

Conference 4

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17/08/2019

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Can the law give us the basis upon which to decide whether to stop or to continue treatment of the unconscious patient on the intensive care unit ?

CLINICAL CASE : the end of the 1990's

Mrs B, 65 years old, is admitted with a profound hyponatraemic coma, caused by diuretic treatment which has not been well monitored. The metabolic abnormalities return to normal in 4-5 days, but she remains in a non-responsive coma which is no better after 2 weeks. The diagnosis is that of central pontine myelinolysis which has a dreadful prognosis.

I inform her son, who has been at her side since the first day, of the risk that this is going to continue long term. 'You saved her, she will wake up, **carry on doing everything for the best.**'

In the third week, the patient moves to the long-stay ward for patients in a chronic coma. Her son stays in close contact with me. Five months afterwards: 'Doctors, nurses and physios are looking after her well' he says. 'She has had two episodes of septic shock secondary to her indwelling urinary catheter from which she has recovered... but nothing has changed neurologically: deep coma, non-reactive, being fed continuously by gastric tube. He starts to ask himself some questions, and his questions are expressed quite simply:

- What is the point?
- Why were her septic episodes treated?
- I go and visit her every day: I'm in the process of wrecking my own family life
- Can't you say something to the consultant in charge?
- Can't you take her back under your care... and **do what is best for her** (an implicit request to shorten her life?)

The request to '**do everything for the best**' persists, but its aim has changed. Having had a conversation with him, I listened a long time to him talking about his life both past and present, about his mother, and I decide to talk about it to the head of the long-stay ward, in order to enable a decision to be made that will be in accordance with the family's wishes.

But I receive a flat refusal:

- Absolutely out of the question to stop the treatments and the supplements
- What would the staff think - they have grown attached to her
- Our duty is to care whatever the cost: we owe it to patients

In total, 5 years pass by. Her son telephones me one more time: alternating between rebellion and resignation; he is trying to make sense of the situation, without really managing to... at the end of those 5 years I am notified of the death of Mrs B with a short note from her son :

'Thank-you for everything... I live again!'

Ways of thinking about this clinical case:

- How 'doing the best thing' for the family relates to time and to context.
- Once onerous treatments have been started, it becomes more and more difficult to stop them: the doctors don't have the courage to stop and don't know how to.
- The lack of communication and of listening during those 5 years. The son, person of trust, was unable to speak: his ideas and his questions made him feel guilty, and the context did not allow him to express them to the team looking after his mother.
- A 'technical cure' in the short term can turn out to be an 'ethical failure' in the long term, for the patient, the family, everyone.
- The survival of one person can result in the death of the other.
- The death of one person can give life back to the other.
- Mrs B. had not communicated to her friends and family her 'end of life' wishes before she fell into a coma.

In practice, who has the power to decide?

Society?

It establishes the norms, by means of the bias of **laws or directives** which relate to the doctor/patient relationship in general: the ban on unreasonable persistence in treatment, on euthanasia, on assisted suicide...but it never applies to individual cases. It is the 'vagueness of the law' which allows it to be adapted to individual situations by professionals. Some wrongly refer to it as 'soft law.' It would be more correct to speak of 'flexible law'.

The patient or his family?

Certain minefields with respect to the reliability of the opinions thus expressed are immediately apparent:

- The highly emotional context can be a major obstacle to the objectivity and the reasonableness of the decision, even if the notion of what is reasonable is up for discussion.
- The quality of the information given by the doctor (which we will return to) poses lots of questions: should we tell the patient everything, when, and how should we say it? And most of all, has this explanation been fully understood and taken in?and also:
- The person receiving the information may not have the physical, intellectual or mental ability to understand and therefore to decide.
- Are the factors motivating the patient at that time whether moral, religious or economic conducive to making the decision?

We should acknowledge that sometimes the opinions and suggestions of close relatives are imbued with a clarity of vision, a serenity, and even a profound spirituality which renders them indisputable.

The doctor?

