

The case of Vincent Lambert: Who Will Be Able to Unravel the Knot?

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THE CASE OF VINCENT LAMBERT: WHO WILL BE ABLE TO UNRAVEL THE KNOT?

ABSTRACT: The focus of the contribution concerns the jurisdictional developments in the case of Vincent Lambert and deals with the recent legislative amendments that the *lonetti loi* introduced with regards to end of life decisions and to the respect of patients' advanced directives.

KEYWORDS: end of life issues; advanced directives; patient will; France.

On 25 June 2014, the European Court of Human Rights (ECtHR) was urgently summoned to ask the French government to stay the execution of the *Conseil d'État* judgment authorising discontinuance of Vincent Lambert's nutrition and hydration waiting for its ruling on the matter, in accordance with art. 39 of the Rules of Court providing *interim* measures to «be adopted in the interests of the parties or of the proper conduct of the proceedings». Only the day before, in fact, and at the request of Vincent Lambert's wife, the *Conseil d'État* had declared lawful the decision taken on 11 January 2014 by the doctor in charge to discontinue the life-sustaining treatment – the most difficult judgment ruled by the *Conseil d'État* in the last fifty years, as commented by its Vice-president, Jean-Marc Sauvé.

While awaiting for the judgement of the *Conseil d'État*, Vincent Lambert's parents had promptly referred to the ECtHR in case of unfavourable outcome. And when the ECtHR delivered the press release staying the execution of the *Conseil d'État* decision, «les larmes de Viviane, la mère de Vincent, qui coulaient à la décision de mort du Conseil d'État, ont été séchées par la Cour européenne à qui nous avons demandé asile», remarked her lawyer. On the other side, in an interview released in 2013, Vincent Lambert's wife had declared: «(j)'ai accompagné Vincent chaque jour pendant quatre ans et demi. J'étais là quand il refusait les soins. On ressent une grande souffrance dans ces moments là. Ses parents, eux, venaient le voir trois ou quatre fois par an. Quand on n'a pas la réalité en face, on peut peut-être davantage fantasmer sur un avenir qui n'est pas»¹. She also insisted on the influence the integralist catholic group Vincent Lambert's parents belong to had on their position – a group Vincent Lambert had markedly wanted to detach from.

Vincent Lambert is a 38-year-old psychiatric nurse who sustained a head injury in a road-traffic accident in 2008. Since then, he has been tetraplegic and kept alive through an enteral system of nutrition and hydration. As always in circumstances like this, the case presents itself as dramatic and

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¹ F. BÉGUIN, L. CLAVREUL, *Laisser partir Vincent est ma dernière preuve d'amour*, in *Le monde*, 29 May 2013.

Commentary

vexed. Despite its own case-law several times confronted with “right to die” claims, the ECtHR never issued a ruling on a case like this, complicated by a radical divide inside the patient’s family, a medical diagnosis unveiling the still partially unexplored subtleties of the states of consciousness after brain injury and their fluctuation, and, most of all, by the conundrum of how to ascertain and respect the patient’s will when no advance directives are available and no guardian has been appointed.

Lying in wait for the ECtHR to unravel the knot and take Vincent Lambert away from the excruciating alternation of measures either supporting life or accelerating death, with a court ruling the withdrawal of the artificial nutrition and hydration and another re-establishing it, let us unfold the clinical and legal implications of this harrowing case.

1. After the accident that caused him brain damage, Vincent Lambert lied in a deep coma which shortly after evolved in a vegetative state. In July 2011, temporarily transferred at the Coma Science Group in Liège to assess his diagnostic and therapeutic state, he was diagnosed with a coma *paucirelationnel* – a minimally conscious state (MCS). This particular condition has left untouched some perception of pain and emotions; respiration was also autonomously controlled, revealing a certain degree of responsiveness. Attempts to establish a code of communication with the patient were strongly recommended, even though it was undetermined if and to what extent Vincent Lambert could understand what he was told.

