ORGAN DONATION AND TRANSPLANTS between an ideal situation and a coherent programme

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According to data provided by the Council of Europe, in Romania in 2009 there was an average of two organ donors per one million inhabitants. In Belgium the figure was 26.4. The differences are even greater when it comes to the use of the organs harvested from deceased donors. Why is that? One possible answer lies with the coherent system of organ donation and transplants that has been put in place in Belgium, which was presented to the author in an interview with Mr Luc Colenbie, transplant coordinator at the Ghent University Hospital in Belgium. (...)

I read recently in a press release by the Ministry of Health that the new health card which, it is hoped, will come into use during the second half of this year will indicate whether the holder has given consent for organ donation. Of course, this is not a new issue: there has also been discussion with regard to gathering the consent or refusal to be an organ donor when documents such as identity cards and driving licences are issued. In addition, a group of three deputies in the Romanian Parliament (Horia Cristian, Eugen Nicolăescu and Akos Derzsi) have submitted a legislative proposal to amend Law No 95/2006, Title VI 'Collection and transplant of organs, tissues and cells of human origin for therapeutic purposes'. Their initiative starts from the premise that under the current legislation in force, it is in most cases the family of a potential donor that has to decide on donation, usually in the absence of adequate information on the procedure itself. The legislative draft, which has already been rejected by the Senate and which does not have the support of the Government, is awaiting debate in the Chamber of Deputies (the decision-making chamber). However, it is not the draft legislation that is of interest to us here. Instead we wish to provide an overview of the situation.

During a workshop organised recently in Brussels by the European Commission's Directorate-General for Health and Consumer Affairs (DG SANCO) on the subject of organ donation and transplants, I learned of data which I believe to be of interest concerning the remarkable experience of European countries such as Spain, Belgium and Portugal in this field. Their experience is quite the opposite of the situation in Romania. We of course have a law in this field, which was considered modern when it was enacted, and we have illustrious specialists and experienced multi-disciplinary teams (admittedly only a few!) working in transplant centres. However, I don't intend to insist on this subject, which is constantly present in the pages of 'Viaţa medicală'. What I do want to talk about is why, with recent legislation in place and despite having its own specialists, our country is among the worst performers in Europe (as it is in so many areas relating to health) when it comes to organ transplants. To claim

that the system lacks resources is not a convincing argument if we consider the conclusions of a study published 15 years ago, which found that kidney transplants are both more effective and less expensive than dialysis for all subgroups of patients examined (Laupacis et al, *Kidney International*, 1996). In that case, what is the explanation? After interviewing Luc Colenbie, transplant coordinator at Ghent University Hospital, I understood that the essential condition for success is as follows: the existence of a coherent transplant programme in which all aspects are carefully monitored and developed so that they form a single entity. Carrying out transplants requires more than just a 'modern' law that lacks any particular purpose, or the existence of professional transplant teams who have no clearly established activity; in fact, the process of organ donation and transplants is a continuum that requires the active participation of all those involved, be it the authorities, medical staff, patients or the general population.

Transplants cannot of course be carried out without donors. However, for the population to be in favour of organ donation, you need quality information that is both verifiable and which comes from authorised sources. Transplant success stories are necessary and are successful in touching a chord among the general public, but these are not sufficient on their own. The press cannot take the place of the authorities when it comes to educating and informing the public. It is equally true that obtaining consent for organ donation is of no use if harvesting from the deceased donor can only be carried out in a handful of centres. And why would a transplant centre be interested in harvesting organs if this activity is not adequately encouraged (by which I mean remunerated) by those in a position to do so? All European statistics show that with regard to donors in a state of brain death, there has been a shift from the victims of road accidents to those who have suffered cerebral or ischemic strokes or brain haemorrhages. Of course, for a stroke patient to be declared brain dead, it is necessary for that patient to reach intensive care as quickly as possible once the stroke has occurred. In other words, there has been a shift from specific intervention programmes (declarations and statements of desiderata are unfortunately not enough) to an increasingly frequent pathology.

This discussion ought to interest the leaders of our health system, particularly in the context of the adoption in national law of Directive 2010/53/EU of 7 July 2010 on standards of quality and safety of human organs intended for transplantation, and also the European Commission action plan for organ donation and transplants: strengthened cooperation between Member States (2009-2015). Starting from the premise that the specific Romanian legislation should be amended anyway, wouldn't this be the best time to lay the foundations of a coherent system based on a successful European model? We hope that the future will provide us with the correct answer to this question.

