Organ transplants unlike any other

4/7/10

This world first carried out in Belgium did not receive media coverage. Deliberately so. Beyond the medical teams and the families concerned, nobody knows that between 2005 and 2007, four adults who had demanded that the law on euthanasia be applied also donated their organs.

There were four of them in number. Three amongst them died in Antwerp, one in Liège. They were between 43 and 50 years old. All four of them suffered from an irreversible neurological disease. Medicine could not respond to their suffering, nor grant them a better quality of life, which had in their eyes become non-existent. All four of them had requested for an euthanasia procedure to be set up, such as was authorised by the legal act of 28th May, 2002. These requests were accepted for all concerned. But these people also expressed the desire that their organs be donated, in compliance with the act of 13th June, 1986. Never before had such a request been officially made and medically carried out. An article published in Elsevier (1) and signed by, amongst others, Professor Yserbaert (Antwerp University hospital) and by Professor Jean-Paul Squifflet (Liège University Hospital Centre), describes how the kidneys, liver, lungs and pancreas of the suffering who had chosen to die were removed and then transplanted into living patients in Belgium and Holland. And the questions raised by such a practice.

'The situation we went through was exceptional,' admits Professor Jean-Paul Squifflet, associate head of the abdominal, endocrinal and transplant surgery department led by Professor Michel Meurisse. And for good reason! Very few countries have, as Belgium does, available both legislation which decriminalises euthanasia and another act which authorises the donation and removal of organs. These two laws have nothing to do
with each other and yet *this double legislative framework was necessary to enable these requests to emerge and be met,*' notes the surgeon.

**The choice to die**

Between the coming into force of the act authorising euthanasia (22nd September 2002) and the 31st of December 2008, 2,698 people have resorted to this form of death, the large majority of them being in Flanders. Last year, of the 705 ill people who died through this 'gentle death', only 126 were Francophones. To meet the law's application criteria, a person has to be suffering from a rare and incurable disease, causing unbearable, constant and unquenchable physical and mental suffering. The request has to be a written one. If it is accepted after the advice of two (or sometimes three) consultants, the euthanasia is carried out, after a delay lasting a moth.

After the death, the 16 members of the Federal Monitoring and Evaluation Commission examine a declaration of notification compulsorily filled in by the doctor who carried out the act. Up until now the Commission has never judged that a practitioner has gone beyond the limits prescribed by this law. It has thus never begun legal proceedings against any of them.


The annual report published by the Federal Monitoring Commission indicates that in 81% of the cases, the people who wanted euthanasia were suffering from a generalised or seriously mutilating cancer, despite curative and palliative care. Fatal progressive neuromuscular affections (amyotrophic lateral sclerosis, progressive neurodegenerative conditions) or, to a lesser extent, the neurological sequela of an accident or disease are at the root of 9% of the requests by suffering people who benefited from the law.

Furthermore, in 80% of the cases euthanasia is carried out for people aged 40 to 79 years. The four people concerned by Professor Squifflet's study were part of this group. They suffered from, for example, severe cerebrovascular accidents or from multiple sclerosis. For three years one of the people suffering had only communicated through moving their eyes. As had been demanded by the Antwerp hospital's ethics committee, these patients were seen by three doctors - rather than just two - before the decision for euthanasia was accepted. But it was also necessary to respond to their unexpected wish to donate their organs. 'On an ethical level there is a clear separation between their two requests and, thus, between the procedure of euthanasia and that of organ removal,' explains Professor Squifflet.

**Before or after the heart stops**

Belgian organ donation law is based on the principle of 'saying nothing implies consent.' Beyond this assumed implicit consent, each person is free to submit a declaration (to the local authority) to signal their willingness to be an organ donor or their refusal of such a possibility. In practice, when it turns out that a removal could be carried out, if neither of these steps has been taken by the ill person, doctors inform the family that their relative has died or is in a condition of brain death and that, as authorised by the law, he or she is in a state
that allows organ removal. More than twenty years after the law came into force family refusals, neighbouring 30%, have been considerably reduced. Exact figures are hard to come by but, according to Professor Squifflet, they do not exceed 15 or 20%. According to figures given by Eurotransplant (an organisation which groups together the transplant centres in Germany, Austria, Belgium, Luxemburg, Holland, Slovenia and Croatia, and which, amongst other things, arranges for the distribution of available organs), in 2008 there were 286 donors in Belgium (291 in 2007, 273 in 2006). They have allowed for example the removal of 446 kidneys and 78 hearts. More than 80 organs / million inhabitants have been transplanted in Belgium: a record!

'There exist three large sources of organ removal,' specifies the surgeon. 'Some come from living donors who give their kidneys, pieces of liver, pancreas, intestine or pulmonary lobes. Nonetheless, the majority of donations are collected from people who have been declared to be in a state of brain death and whose hearts are still beating: beating heart donation. Finally, organs can also be removed from people whose hearts have stopped beating, but not every country accepts such scenarios: Germany, for example, contrary to Belgium, refuses such cases.’ The four people who were the subject of euthanasia were amongst these patients whose hearts had stopped.

To remove or not to remove

A brief return to the history of transplantation allows us to understand to what extent the definition of a person's death - and thus the threshold beyond which organs can be removed from him or her - has been subject to change and heated discussions. At the end of the 1950s, Professor Pierre Mollaret, a French resuscitator, was the first to describe the principle of ‘beyond coma’ (‘coma depassé’ in French), and thus that of ‘brain death’. The framework of determining the conditions of stopping resuscitation for such a person could thus be defined: his heart is still beating, but neurologists have observed an irreversible destruction of his brain functions. The first organ removals were carried out on such patients, even before the introduction of laws on organ removal.
This practice has been considered ethical since 1968 and a conference at Harvard, in the United States. 'Since then, in Europe as well as across the Atlantic, this type of removal, the main source of removed organs, has been that which allows heart transplants,' specifies the surgeon.