He/she always bears the weight of the overall responsibility and of the final decision. But the doctor must not have or claim absolute power for themselves, for their abilities and motivations can potentially vary according to their age, their courage, their convictions, their faith in the medicine, their willingness to overcome, their refusal to accept defeat, their taste for technical intervention, their worry about their personal performance statistics, their desire to do more procedures to make money and of course their refusal to face the prospect of their own death.

For the last almost 20 years, the laws have allowed us to make advances in a certain number of areas.

What do these laws bring to this question and what do they have to say?

The notion of **respect for the Rights of the patient**, introduced in the legislation, has played an essential part in the practice of medicine, complementing perfectly the duty of doctors, enshrined in law and conveyed by our university education. **B. Kouchner**, then health minister, introduced it in 2002 to French law by making it societally, ethically and humanly incontrovertible.

Straight away the principles and the values relating to respect for autonomy, liberty, consent, explanation and trust were highlighted....at the heart itself of the relationship between doctor and patient. But all of this didn't adapt itself well to the unconscious patient, whether end of life or not, having lost their capacity to understand and to decide. Decisions to stop or to pursue treatment in the context of unreasonably obstinate refusal were taken (or not taken) by the doctor certainly for the most part in good faith and with conviction, but in a disorderly, sometimes irrational manner, often without discussing it and almost always with the unanswerable question of whether the decision is the right one...even though many thought then that the rightness of the decision had to be outside all law (by definition generalised) to allow and even constrain every doctor to treat each decision as an individual case.

The **Leonetti Law** of 2005 (unanimously voted in), followed in 2016 by a complementary law, the **Claeys-Leonetti Law** (voted in with near unanimity) met the need of the citizens and was a relief for the majority of members of the medical profession who were thus able to find in them a guide to reflection and action, while also allowing them to have their point of view, both collective and personal, as applied to each individual case.

We should remember that these laws '**apply to the rights of sick people AND those at the end of life.**' They therefore apply to all patients, whether they are end of life or not, conscious or unconscious. They pursue several objectives:

- The respect for the patient's **Advance Directives**: an expression of the wishes of the patient, when they have full capacity, for the time where they will be at the end of life and/or incapable of expressing what they want. Before 2016 they were just a guide, a direction of travel for the team looking after the patient. Since 2016, they have become definitive while capable of being revoked at any time, and they have become a constraint on the doctor who cannot go against them without justifying it to their colleagues and without full documentation in the patient's notes (the context having evolved, other therapeutic options becoming possible...) It is the expression of respect for the rights of the patient; the doctor must not seek to convince or force someone to do something; they must listen, 'consider' and respect the patient.
- To ask the patient to designate a '**person of trust**' while they have full capacity who, when the time comes, will be the advocate for the patient's wishes when it comes to pursuing or stopping treatments. This designation which is not obligatory has to be in writing and can be revoked at any time. It can be any person chosen by the patient, family or not. Where there are differences of opinion that person's opinion will take precedence over the wishes of the family. The person acts as a real substitute for the patient.
- The **refusal to allow unreasonable demands** - useless and disproportionate care, maintaining life in unbearable conditions, refusal to take account of the wishes of the patient or of their representatives. This can apply just as well to therapeutic procedures as to diagnostic tests, but not to comfort measures and keeping the patient company which must on the contrary be reinforced.
- The necessary **collegiality** of the review and of the decision-making (a 'wise counsel committee' according to Ricœur); a group discussion between the doctor responsible for the patient, the person of trust, the family, the team looking after the patient, and a consultant from outside if necessary in order to help the consultant in charge of the patient to examine their conscience, before they take the decision to limit, to stop or to pursue treatment in a serious or terminal illness. The doctor however cannot share the

responsibility, it belongs to them alone; neither the team, and above all not the family nor the patient's advocate must bear the weight of the final decision, which could end up with them having feelings of guilt.