The Belgian experience

Interview with Luc Colenbie, transplant coordinator, Ghent University Hospital, Belgium

- The transplant system in Belgium seems to work very well. What is your secret?
- I think there are many possible answers. Firstly, here in Belgium we have a very good transplant law. The system is based on the concept of presumed consent, in other words, every inhabitant of the

country is a potential donor. Those who do not wish to be organ donors must present a written refusal of consent to the local council. We also have a national register containing details of 300 000 people who have either refused or consented to be organ donors. As I was saying, we have a very good law. The law also states that doctors have the right to harvest organs, except in cases where the deceased has refused this by any means and on any grounds. In Belgium, in 15-20% of cases, objections to organ donation occur at the last minute. We also have numerous transplant programmes. We have seven medical schools, which run kidney, liver, heart and lung transplant programmes. But also in the other collaborating hospitals, continuous training is held for intensive care doctors and neurologists, with the emphasis placed on the fact that the availability of organs for transplant means that patients' lives are saved.

- In other words, doctors in university medical centres directly promote transplants...
- That's right. Thirdly, we have very good collaboration with the Government. There is the GIFT project, under which the Government offers hospitals (all hospitals, not just university hospitals) money to record all intensive care deaths in a register, together with an explanation as to why the patients did not donate organs. If the deceased patient is an organ donor, a larger sum of money is offered, as the administration of the act of donation involves additional costs. In this way the Government is able to raise hospitals' awareness of this issue and get them involved. At the same time, patient associations have done a lot to raise awareness. Transplant coordinators also organise meetings with patients who have received a transplant and with the families of donors in order to emphasise the positive impact of organ donation and transplants.
- Belgium is in first place in Europe in terms of the number of organs transplanted, even though Spain is in first place in terms of the number of donors. What is the explanation for this?
- As I was saying, we have a number of transplant programmes. We have of course many doctors involved, who are very good specialists. We also use a number of different techniques, such as split liver transplants, which increase the number of beneficiaries. We also collaborate closely with Eurotransplant. At the same time we have special programmes such as the 'old for old' programme, under which the kidneys of all donors over the age of 65 can be transplanted to patients who are also over 65, who are kept on a separate waiting list. In this way, the ischemia time for the transplanted kidney is very short, which is important in order to ensure the survival of organ. This would not be possible if the kidney were sent to another country.
- What are the latest trends in terms of organ donation in Belgium? Have there been any changes in recent years? Here I am thinking in particular of the age of the donors and the circumstances in which patients become organ donors.
- Yes, we have seen a change, not only in terms of the donors, but also in terms of the patients who receive transplants. In this respect we have witnessed a continual rise in the age of such patients. In addition, in Belgium we have seen greater emphasis on road safety, and as a result fewer patients are dying as a result of traffic accidents, which means that the number of donors resulting from such

situations has fallen. Consequently, the age of donors is rising markedly. Last year the average age was 48-49, but our experience in transplanting organs from older donors has also improved. It should also be noted that elderly patients are now on transplant lists. Ten years ago, there were no 70 or 75 year old patients waiting for a transplant. Today the situation is different. If elderly patients are capable of surviving a transplant operation, they too are eligible for transplant.

- How has the situation changed in terms of the criteria for inclusion on waiting lists? Given the increase in the number of transplantable organs, have absolute contraindications diminished over time?
- There are no longer any absolute contraindications. Of course, when a patient is inoperable, they cannot undergo a transplant. But in normal circumstances there are no contraindications. In other words, any patients can be placed on a transplant list once they have undergone a complex examination carried out by a medical team. There are, of course, eligibility criteria. For example, patients with liver failure due to cirrhosis resulting from chronic alcoholism must demonstrate that they have abstained from drinking for one year in order have a chance of being included on a waiting list for a liver transplant. The surrounding context is also important. In Belgium, we have a high number of patients who die while on transplant waiting lists (two deaths a week). In the case of heart or lung transplants, for example, we are seeing an increase in the number of patients on waiting lists. However, as the average age of donors grows, the quality of the transplanted organs has decreased.
- What is the general perception of transplants in Belgium? Do you have the support of the general population?
- Yes, the general perception is positive. Organ donation is regarded as a worthy gesture. It is an act of altruism to help someone else after your own death. There are numerous cases where the family of donors (husbands, wives, children, parents) acknowledge that if their loved ones were not to be donors then other families would also lose a loved one, and so it is better to be able to help someone else.
- Belgium is a member of Eurotransplant. How does this help you in your work?
- We work closely with Eurotransplant, even though the rate of organ donation in Belgium is high. Some might argue that we don't have much need for cross-border collaboration, but that isn't true. In the most urgent situations, where we are facing a case of sudden organ failure and we can't find a donor in Belgium, in a day or two we receive a liver or another organ for transplant and in that way the patient's life is saved. Of course, the system is based on reciprocity: if we use a donor from another country, we have to offer that country the next organ donated in Belgium.
- Transplants also involve aspects other than the visible surgical and medical aspects. Do you have psychologists trained to counsel the families of donors and others?
- In Belgium, we have special programmes for intensive care doctors and for nurses. These special programmes on organ donation also deal with how to speak to the loved ones of donors. We use

