Lifting the veil: what really happens in Belgium's healthcare system with euthanasia

Claire-Marie LE HUU.

As a nurse in Brussels, I first worked in a cancer ward and in a care unit support. So I was very quickly confronted with the demands and the practice of euthanasia. For six years, I have seen how this law significantly undermines the links of solidarity we have for the sick. More than just highlighting dubious procedures, today we are now helping along a radical change in attitudes towards death and care of the dying.

Euthanasia legal, ethically precarious

From my arrival in Belgium in 2008, I witnessed first-hand many euthanasia deaths. All were accountably legal and registered officially in the medical records of patients. From the moment I took on the role, and despite my limited knowledge at the start, I found serious failures of ethics and moral obligations. Through my personal experience in care services practising euthanasia in Belgium, I wish to show that it is possible in a hospital room, just like in a television programme, to manipulate opinions and consciences, to transform euthanasia into an ideology of dying with dignity'.

- ***Monsieur R. never asked for euthanasia: he was released out of 'compassion'***

This was the view of an oncologist just after the euthanasia of Mr R. Some days before, the doctor informed his wife that her husband was in the terminal phase of lung cancer. The doctor added that the patient 'will suffer enormously, even though he was showing no signs of pain or distress at the moment'.

The wife asked the specialist not to say a word to her husband 'so he doesn't suffer further' and at the same moment seeks euthanasia to spare him the 'horror of the end of life'. Mr R died by euthanasia without ever knowing of his illness and without deciding or even once expressing the wish to have recourse to euthanasia.

Following this euthanasia death, I asked for explanations from my superiors in the multi-disciplinary team meeting. In a chorus, the psychologist, the head of service, the nurse director and the cancer specialists explained to me how this death was 'gentle, peaceful and painless' 'a dignified end of life' ('a fitting end') in summary. In a patronising tone, they reminded me that 'in respect of caring, we must be compassionate' that 'the prognosis of Mr R was imminent death' and that 'he would certainly have suffered terribly'. The aplomb of their speeches, the logic, appearing implacable and reasonable, reduced the care team to silence.

- ***Monsieur L. 'benefited' from emergency euthanasia for the relief of terrible suffering not sufficiently relieved***

Monsieur L. suffered from an osteosarcoma of the right femur. Hospitalised, he asked for euthanasia should his health deteriorate. One day, in a crisis of overwhelming pain, his wife, desperate, calls for help from the medical staff: she believes it is imperative to respond to her husband's request for euthanasia. The nurses, panicked, call the emergency oncologist. They propose to increase the dose of morphine and set up a provisional protocol for sedation to relieve his symptoms and distress. But the oncologist refused. Amid all the anguish and agitation, the physician directs the care team to prepare a lethal injection which he immediately administered to Mr. L. A year later, his wife returned to the service accusing the care team of having 'murdered her husband'.

Oncologists are reluctant to use morphine treatments. Even today, despite frequent and well-controlled use of morphine, some doctors are still afraid. Many patients in terrible suffering are [therefore] not getting adequate pain-relief. In this context, we can see imagine how despair can be the source of a request for euthanasia. On the other hand, the undue haste with which this euthanasia was carried out resulted in a deeply shocking and inhumane brutal death, for the wife as well as for the care team. However, the patient is deemed to have met the criteria of law, repeated request, unbearable suffering, incurable disease, etc.

- ***Madame G 'released' from prolonged agony***

Palliative sedation was administered to Mrs. G. She was in a coma for five days. Her family, deeply upset, were watching for the slightest sign of end of life. The healthcare team, continually pressurised, was tested by the incessant agitation. It was then that the doctor clearly weary of the prolonged dying, decided to 'shorten [Mrs G's] days to save her from the long decline'. Nobody condemned this act which, in the minds of the family and care team, demonstrated the altruism and humanity of the doctor. A brutal act however that drastically solved the 'problem of dying [in great pain]'.