According to the latest acquisitions of neuroscience, the hiatus between coma and brain death – with its corollary of questions: is the patient aware and to what extent?; does she feel pain? – contemplates a host of newly defined brain states «beyond the ubiquitous but still confusing PVS [...]. Responses to questions like these [...] have increasingly become more nuanced in sight of new evidence about severe brain injury and how the injured brain recovers»².

Permanent vegetative state (PVS) patients are unresponsive and unarousable, but they keep their eyes open and reactive: «the vegetative state remains a disquieting one. It defies normal expectations about awareness and consciousness. Usually when the eyes are open there is awareness, but in the vegetative state a patient is stripped of ability to interact with others or the environment»³.

It may happen that PVS patients move to MCS, which corresponds to a variable state of consciousness. «MCS patients demonstrate unequivocal but fluctuating evidence of awareness of self and the environment. They may say words or phrases and gesture. They also may show evidence of memory, attention, and intention. However, these behaviours may be fleeting»⁴.

During the diagnostic session at Liège, it was proven that Vincent Lambert was in an MCS and retained some degree of consciousness. Unfortunately, though, despite eighty-seven sessions of speech therapy undertaken at the hospital in Reims where he was moved back, no code of communication could be successfully established.

² J.J. FINS, *Brain Injury: The Vegetative and Minimally Conscious States*, in M. CROWLEY (ed.), *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book for Journalists, Policymakers, and Campaigns*, The Hastings Center, 2008, at 15.

³ *Ibidem*, at 16.

⁴ *Ibidem*, at 16-17.

Vincent Lambert's uneventful existence – apart from several moves in different medical structures since the moment of the accident, passing from the resuscitation centre to the neurology ward at the hospital of Châlons-en-Champagne; from the physical therapy centre to the department of brain injury in Berck-sur-Mer; finally, hospitalised at the teaching hospital of Reims – had a turning point at the end of 2012, when members of the medical staff in charge and Vincent Lambert's wife – also a nurse – repeatedly noticed some reactions, like rubbing his arms, leading to suppose he was offering resistance to the everyday care provided by the nursing staff. It was at that point that the physician in charge of the patient initiated the procedure involving the entire medical staff and some representatives of the family to evaluate collectively whether the artificial nutrition and hydration constituted an *obstination déraisonnable*, according to the definition given by the French *Code de la santé publique* as amended by the law nr. 2005-370 regarding the rights of the patient and the end of life, also known as the *Leonetti loi* (from the name of the representative who proposed it). In particular, it provides that the physician in charge of the patient takes the decision only after consulting with the medical staff:

«la décision de limiter ou d'arrêter des traitements dispensés ne peut être prise sans qu'ait été préalablement mise en œuvre une procédure collégiale. [...] La décision de limitation ou d'arrêt de traitement est prise par le médecin en charge du patient, après concertation avec l'équipe des soins si elle existe et sur l'avis motivé d'au moins un médecin».

The withdrawal of treatment must take into consideration the wish of the patient, either expressed in advance or through a guardian or a relative:

«(l)a décision de limitation ou d'arrêt de traitement prend en compte les souhaits que le patient aurait antérieurement exprimés, en particulier dans des directives anticipées, s'il en a rédigé, l'avis de la personne de confiance qu'il aurait désignée ainsi que celui de la famille ou, à défaut, celui d'un de ses proches. [...] La personne de confiance, si elle a été désignée, la famille ou, à défaut, l'un des proches du patient sont informés de la nature et des motifs de la décision».

The definition of *obstination déraisonnable* is also specified by the *Code de la santé publique* as amended by the *loi Leonetti*:

« (t)oute personne a, compte tenu de son état de santé et de l'urgence des interventions que celui-ci requiert, le droit de recevoir les soins les plus appropriés et de bénéficier des thérapeutiques dont l'efficacité est reconnue et qui garantissent la meilleure sécurité sanitaire au regard des connaissances médicales avérées. Les actes de prévention, d'investigation ou de soins ne doivent pas, en l'état de connaissances médicales, lui faire courir de risques disproportionnés par rapport au bénéfice escompté. Ces actes ne doivent pas être poursuivis par une obstination déraisonnable. Lorsqu'ils apparaissent inutiles, disproportionnés ou n'ayant d'autre effet que le seul maintien artificiel de la vie, ils peuvent être suspendus ou ne pas être entrepris».