actors to play the role of loved ones, and with the help of a video camera, we discuss what the best approach is, what is good practice and what isn't, so that we can train doctors how to break bad news to families and show them what action needs to be taken when loved ones become aggressive and reject the idea of organ donation.

- You said earlier that the age of donors has increased in recent years, but there is also more frequent pathology. What is the main cause of death in organ donors at present?
- The main causes of death are brain haemorrhages and cerebral infarctions.
- That resolves the question of brain death...
- That's true. We also have another group of donors in Belgium: those in cardio-respiratory failure. In some cases, these are intensive care patients who are clinically brain dead, but for whom cerebral blood flow tests do not permit a diagnosis of brain death to be given. In such cases, the removal of life support (in accordance with the wishes of the patient or the patient's family) would result in the patient's death. If the patient in question is an organ donor, the standard practice is to wait five minutes after the life support tube has been removed before harvesting the kidneys and the liver. When you have to wait for cardiac arrest, there is a relatively long period of hypotension when organ perfusion is deficient, with the result that the quality of the organs is not as good as in the case of donors in a state of brain death.
- What other problems occur in connection with donors in a state of cardiac arrest?
- A five-year study has shown that patients who receive such transplants suffer more complications. In the case of liver transplants, biliary atresia and biliary stenosis are more frequent. For kidney transplants, there are differences compared to donors in a state of brain death: the transplanted kidney is on average viable for only 8 years instead of 10.
- Even so, is there a viable solution for increasing the number of transplanted organs?
- In order to overcome this problem, a device has been developed which enables the harvested kidney to receive a permanent drip, which permits us to carry out biopsies to monitor the quality of the organ and to determine whether or not it can be transplanted. In this way we buy time to decide which patients (even marginal recipients) could receive the harvested organ with certainty.
- What would you recommend to a country that wanted to follow Belgium's example in the field of transplants? What are the keys to success?
- A good law, first of all. Next, the support of the authorities. And of course, a good level of public awareness. More specifically, when a hospital has an organ donor, the intensive care unit receives money from State Insurance for the conditioning of transplantable organs. For each organ, the Government offers money for part of the cost of the circulatory medicines administered and other associated costs. For State Insurance, the procedure is codified, listed and reimbursed. Similarly, when an organ is harvested, the State provides the money needed to prepare the transplant: the liquid

for the intravenous drip for example costs around EUR 250 per litre and you may need as much as 5-6 litres, but this procedure is also codified and reimbursed.

- What transplant programmes does Belgium offer?
- Heart, lung, liver, kidney, pancreas and intestine.
- Why is a distinction made between donors of tissues and donors of organs, at least in terms of the rules governing the procedures?
- Sometimes donors die outside of intensive care, and the time that elapses until organ harvesting can take place means that the organs can no longer be donated. In such cases we check whether the patient in question can be a tissue donor. We have very good screening of the level of mortality in our hospital. For example, I receive a telephone call every time a patient dies in the hospital where I work. I then check whether there are contraindications for a donation of tissues in that case. The types of tissues that can be harvested include vessels, cornea, etc.
- What I was referring to in my previous question was the fact that the transplant of organs and tissues are legislated for separately at European and national levels.
- As regards the harvesting of tissues, the criteria are stricter, with more checks than in the case of organ donation. For example, when I send a heart to the tissue bank so its valves can be used and the donor's other organs are transplanted, the tissue bank is required to call me after six months to ask whether any of the patients who received the organs has developed a problem that could call into question the use of the valves.