite the clear benefits which transplantation offers the patient, reversal of the trend where clients of haemodialysis centres are on the rise, without the number of candidates for transplants on the waiting list also increasing, has not been achieved. "When I left the Ministry of Health in 2006 we had 47 haemodialysis centres,

now there are 100. That indicates something," warns the TCC Director and former Director of the Health Ministry Health Care Department Pavel Březovský. "There are about 6000 dialysis patients, while only 11% of them are on the waiting list. That's a very low number. There are about 350 transplantations annually, which gives a waiting time for an operation of about one year, which is presented as a success. I'm afraid this is not a success. If there were four times more patients on the waiting list, as in Western Europe, that is, more than 40 percent of all those sick, we would have waiting times of 3 to 4 years, as in other parts of Europe," warns Chief Physician Froněk also. According to him, dialysis should be offered to the patient as a second choice after transplantation or in cases where it is unsuitable. However, more than 60 percent of the clients of haemodialysis centres are patients over 70, meaning that their comorbidity is contraindicative to transplantation. A way is feasible, according to Březovský, for more intensive placement of patients from haemodialysis centres on the waiting list. "There is a relatively simple solution to this situation, which is a common budget for transplantation and haemodialysis. The savings could also be shared with the insurers," he adds.

The Ministry of Health is also trying to get haemodialysis centres to be more efficient. The Director of the Health Care Department at the Health Ministry, Dr. Stanislava Pánová has confirmed that in the coming year the tasks of her department will also include discussions with the Association of Dialysis Centres and the Czech Nephrology Society. She believes that this will result in a system of financial rewards for those centres that get more patients onto waiting lists.

Organs from living donors are better

"VZP is well aware of the advantages transplantation offers, especially for the fate and prospects of the given patient, as well as the possible financial savings. These are significant especially for kidney transplants. Therefore, VZP has also been working actively on the creation of the National Action Plan for the Organ Donation in 2010 to 2015," promises the insurance company which, in the words of its spokesman Rod, supports transplantology. The Czech Republic significantly lags behind other European countries in its organ transplants from live donors.

Here, there are only eight live organ donors per million inhabitants. For comparison – in Croatia, for example, which is working very intensively on implementation of the National Action Plan for Transplantation with the support of the government and insurance companies, 30 organs are donated per year (from living and deceased donors). Czech transplantologists blame health care for the lack of public support in organ donation. It is also very disadvantageous to lag behind in this area. Transplants from live donors lead to significantly better medical and economic results than from using organs from deceased donors.

Survival depends on the organ

"The success of transplants from live donors is approaching 99 percent compared to 95 percent from deceased donors. The expected length of survival of patients with an organ from a live donor is 25 years, while it is between 8 and 12 years for those receiving organs from deceased donors. Imagine how important it is for a young patient with a kidney transplant to know whether he will survive 12 or 25 years. The expected survival after transplantation and on dialysis is twice as long," remarks Chief Physician Froněk and points to the huge scope offered by paired exchange of organs. This is practically non-existent in the Czech Republic. However, in the event that 100 000 potential living donors get tested, only 20 percent donate their organs and among another 20 percent the organ cannot be use due to incompatibility – but they can be put on the European waiting list. The number of opportunities for donation and acceptance of organs is thereby significantly increased.

The most effective of all however is, according to Dr. Froněk, to transplant a functioning kidney before starting haemodialysis. "The results are clearly the best. However, we have no information in the Czech Republic on the number of patients whose kidneys are failing, who are in stage 4 and could undergo a kidney transplant from a live donor before starting dialysis. We should actively seek out these patients at nephrology outpatient departments," Jiří Froněk concludes with a view to one of the other system steps that could lead to greater efficiency for Czech transplantology in the future.

Petra Klusáková

Topic of this edition:

We doctors aren't good at communicating with family

In addition to the maintenance of organs in a fully functioning state, the administration and cooperation with the transplantation centre and Transplant Coordination Centre (TCC), it is the donor consultant's tasks to communicate with the family of a deceased patient.

During the training a donor consultant is instilled with the principles of correct communications with families through comprehensive procedures, known as the "family approach", which was developed in collaboration with psychologists. Although the institution of prior consent to donate organs is legalised here, the doctors always communicate with the family of a potential deceased donor. "We cannot risk discrediting the transplant programme because we do not ask the family. We do not formulate this as a question, but more as an expression of gratitude that the family should allow this," says TCC Director Pavel Březovský.

The disagreement of the family is not a big problem here. Only about 5-10% of families refuse here, while in Germany, for example, more than half of the survivors disagree with donating the organs.