After a long confrontation with other colleagues of the ward and Vincent Lambert's wife, on 10 April 2013 the physician in charge took the decision of discontinuing the artificial nutrition and of reducing the hydration to 500 ml per day. Vincent Lambert's wife agreed, joined shortly after by one of the patient's brothers, three half-brothers, a sister and a half-sister.

Vincent Lambert's parents, a half-brother (also tetraplegic), and a sister appealed to the *Tribunal administratif* of Châlons-en-Champagne since they had not been involved in the process of delibera-

tion. On 9 May 2013, the *Tribunal administratif* acknowledged that the procedure followed by the physician in charge did not comply with article R.4127-37 of the *Code de la santé publique* and ruled that artificial nutrition and hydration were to be started again.

At that point, the medical staff launched again the procedure, this time involving the entire family of the patient, which gathered twice in advance to discuss the matter and be prepared for the medical confrontation. On 11 January 2014, the director of the ward where Vincent Lambert is still hospitalised announced the determination of discontinuing the artificial nutrition and hydration starting on January 14th, so to leave enough time for any legal complaints. The medical and nursing staff, three out of four physicians consulted, the patient's wife and some of his brothers and sisters concurred, whilst Vincent Lambert's parents, one of his sisters and a half-brother appealed again to the *Tribunal administratif*, claiming that this case did not fall under the terms of the *Code de la santé publique* as amended by the *loi Leonetti*, given that Vincent Lambert was not dying and no urgency was deemed necessary to interrupt the treatment. Moreover, they argued that Vincent Lambert's condition was recognizable as a handicap rather than as an incurable and irreversible cerebral damage.

2. The decision of the *Tribunal administratif* opens clarifying that, despite the appellants' claim, the *loi Leonetti* could be applied to the case, even though its title does not explicitly refer to cases like Lambert's, and also that artificial nutrition and hydration had to be considered a *traitement* (a medical procedure) and not a *soin* (an aid founded/based more on humane attention than on medical evidence).

Regarding the merit of the case, two issues needed to be dealt with: if the content of Vincent Lambert's will was somehow ascertainable and if, in this circumstance, the continuation of artificial nutrition and hydration had to be considered an *obstination déraisonnable*.

As for the first question, given that the patient had neither signed advance directives nor appointed a guardian, the only conceivable way for the tribunal to formulate a hypothesis on his will was by relying on his statements or points of view expressed before the accident. «Mais cet élément – the *Tribunal* argued – semble également fragile, exposé au risque de surinterprétation par les soignants ou les proches», especially considering the evidence of the extreme fluctuation of will among those who, affected by very serious diseases or weakened by the deterioration of old age, may have asked for an anticipation of death.

If Vincent Lambert's will cannot be proven with an acceptable degree of certainty, the second question to solve is if the nutrition and hydration as administered to Vincent Lambert represent an *obstination déraisonnable* according to three criteria: whether the treatment is *worthless* («inutile»), *disproportionate* («disproportionné») or *functional to/aimed at the mere artificial prolongation of life* («n'ayant d'autre effet que le seul maintien artificiel de la vie»).

With reference to the first criterion, the *Tribunal administratif* remarked that the futility of treatment can be assessed only by focusing on an evaluation of the patient's quality of life, which is not for the judge to say. Regarding the disproportionality, it was not demonstrated that keeping on with artificial nutrition and hydration would have caused an aggravation of the pain supposedly suffered by the patient. Lastly, the preservation of Vincent Lambert's life was not artificial, for the MCS implies some emotional activity of the patient.