- The ability to resort to **profound continuous sedation in the terminal phase** (powerful analgesics and anaesthetics) in order to sooth and 'make the patient fall asleep before they die' (not actually making them die), for the patient whose physical and/or psychological and/or spiritual suffering or whose agony has become unbearable. The possible 'double effect' (respiratory depression if given too much) poses the problem of 'intentionality' of the prescription as much for the medical team as for the relatives and makes possible a 'transgression' which can be more or less accepted (see above).
- **The framing of good medical practice** for the patient whether or not they are end of life, conscious or not. By mandating the recording of reflections and decisions in the medical notes, the Law protects both the patient and the medical practitioners.

To keep things very simple, **these laws describe 4 distinct situations**: the patient who is end of life, conscious or unconscious, and the patient who is not end of life, conscious or unconscious. We will just sketch out the situations where the patient is unconscious and incapable of deciding for him or herself.

The patient is unconscious, end of life (prolonged stay in intensive care or lingering death...) or not (vegetative state...). The question of limiting, stopping or pursuing treatment occurs to the family and/or the medical team looking after the patient. The solution must rest on the two imperatives I have described: the respect for the individual will of the patient (advance directive, person of trust, family) and the collegiality of the decision and the process by which it is arrived at. Everything must be documented in the medical records.

We can't emphasise enough the importance of **comfort measures, keeping the patient company and offering them care** (not treatments), and in those cases where the decision is to stop or to limit treatments to straight away offer **'to take care of them'** :

- Profound sedation continues into the patient's terminal phase
- Psychological support offered to the relatives and the staff looking after the patient
- Stopping all invasive procedures or organ support which has become harmful and useless
- Limit or stop active treatment
- Respect the comfort of the patient's environment and put in place palliative care.

For those working in intensive care, these laws have become a point of reference which is irreplaceable nowadays...and yet everyone, including doctors and those involved in resuscitation agree that they are not well known and therefore badly applied.

The reasons are multiple and complex. Even today, they basically have as their foundation **our awkwardness and our lack of medical culture when faced by a patient with few relatives, at the end of life, or dying**: in the course of our medical studies we will have learned and relearned the recognition of symptoms, elements of the diagnosis and treatment of illnesses, as well as the basic sciences which allow us to learn them... But 'we have not learned to help people to die, nor have we learned how to let people die.' (J. Leonetti). Until the last few years, before the teaching of ethics was programmed into medical studies, did we ever have a lesson on 'death'? ... Except maybe in classes on medical law!! Have we been taught about situations where the patient totally loses autonomy and becomes incapable of saying or simply expressing his wishes, his anguish, his regrets, his forgiveness, his spiritual expectations?... The ability to 'know how to read a patient, how to enter into their situation' was usually left to the individual doctor, communicated to his team, and dependent on their psychological or spiritual receptiveness, their ability to listen and to provide companionship.

The ethical principles underpinning these laws:

They try to respond to the four presumed existential sufferings of the patient, whether or not they are end of life, when the patient is incapable of expressing them:

- I need to be relieved of my physical and psychological suffering.

- I don't want to be abandoned.
- I want to make sense of my life... and to have someone to help me do so.
- I don't want my life prolonged for no good reason.

The dialogue, impossible to have with the patient, has become essential to have with relatives and with the medical team: it is the pledge that the patient will not be abandoned. This dialogue telescopes the desire of the medical team, sometimes not thought through, but always inhuman, to 'keep the patient alive right until the end' and that of keeping the patient company and allowing their loved ones to live that death with serenity. It is man's existential dialogue.

The rigor and transparency, attentive and well-meaning listening, explanation (we will come back to this) are a response to the desire of all involved for truth, and contribute to a climate of confidence and serenity, and can sometimes open the way to spirituality.

The responsibility and the scientific authority personally assumed by the doctor in charge of the patient, illuminated by the collective dialogue which preceded and which led to the decision, reinforces his **human authority**, and lightens the psychological weight of the responsibility for the decision which has been arrived at.