In Belgium, attitudes have changed

After eleven years of legal euthanasia practice in Belgium, attitudes about the image of death are profoundly changed. More and more, unlike euthanasia, palliative sedation at the end of life is considered a death without meaning, devoid of humanity and discouraging. Some doctors even consider it hypocritical if we liken it to a natural death: 'Conflating sedation and natural death is actually a construct that serves to remove guilt and consider the act to be morally good, superior to other possible medical interventions.'[1]

It is certainly difficult for relatives to 'journey' with a person at the end of their life. However, I have noticed over my different experiences (in a palliative care unit in France and then in oncology and care and support units in Belgium), how the ideas and choices of a family are influenced by the image that their healthcare team reflects about the patient, themselves and their situation. The difficulty for a family to live through a loved-one dying, is largely due to the perception that the environment (caregivers, institution, society) has of dying.

From the moment the healthcare team is clear about an agreed plan of support for living people, but also on its representation of death and the intention it puts behind palliative sedation (it is not to 'kill the person' but 'to relieve suffering'), the family's support is much calmer. On the contrary, when there is the possibility of euthanasia, it can plant in people's minds the idea of a death more 'swift, painless, clean, clear' The period at the end of life no longer has any value, no reality, it is a piece of life which is considered superfluous. This confusion stems from the fact that the Belgian law, unlike the Leonetti law, did not frame the practice of sedation, does not define and does not integrate it into the practice of care.

The marginalisation of the care team

It is from these real-life situations that I realized that caregivers were deliberately kept in ignorance or silenced.

Ignorance of the law on euthanasia and end of life

In a service where I worked, some patients are greeted in the morning in a room and leave two hours later for the morgue, after euthanasia programmed by the oncologist. Nurses are not aware. One can easily imagine the emotional impact that this deliberate lack of information and communication may cause. Even if they are upset, caregivers do not revolt because they know little about the law. No training is offered.

Fear of reprisal

In this same service, management (doctors, care manager, health managers) puts caregivers in fear of reprisals. Many of them regularly express fear of losing their jobs if they were to question the system. This fear is well founded: some caregivers wishing to leave the service were threatened with exclusion from the entire network to which the hospital structure belongs, management can exert pressure so they do not find work.

The evidence of nurse is suppressed

At multidisciplinary team meetings, originally created to share our views on the care of patients, the voice of nursing is completely silenced. Nobody dares speak of euthanasia deaths [where the patient experiences difficulties] or can call to account certain medical decisions. When nurses questioned a euthanasia death, the conversation on the merits and facts is diverted. Physicians and healthcare executives respond systematically with the same formula: 'the act was chosen, [it was] humane'.

No remedy

Not being heard by my immediate line-managers, I went to [higher] management to denounce these illegal acts. The nurse director would not listen to me. She ordered me to shut up. Also, litigation seems impossible, as this requires evidence, the testimonies of families who wish to engage and report, and the courage of caregivers to confront a health system that protects doctors.

For eleven years, the Commission on monitoring and evaluation of euthanasia never, not even once, sent a file to for legal investigation [2], nor found any disturbing practice among cases for which clarification was requested. Does this not show that the law is not so restrictive and that the conditions required to be met can be easily manipulated?

Add to this context, the increasingly important requests for euthanasia due to emotional suffering unbearable when the person is tired of living in a situation where they are not even suffering from incurable disease or in physical suffering.

Mental suffering: the new Eden of the "good death"

Through examples of media-staged deaths deemed ‘exemplary’; then through a euthanasia death recently experienced, I would like to show how euthanasia stands as an ideology. Eleven years after the decriminalization of euthanasia more and more applications are related to mental distress. At the ethical level, these applications raise many questions, often the subject of discussion and disagreement between caregivers, as they are on the frontier of what is legal.
The media themselves, see no contradiction or offer no caution. The euthanasia deaths they report can therefore seem emerge as a logical step in the natural extension of the law.