All this considered, the *Tribunal administratif* suspended the medical decision to withdraw artificial nutrition and to reduce hydration. As a consequence, after a few weeks of discontinuance of treatment, nutrition and hydration were provided again.

Vincent Lambert's wife and some of his brothers, sisters, half-brothers and half-sisters opposed to this ruling and appealed in February 2014 to the *Conseil d'État* that – after stating the necessity of the most thorough, complete and updated information to assess Vincent Lambert's clinical condition, as the last examination on the part of the Coma Science Group of Liège went back to July 2011 – disposed an entirely new medical evaluation put in the hands of acknowledged skilled neuroscientists in order to make an independent and collective survey of the patient, also by meeting the medical and nursing staff in charge, «aux fins de se prononcer [...] sur l'état actuel de M. I... et de le donner au Conseil d'État toutes indications utiles, en l'état de la science, sur les perspectives d'évolution qu'il pourrait connaître».

Four months later, once received the report of the three physicians appointed for the new clinical evaluation, the *Conseil d'État* took its final decision. Its task was to verify whether the determination to withdraw the artificial nutrition and hydration announced by the physician in charge on 11 January, 2014 complied with all the conditions and terms provided by the *Code de la santé publique* as amended by the *loi Leonetti*.

To begin with, the *Conseil d'État* remarked that

«si l'alimentation et l'hydratation artificielles sont au nombre des traitements susceptibles d'être arrêtés lorsque leur poursuite traduirait une obstination déraisonnable, la seule circonstance qu'une personne soit dans un état irréversible d'inconscience ou, à plus forte raison, de perte d'autonomie la rendant tributaire d'un tel mode d'alimentation et d'hydratation ne saurait caractériser, par elle-même, une situation dans laquelle la poursuite de ce traitement apparaîtrait injustifiée au nom du refus de l'obstination déraisonnable».

Furthermore, in order to determine if the life-sustaining treatment could be suspended, the court specified that the physician had to rely on a variety of elements, medical and non-medical, «dont le poids respectif ne peut être prédéterminé et dépend des circonstances particulières à chaque patient, le conduisant à *appréhender chaque situation dans sa singularité*». In addition, «le médecin doit accorder une importance toute particulière à la volonté que le patient peut avoir, le cas échéant, antérieurement exprimée, *quels qu'en soient la forme et le sens*»; and finally, the physician must make the effort of bringing out «une position consensuelle» within the family of the patient.

All this considered, the *Conseil d'État* ruled that the procedure followed by the physician in charge had no irregularities; that the clinical condition of the patient deteriorated since the investigation in 2011 in Liège, now corresponding more to a PVS than to a MCS, as the medical evaluation undertaken by the teaching hospital de la Pitié-Salpêtrière in Paris observed, and that the cerebral damage affecting the cognitive functions and the consciousness of the brain has to be deemed irreversible; that, despite the fact that the patient did not sign a statement of advance directives, his will in this matter was proven by the conversations he had with his wife over on? some patients hospitalised at the intensive care unit and by some of his brothers and sisters who attested its correspondance to his personality and intimate creeds; that the family had been thoroughly and repeatedly consulted, despite the impossibility of reaching a unanimous consensus in the end. Finally, the *Conseil d'État* re-

affirmed what the medical report had stated, namely that Vincent Lambert's reactions, registered both by the medical and nursing staff and part of the family as signs of pain and refusal of living, could prove nothing and that the physician in charge was in the right not to rely on them for his determination to withdraw life-supporting treatment.

3. If there is a dramatically nonsensical Hobson's choice, it is the one between the two equally undesirable options in front of a patient, that of carrying on with an irreversible vegetative state, on one side, and that of putting an end to it, on the other. Admittedly, the request for withdrawal of life-saving or life-supporting treatments applied to an incompetent patient, unable to assess his or her own condition and, even more, to express whatever personal determination in this regard, brings along a series of unresolved paradoxes, starting by saying that it is the ultimate defense of an existence for which – as remarked by the House of Lords in one of its rulings⁵ – it does not seem to make any difference whether to live or to die. Actually, any kind of legal devise intended to maximise the autonomy of a comatose or vegetative patient (a wide array going from substituted judgment on the part of a guardian to a living will or any other form of advanced directives) ends up after all by involving people «the least able to appreciate whatever autonomy benefits the document provides them»⁶.