Paradoxically, this law does not dictate 'a law or a duty to do or not do' like most laws but creates '**a duty to ask questions**' about how to do the best thing in this particular ethical and spiritual context. This duty to question must be shared with the relatives and with the team looking after the patient: the doubt which intrudes itself is the reflection of our uncertainties. It is necessary for a decision to mature and then be fully embraced. This law is neither perfect nor definitive; on the contrary it invites us to question ourselves, and to do so again and again: 'Those who know are dangerous!' One is at the centre of a triangular relationship: the possessor of wisdom who treats the patient and must decide, the suffering patient who is dying and cannot express himself, and the relatives and carers who cement this relationship, by substituting themselves for the patient.

St. Ignatius often evokes the necessary personal and collective 'deliberation', as a necessary precondition for the 'discernment' which will guide the decision-making. The collegiality, the climate of serenity, the transparency, the necessity to write down the discussions and decisions in the medical records all contribute as well.

These laws meet and are intertwined :

- **An ethic of Autonomy** : 'You are ill, you knew what used to be good for you, you have assumed rights for yourself, and you have created a duty for us, you said to me : you can count on me to bear witness to your words'. 'The respect that you have for me, I will have for you right until the end.' For these exclusive defenders of autonomy, this is a justification of the ontological Liberty and Dignity of mankind, which is more and more widespread in our current society. The 'It's my choice', becomes 'It's my right'. My death becomes my affair and rules out 'amongst other people'. **This is the ethics of 'I'**. But the Law, republican and democratic, while protecting the place of the individual, always seeks to place them back in the heart of the community on which it depends, and which supports the individual.
- **An ethic of Vulnerability and of Respect** (C. Péluchon) : 'You are ill, you are more and more vulnerable, but you must keep right until the end what is left of your autonomy, and I am going to protect you beyond yourself...I am standing by you : I will walk with you.' **This is the ethic of 'US'**, which values the relationship between people (P. Ricœur).

Where certain cultures find euthanasia to be the solution to the unbearable side of the end of life, the French law aims first to relieve suffering, while integrating the patient's liberty (the ethic of I), and by calling on a progressive and proportionate substitution (the ethics of US) **for autonomy is not a matter of all or nothing** (M.-J. Thiel).

- **Fairness and distributive justice**, often implicit, are the guide wires of these Laws. They are the foundation of all democratic regimes. I am not going to tackle the subject of substitution of consent in the unconscious patient.

Persisting questions:

Is the patient really unconscious, and has he lost all his capacity to decide for himself, to express himself and to consent? This isn't about a limit to the Law, but it concerns a pre-existing existential question. The AGGIR grid (autonomy, gerontology, group iso-resource) which classifies patients from 1 to 6 according to increasing loss of autonomy is an example of the classification of degrees of dependency, which is ethically problematical: in reality mankind is dependent on others to different degrees for the whole of their existence, and does the growing loss of autonomy imply that these people can no longer make decisions for themselves?

And in reality, can we be totally sure that the patient is incapable of communicating? Talk to him, touch him, give him mouth care... and look at his face which speaks to me, gives me a sign, makes me think and review my decision. The comatose patient is a challenge: he belongs outside but is still on the margins of society. He poses me the challenge of always being my brother.

The Leonetti laws don't solve everything: we are on a slippery slope where, in particular, we ask ourselves what is the threshold for what can be tolerated in a society where anything which alters a person's ability to reason is intolerable: the patient is denied capacity and becomes the prey of arbitrary decisions. Let us remember the Bonnemaïson story at Bayonne where the doctor confused his personal convictions with social certainties (tr. note: a former intensivist convicted of giving lethal injections to 7 patients nearing end of life between March 2010 and July 2011, initially acquitted, then convicted on appeal). We need to be particularly careful with older people suffering from Alzheimer's or dementia. It is more sensible to talk about loss of the ability to express autonomy, which does not deprive the person of their liberty and obliges those close to them (family, care-givers...) to respect and seek their consent by using other resources: the disappearance of the capacity to express consent can be replaced by a situation of abandon, of dispossession of the self, of letting go. This obligates the caregiver to commit to leading the patient closer to himself by furnishing him, by substitution, with the necessary resources. This is, in truth, the ethics of care or of vulnerability, as described by C. Péluchon.