The authorisation to carry out 'non-beating heart' removals, following an 'irreversible cardiac arrest,' was for its part was only accepted in 1995, at the Maastricht Conference. 'It only concerns 4 well defined categories of death,' continues Professor Squifflet. 'In the first group, a resuscitation team, called out for example after an accident or for a heart attack outside the hospital, establish that their actions remain useless. The second category concerns people having been subject to a serious accident - such as an explosion, for example - and whose outcome is hopeless, but who do not meet the definition of brain death because a small part of their brain might still be capable of functioning. The third group consists of patients in intensive care, after, for example, cranial trauma or an aneurysm rupture with lesions due to anoxia (oxygen deprivation) having destroyed a part of their brains. Finally, organs can be removed from a donor whose condition of brain death has been diagnosed but not yet confirmed, and who dies from a cardiac arrest.' In Belgium it took around ten years for such non beating heart removals to begin. The obstacles did not come from our law: our legislators were careful to define what death was, and thus the moment when removals could commence. The law only specifies that the death has to be certified by three independent doctors, without links with the 'transplanters', as they are called. Nevertheless, before launching onto non beating heart removals, a group of the Belgian Transplantation Society first of all drew up a common protocol with all the Belgian teams, and the latter was submitted to the ethical committees concerned, and then to the Council of the National Order. Furthermore, as a sign of the constant evolution of the practice of transplants and the ethical reconsiderations that spring from it, the definition of irreversible cardiac death should also soon be reviewed. In effect a team at the centre of paediatric surgery at the Denver hospital (Denver, USA) has managed, after having removed the hearts of infants whose resuscitation had been stopped (the babies having suffered serious brain injuries at birth), to make them beat again, and then to transplant them successfully. The origin of this 'feat'? Rather than
waiting five minutes after cardiac arrest and the declaration of death, as had usually been the practice, the hearts were removed after only two minutes: this shorter delay had allowed some of them to be restarted and be then grafted. Three children thus received a 'new heart'. This experiment, which is continuing, has been the subject of a publication in the New England Journal of Medicine in August 200.

**Faced with death**

To come back to the situation in Belgium, 'On an ethical level, the requests for euthanasia on the part of these four patients were not addressed to us. The response to their expectations in no way depended on our skills, our decisions or on potential needs in terms of organs! This strict and constant separation between the two procedures and the two steps in our eyes authorises the use of the organs of people who have died through euthanasia and who expressly wanted to donate,' insists Professor Squifflet. '*It is also very important to understand that for the practitioner who carries out the removal, the donor, whoever he might be, was considered dead by other colleagues - in this case, the official certificate was drawn up by three independent doctors - and that he is thus also in their eyes.* Should this reassure all those who feared that pressure would be placed on certain patients, encouraged to ask for death so that recipients could benefit from it?

For the four patients it was requested that the death take place at hospital, in a bedroom close to the room where the removal would take place. In practice, as the ethical committee had recommended, the Liège organ removal team had been informed beforehand of the situation's unusual nature. And each caregiver was free
to refuse to participate in the operation, if he considered it against his principles. Some preferred to give up their place.

'Ve had been warned quite late as to the moment when the euthanasia would take place but, on a medical scale, the removal was no different from any other of this type,' recounts the surgeon. During a non beating heart removal, an abrupt fall in tension and the state called 'warm ischemia' that follows this moment has the disadvantage of risking damaging the organs, which have not yet been able to be preserved by the injection of a liquid which makes the body cold. Nevertheless, for these four patients the period of warm ischemia was minimal and all the organs removed could be grafted in their recipients: kidneys, liver, heart valves, lungs in two cases and the pancreas, in order to isolate within it its islets. For the first Antwerp case, the hospital's ethical committee judged it preferable that the organs were not transplanted locally, into another of the hospital's patients. They were presented to Eurotransplant. Belgian and Dutch patients benefited from them.

Words and silences

At Liège, at the request of the ethical committee, a debriefing gathered together the team which had participated in the organ removal, in order that all the questions and potential interrogations could be outlined and discussed. But the carers didn't seem to have experienced a moment that was any 'different' to others, notes Professor Squifflet. Just as in any other organ donation, none of the recipients of the origins of the grafts they had received. 'At the frequent information meetings we hold and which are led by the coordinators of the transplantation centres, we explain to the people on the waiting list and to their near ones the different possible sources of organ removals and the rules governing organ distribution. We remind them, for example, that the kidney of someone aged sixty is not grafted into a child. But we also confirm for them that they will never know the origin of the organ or organs that they will receive. There are no exceptions to this rule.' The ethical committees concerned had decided not to give media coverage to these out of the ordinary removals. These grafts of a totally new origin were presented at medical meetings, in particular amongst the members of Eurotransplant. They sometimes raised reluctance or, at the least, opened up heated debates, despite their inevitably rare character. In effect, 'non beating heart removals still represent a quite small 10% of all our removals,' Professor Squifflet reminds us. 'Furthermore, from only 5 to 10% of the hundreds of people who each year decide to die by euthanasia are likely to be able to offer their organs.' Since 2007, no patient benefiting from euthanasia has, it seems, expressed the wish to donate his organs. And no person who has received a graft, in Belgium or Holland, has suspected that he has received a kidney or a liver that has sparked so many debates and supplementary ethical guarantees.