It may sound unexpected that a life understandably compared to a vegetable has, on the contrary, the potential to raise around it a complexity of relations and interpersonal connections. Indeed, the idea that, around that bed in the hospital, there is a vacuum emptied of every/any human connectivity is simplistic: PVS patients, as vegetative as they may appear, keep on stirring reactions and responses in people around them. Whether they are still considered alive and worth caring or not has to do with being at the core of a number of different connections which affects the perception family and professionals maintain, even beyond the mere clinical evidence and with much more intricacy. In more than a sense, that patient lying unconscious in his or her bed is an unknowable, unfathomable being, whose silence echoes the tension between human sovereignty and dominance of technology, between the two opposite images of the individual either autonomous and self-sufficient or depending and in need of others, the rational actor *vis-à-vis* the corporal being.

Vincent Lambert's case has split his large family in two totally antithetical views on his clinical conditions and on the consistent decision to take: reportedly, nobody questioned the content of the medical evaluation or its scientific reliability, but what some opposed was rather a different social and personal assessment of his state – the *perception* of his state: for his parents and a few brothers and sisters (among which one is tetraplegic), Vincent Lambert is severely impaired, polyhandicapped, but not on the verge of death, so the *Code de la santé publique* as amended by the *loi Leonetti* should not apply. Such a radical, irreconcilable rift between the two sides exacerbated especially because of the lack of advance directives on the part of the patient and of a guardian appointed to decide on his behalf. Despite the several informal occasions in which Vincent Lambert exchanged his views on the matter with his wife, and despite the compatibility of these positions with his personality affirmed by

⁵ Airedale NHS Trust v. Bland [1993] 1 All ER 821 HL.

⁶ A. L. CAPLAN, *Can Autonomy Be Saved?*, in *Id.*, *If I Were a Rich Man Could I Buy a Pancreas? and Other Essays on the Ethics of Health Care*, Bloomington and Indianapolis, 1994, at 269.

some of his siblings, no incontrovertible evidence was/has been registered for such a circumstance. And the provisions of the *Code de la santé publique* applicable to the case cannot help in this regard, since they refer generically to «la famille» and only in lack of it to «un des proches» – understandably omitting any hierarchical order among the relatives, even though some may take care of the patient more directly and follow more closely his or her clinical evolution than others.

Before the entire troubling sequence of events concerning Vincent Lambert since the accident – the fluctuating answers on how extended the brain damage had been and on which level of consciousness and communication had remained untouched, the uncertain evidence proving his genuine will, the patrimony of values, convictions and orientations in his family anything but homogenous –, the amendments to the *Code de la santé publique* introduced by the *loi Leonetti* look somehow worn-out already.

At the beginning of this long judiciary story, we have the observation on the part of the nursing staff and of Vincent Lambert's wife of certain reactions seemingly disclosing an intolerance, if not a rejection, of the everyday toilette care implying a refusal to keep on living in that state. The physician in charge started then the collective procedure as provided by art. L1111-4 of the *Code de la santé publique* («Lorsque la personne est hors d'état d'exprimer sa volonté, la limitation ou l'arrêt de traitement susceptible de mettre sa vie en danger ne peut être réalisé sans avoir respecté la procédure collégiale»). The collective procedure aims at assessing whether life-supporting treatment in the given case may be judged as worthless, disproportionate, or only functional to the support of a life which is merely artificial.