'The face of my relative signifies an irrecusable responsibility, ahead of any free consent, any pact, any contract.' (E. Lévinas)

Is consent really informed? Even if it doesn't concern that of the patient, but rather of their trusted person, the family and the medical team, the problem remains the same. Consent is a right expressly established as a fundamental liberty by the highest administrative jurisdiction in France. It only makes sense if there is the possibility of refusal. It must be free and preceded by complete, clear and appropriate information.

- Even if the information we give wants to be complete, it will always reveal our personal position. We need to be humbly aware of this inevitable subjectivity which has a bearing on the consent process with relatives, but which often represents implicitly or explicitly a point of reference which they can relate to.
- The evaluation of the validity of consent needs to take account of the 'quality' of the explanation and the ability to understand of the family. But how far can we or should we go with this explanation? There is a zone of discernment based on pedagogy and well-meaning companionship which lies between 'saying everything' and 'saying nothing'. We explain not only for the good of the patient, but also for the good of the relatives in relation to the continuation or cessation of treatments, to the degrees of uncertainty of the prognosis (based on statistics: are we on the left or to the right of the curve?), to the effectiveness of the treatments, possible complications, and the often destructive burden of a severe handicap for a family, as well as the load it places on Society.
- They need to know: ignorance is rarely a contributor to liberty...but saying too much can also be unbearable...but in the end, doesn't explaining things to the relatives give them the competence to give their opinion which if not decisive, is at least to be

trusted? 'The awareness of a situation is a state; understanding it is a much more complex process.'

Is the relationship of trust a necessity linked to circumstances, or a truly subjective debt, both voluntary and shared? It is at the centre of the decision. It is the 'contract of trust' which makes the informed will of the patient or their relatives conform with that of the doctor who is informing them. It realises the reciprocal expectation of a common respect for norms: those of the relationship with the other, and those of medical science. The rights and the duties of each towards the other come together as a subjective debt. (P.-Y. Quiviger)

We find again that 'self-esteem', dear to P. Ricœur, which harks back to the sense of our limits, the sense of what is possible, the sense of each person's duty, the sense of the individual and collective mandate entrusted to each of us....to the sense of other.

The participation of the family in discussions (but not in the decisions) is a delicate matter, which needs to be fostered while knowing that it never leaves either the family or the team looking after the patient unscathed. It can be individual, in the course of a single conversation, or can take place in the course of a team meeting specifically about the patient (the nurses and the nursing assistants know the patients and their families better than the doctors and have points of view not available to the doctors.) But does this participation by the family represent an increase in liberty or an unbearable responsibility in this context? The family must feel free to participate or not, never feeling guilty for considering one or other solution, active and confident in the expression of their views. The family needs to see in the doctor their scientific, managerial and moral authority, never in doubt, and the unanimity of the medical team looking after the patient.

Are the ethics of the principles of Beauchamp and Childress upon which these laws are based not too pragmatic (rather American, say some)? They are centred on action: respect for autonomy, beneficence, not doing wrong, equity or distributive justice. This ethical foundation of the principles is one of the (very simple) guiding principles of the group discussions in intensive care units. It does not propose a hierarchy if the principles are in conflict; it is minimalist and reductionist: it short circuits any reflection on what can be the substantial well-being of an individual immersed in their familial and social surroundings. It often serves as a pretext for those who don't wish to spend ages on multiple questions, often interminable and judged to be fruitless.

So, there is a precondition: that of deliberation and of reflection which must precede acting on the decision. The analysis of values must precede that of principles, even if the latter spring from the former.