Part for the family, part for themselves

In addition to basic training course, doctors can undergo a course in reporting bad news, which is organised twice a year at IKEM by Dr. Eva Pokorná in collaboration with the psychologist Dr. Blanka Čepická and psychiatrist Dr. Jan Čermák. 18 physicians attend the three-day intensive training in communication and practical skills for communicating unpleasant news; a larger number cannot be included in a course because it needs to be as practical and intense as possible.

"The first course is devoted to just communicating unpleasant news, explaining, discussing and rehearsing practical matters, methods for communication and the reactions of relatives. Course participants are told that conveying bad news is always difficult. It needs not always to be done perfectly, but it is important that they manage it well and feel confident and have no concerns about communication. The second part of the course, usually held six months to a year after the first, focuses more on the actual medical professionals – here they learn to cope with stress and also to take care of themselves," explains Dr. Pokorná.

When there are three incoming patients it is not enough to indicate the donor

What's the most difficult thing for medical workers? "Communicating negative news is always challenging. We doctors aren't good at it either. It's hard and unpleasant for us. We're overworked. Where three people worked before, now only one works, with the same workload. The truth is that when a doctor receives three potential donors in the department, who he has to take care of and maintain, he cannot absolutely indicate the donor, it is not objectively possible. The whole process of confirming clinical death, indication of the donor and organising collection of organs takes about 12 hours," as a doctor reveals the unpleasant fact, though she considers communication with the family doctor as her duty. "We are trying to get doctors to learn to feel okay about disclosing bad news, not to fear it or feel stressed. They must take away some personal fulfilment, because they will use techniques of disclosing bad news throughout their practice and life," says Dr. Pokorná.

A common European list is unsuitable for us

Dr. Pavel Březovský – Director of the Transplant Coordination Centre – puts Czech transplantation in the European context.

How are doctors abroad motivated to report potential organ donors?

In Spain and Croatia doctors get a 20 percent salary bonus for finding a patient. The number reported there has increased enormously. We cannot do that here because the obligation to report potential donors to the transplant centre is statutory. At the same time, however, there is no practical sanction for non-compliance. Turning off the machines and reporting death without any further actions concerning transplantation is very simple.

Would participation in Eurotransplant help us in this regard?

Eurotransplant was established as a non-profit organisation of surgeons who agreed among themselves that they would share waiting lists and organs between individual states. It's not something organised or set up by Europe. Yes, there are certain advantages. The volume of people agreeing together the reciprocal exchange of organs is relatively large. Now Croatia, Slovenia and Hungary have also joined. In all the countries collection of organs has increased, the quality of the process of collection has improved, though the system also functions on the basis of certain financial motivation. Member countries pay for registration and maintaining the system. Here, registration on the waiting list is free, while it costs \in 460 (about 11 000 crowns) in Eurotransplant. In addition, there is an annual fee for a place on the list. The contribution is then divided according to how the individual member states participate in collections or transplants or the use of donations. Each country must work out whether this system is beneficial for it.

Is such membership beneficial for us?

A common European waiting list would be unsuitable for the Czech Republic¹. There are indications of the intention to connect countries in this way. In my opinion, however, we should only share waiting lists of special groups of patients, for example, those who are hypersensitive to human blood or tissues (that is, patients with repeated kidney transplants) or patients with urgent liver failure.

In such cases it would be advantageous, because the number of suitable potential donors would increase. But I am concerned that if a common waiting list was created for all patients, there would be an initial tendency to balance out the waiting times. Here the waiting time for a kidney is one year, while in German it is three years. That would put the Czech Republic in an undesirable situation.

What is the TCC currently involved in at European level?

We are currently preparing an international IT portal together with representatives of the European Organ Exchange Organisations, which should allow the replacement of the organs of an urgent or very urgent patient between countries. If a situation occurs where the organ is not used by any Czech patient, it can be used by a patient from another country. This particularly concerns children's hearts. These are very sad numbers. About 97 percent of paediatric patients do not live to see a heart transplant and they die on the waiting list. There are a range of support activities to help the heart to work, but the age and size of donors are so different that a donor can rarely be found. The exchange of such organs would greatly contribute to the possibility of finding a suitable heart size and reduce mortality on waiting lists.

It is currently possible to transplant a Czech organ to a foreigner and vice versa?

Of course, it is possible to import and export an organ, but it has a statutory limitation. This means that if there is someone on the waiting list who could use the organ in the Czech Republic, it cannot be exported.

Collection of organs from foreigners is not practicable in the Czech Republic. This should change with the current amendment to Act No 285/2002.

¹ Note from the European Commission: "The EU has no mandate to establish such waiting lists and does not intend to do so"