It seems, then, that the procedure was ignited by the presupposition of some sort of communication from Vincent Lambert himself to free him from that condition and accompany him to death. According to the law, the family or, in lack of it, one of the relatives should be/ are to be? consulted during the procedure in order to reconstruct the patient's will, but it is also provided that the family or one of the relatives are then informed on the nature and motifs of the decision. Hence, it is implied that the participation of the family in the collective procedure serves the only purpose of producing elements contributing to prove the patient's will, when it is not the case of relying on advance directives or on the deliberation of a guardian; beyond that, the decision is taken by the physicians involved in the procedure and only after it is communicated to the family. Nothing in the law suggests that the family is actually associated to the hearings and to the final determination of the medical staff. If the family proves to be uninfluential in recreating the patient's will, the law does not contemplate to involve it otherwise.

Moreover, it is noteworthy that in France there is no such thing as a public register to lodge advance directives. They are delivered to and kept by the reliable person the patient confided in. When such directives get into the hands of the physician in charge, out of no actual formal registration and filing, she determines to what extent relying on those declarations to support the final medical resolution.

In those cases when the patient's will turns unfathomable, the *Code de la santé publique* provides that the collective procedure scrutinises whether the administration of the treatment may constitute an *obstination déraisonnable*. This is indeed an essentially and exclusively medical judgement: is the treatment worthless for the clinical state of the patient? Do pain and discomfort inflicted to the patient because of the treatment exceed the beneficial effects to the extent of turning out as dispro-

portionate? Is the treatment's only function that of sustaining an artificial life? And even if the *Conseil d'État* has remarked that the assessment of the physician must not be predetermined and must rely on «un ensemble d'éléments» to understand the unique situation of that particular patient; even if it has underlined that the physician must take into account also information concerning the history and the prognosis of the disease, the decision is always put in the hands of the physician and the physician only, possibly surrounded by other colleagues involved in the collective procedure.

In both the *Conseil d'État* rulings of February and June 2014, the *Union nationale des associations de familles de traumatisés crâniens et de cérébro-lésés* (UNAFTC) presented a memory in court in which it argued that «seule la personne concernée est à même de se prononcer sur le caractère artificiel de son maintien en vie; que décider de l'arrêt de l'alimentation et de l'hydratation artificielles pour autrui revient à se prononcer sur l'utilité de cette vie». The UNAFTC stressed that this kind of procedure hinged on the evaluation of the physician in charge denies the paramount element of the patient's will and the salient and unsuppressible, role it should have in determining a certain course of action. In spite of what the *Conseil d'État* emphasised, that the physician cannot reckon only on predetermined evaluation of the patient's condition and that, on the contrary, should make the effort to understand the uniqueness of his state, it is a fact that the *Code de la santé publique*, as amended by the *loi Leonetti*, puts the medical judgement at the core of the process at the end of which a choice will be made.

The UNAFTC gathers more than five thousand families in France. Its mission is to promote national and EU policies in favour of brain injured patients in order to improve the services of care and assistance and to accompany, support and inform the families. On the website, people leave the account of their experience: the most recurrent complaints have to do with a state of abandonment and solitude they endure when it comes to deal with institutions, local authorities, public services. The idea of a collective procedure involving only physicians and implying a potential collateral effect of standardising the approach towards patients sharing a similar diagnosis must look to them like a nightmare coming true: an old-fashioned approach – the paternalistic supremacy of doctors over patients –, according to which truth lies in the highbrow, mysterious rituals and knowledge of physicians.

In this scenario, the impression is that, despite the effort the *loi Leonetti* attempted to make to amend and update the *Code de la santé publique*, it ended up overlooking some crucial implications. Too frequently – and the Vincent Lambert case is only the apex of the uncountable bulk that rests under the surface – no evidence is available to prove the genuine will of the patient. Generally speaking, only a miniscule percentage of individuals drafts and signs advance directives in those countries where it is admitted – and France does make no exception. In addition, no public registry has been constituted to file advance directives, and the policies to raise awareness on this topic are fortuitous and vague.