'Religion unveils a truth, morality erects rules, ethical debate questions itself.' (J. Leonetti). But this debate can't remain theoretical and must, in spite of its uncertainties, make decisions! Does it stir up anxieties and hesitations? It's now or never that we must share them while relating them to concrete scenarios: 'the practice of what is possible' questions the values which, more than principles, are unchangeable. For the question is this: which bonds of humanity and of personal dignity do I potentially risk changing by choosing one process rather than another?

We come back to this: the application of democracy oscillates between 'It's my choice or it's his choice' and the systematic research into collective choice in the name of values which are not recognised by everyone and therefore are an imposition for some people.

Of course, these questions can't be aired with relatives in that difficult moment when a therapeutic strategy is being deliberated and decisions made about an unconscious patient. Nonetheless the team caring for the patient are aware of them since they have been in similar situations in the past and are prepared for it and can prepare the family for it: the ethical worries which influence the reflection of the medical and care staff in the team must be clearly known by everyone: this 'implicit sign-posting' results in trust and peace of mind.

Continuing profound sedation into the terminal phase can be resorted to, authorised by the Laws of 2005 (which needed to be read in a certain way to arrive at this interpretation) and of 2016 (which clearly confirmed it). It has become the object nowadays of passionate discussions between those who reproach its hypocrisy and the fact that it is just euthanasia by

another name, and those who recognise the primary concern for the comfort of the patient, the refusal to anticipate a death which must remain natural, and the finesse of allowing the gate of discernment to remain open in complex situations, without altogether opening the floodgates of everything being allowed by authorising euthanasia. The decision to do this has to be taken in consultation, particularly with the family who may even insist on it.

The real problem lies in the absence of a dosage threshold, despite up-titration, and therefore the 'double effect': yes, sedation, but overdose can result in respiratory arrest. This 'undesirable effect' is recognised by the law as an ever-present possibility not to be condemned, it may be desired, more or less implicitly by both the carers and the relatives, to bring to an end a situation which has become unbearable. We touch here on the difficult problem of implicit 'intentionality' of a transgressive act under cover of an accepted risk. If it is necessary to be aware of it, and to raise awareness of it, is it necessary to express or to bring into the open what is not spoken of?

The response to that question is not unanimous :

- By respect for the privacy of relatives, in the context of 'secular or spiritual modesty', it may be preferable, in certain situations, to not dot the 'I's, leaving each to grapple with themselves and with their conscience.
- But deciding to set up terminal sedation, that is to say with only one possible outcome, means in contrast for some that they must inform the family, ask their advice, talk to the team and mention it all clearly in the medical notes.

A thought through and shared transgression of the law can enhance the law itself, for it obliges one to analyse it and to explain its limits. It provides an answer to a dilemma which emerges when, according to the terms of the National Consultative ethical committee (CCNE) 'the strict respect for the law leads to a situation more painful and more violent than if the law were disregarded.' The law is not the only ethical recourse: to ignore the suffering of a family is not ethical but inhumane, and a democratic system is alone compatible with the transgression of laws which it has created and which it administers.

Conclusion

If we return to our clinical case from 20 years ago, we can see that our reflection and our medical and care-giving behaviour nowadays, have changed considerably compared to that period when the 'peak vulnerability' of certain patients posed an obstacle to reflection and to communication.

Respect for their rights even after the fact (advance directives), trusted person, family, collegiality, dialogue, companionship, consent, ...

Today, one could say that **medical decision and responsibility** are buoyed up by safety nets which protect both the patient and the doctor. But at the same time the **dynamic of ethical reflection**, has become more intense, as it follows closely situations made more and more complex by the evolution of technology and the complete change in medical practice and how it is delivered as it follows the change in society's way of thinking about things. The role of **individual and collegiate understanding** has been strengthened and the sharing, the communication, the substitution, have become the cornerstone of therapeutic decision-making and care in the hugely vulnerable patient.

The university teaching of ethics: whether conventional or using clinical cases or using simulation, introduced some years ago to medical studies, are contributing in a spectacular fashion to the development of ethical reflection in our future doctors... in the same way that the intense national democratic debates on this subject are preparing the future Bioethics Law of 2019.

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