Introducing procedures to face dramatic cases like Vincent Lambert's one may surprisingly turn efficient only to shift the critical point of the issue to a different level, without really contributing to remove it. The provisions of the *Code de la santé publique*, as amended by the *loi Leonetti*, still do not seriously face the controversial nature of situations like Vincent Lambert's one, that is how to ascertain the patient's will when no official, formal statement is available. Large part of his family – and his wife more vocally than anybody else – testified that he had repeatedly confirmed his determination

to put an end to a hopeless state of unconsciousness and isolation. Nevertheless, he never signed advance directives, even if he was a psychiatric nurse, certainly more acquainted with clinical details and medical implications of comatose patients than a common man. Needless to say, the absence of advance directives cannot correspond to an implicit acceptance of life-supporting treatments or of the PVS *sine die*. But it is perhaps reasonable to wonder why he did not draft and deliver to his wife a clear statement reflecting his convictions on the matter.

Maybe it would seem not entirely unreasonable to wish for policies fostering a *compulsory* system of advance directives at least for circumstances as extreme and reportedly uncontroversial as Vincent Lambert's one, verified through cross-examinations on the part of at least a medical team different from the one in charge for the patient. Especially considering the high percentage of population currently dying in intensive care units in the Western world – or, for the elderly, in health care facilities –, the improvement of such a system would possibly be twofold: firstly, for those truly wishing, beyond any doubt, for themselves the withdrawal of life-saving or life-supporting treatments in cases similar to Vincent Lambert's one, their will – conveniently kept updated according to a predetermined and adequate regularity – would be incontrovertibly stated and removed from the somehow arbitrary and, in the best of circumstances, approximate evaluation of others. Secondly, a declaration properly signed, officially and formally, would spare the family, the medical staff in charge and the courts potentially referred to the dreadful distress and tragic inconvenience of disentangling and probing the mystery of the true, authentic will of the patient. In this way, in “right to die” matters, at least those involving PVS patients, the will would be unequivocally and responsibly declared.

In addition, the legal obligation to draft and sign advance directives should go hand in hand with the constitution of a public registry especially dedicated. Each personal file might include instructions on the acceptance or refusal of life-prolonging treatments in extreme cases of PVS, the name of the person to appoint as a guardian to supervise the execution of the advance directives, the expression in favour of organ donation.

Several would be the opportunities of improvement coming from a system more or less like this:

- 1) each individual has to declare, formally and officially, her own orientation for circumstances as hopeless and uncontroversial as Vincent Lambert's one. A formal declaration would generally require a more systematic and profound reflection on the matter and a serious assumption of responsibility for what the individual is going to declare.
- 2) the process each individual would have to undertake in order to evaluate and opt for such extreme circumstances should be accompanied by an intelligible and comprehensive information regarding the scientific evolution in the matter of brain damage and the stages of consciousness after a brain injury and before the brain death. At that point, the dense confrontation among scientists and physicians should find a way to percolate in some form in the public debate.
- 3) the loss (partial or total) of consciousness, the role of technology in prolonging life, the different moral orientations in this regards and, most importantly, the prospect of death would enter at last the public fora – a process necessarily implicating a reflection on the inaccessibility of the idea of death in our culture and the deep reasons why it is removed

from our everyday perception. In other terms, it would constitute the first act of the battle against death as a taboo.

Advance health care directives are contemplated in several legal orders, each one with its own system of rules, but none of them introduced a *compulsory* declaration, imposing to take on such a personal responsibility. This kind of system would certainly challenge some of the most entrenched rituals of our times – death and its ramifications are not at all part of the public agenda and only seldom of the interpersonal communication. A legal obligation to anticipate one's own determination would certainly arouse some thick scepticism and a plethora of counterarguments: perhaps its provocative potential, more than its actual feasibility, represents its real strong suit. In fact, dealing with "right to die" issues without opening the public debate up to what lies underneath our fears of death, how it is dispelled and at what price, is plainly delusional, as much as confiding only in the technicalities of the law to mitigate our most hidden dismay in front of death is a wishful thinking.