Cases [reported in the] media that shape the dogma of the ‘good death

Anticipation of future suffering:

These are people who do not suffer now, but anticipate probable suffering linked, for example, to loss of autonomy.

Marc and Eddy Verbessem …[we know the story of these deaf twins that Distelmans euthanized]
We see the implied ethical risk: can we euthanize people who do not fall within the criteria of the law in the name of potential future suffering? In this particular situation, the request for euthanasia was justified on the basis of legal criteria and not ethics. A reporter asked Jacqueline Herremans, president of the Association for the right to die with dignity (ADMD), and a member of the Control Commission of euthanasia, if ‘The request for euthanasia meets the legal requirements’ [4] , raising it was exclusively ‘mental suffering’. The President replied: ‘Indeed, they did not suffer actual physical pain. That said, if one refers to three essential requirements of the law, they meet the criteria. They have been requesting [euthanasia] for a year. For this type of case, where the death is not predictable in the short term, we need at least two consulting physicians, the second paying special emphasis to the quality of the application. You have to see whether this is a voluntary request, repeated and deliberate and if you have discussed all possible options before reaching this decision. The second condition is suffering, which can be physical or psychological, which was the case here. The third condition is that suffering is caused by a serious and incurable condition, which is also the case. Currently at least, even if in the future we can expect to find solutions.’[5]

The conditions of the law are therefore fulfilled. On the other hand, [think again how] society sees the plight of these patients, or raise the lack of creativity in human relations, or finally, consider the support for the twins to adapt to their disability, none of this is in question.

Old age as suffering:

Christian de Duve, Nobel Prize winner for medicine in 1974, died by euthanasia May 4, 2013 at the age of 95. In honouring him the president of the ADMD failed to show that the professor met the criteria of the law: 'Must we justify ourselves when choosing euthanasia?' [6] Why choose death at age 95, still in good physical and mental health? The professor went every day to the swimming pool and participated regularly in television programmes. The first sign of weakness (a fall) made him understand the natural vulnerability which comes with old age.

No matter Christian de Duve was not suffering from any incurable disease; old age can be considered as suffering. Prime Minister Elio di Rupo himself welcomed 'the commitment of a citizen shown by Christian de Duve throughout his life'. [7] This tribute reveals a central idea: euthanasia is the 'act of a citizen', a model of society. The wise example of this Nobel winner was honoured in the press: everyone applauded his lucidity and strength. A journalist with the daily Le Soir tells us his last interview with the old man: 'I am much closer to death than that, I have to organize my passing' he told me. He had felt unwell and remained on the ground, unable to get up. He acknowledged that it was a sign. This was an extremely dignified man, happy and satisfied with his life […], but in fact, diminished.' His euthanasia appears as an obvious choice, even an act of generosity, having decided to die before [he represented any] cost to society. The value of his life depended on his ability to be productive and useful in society (mobility, vitality, achievement), up to his control even of his death. Can we ask for euthanasia in anticipation of a state of decline due to age? What message is relayed through the media to elderly people?

Loneliness:

Caregivers begin to be concerned about the growing number of euthanasia deaths of people who are deeply lonely. This was the case of Nathan…the transsexual person….Mental illness, depression, were they diagnosed? Had he already been assessed by a psychiatrist, a psychologist? Officially, he's not depressed, this criterion does not fall within the scope of the law. To accept the request for euthanasia, it is therefore concluded that Nathan is in unbearable emotional distress due to a body that he could not accept.

A model of 'a good death': the couple:

'An elderly couple from Brabant (in the Flemish part of Belgium) sought and obtained a double euthanasia. This was a first in Belgium. The man, aged 83, was suffering from terminal cancer. His wife, aged 78, had conditions related to old age, incurable and painful, and could not imagine life without her husband. The couple had no children and was relatively isolated. They died Tuesday at home.' [11]

Dr. Mark Englert (Honorary Professor ULB, rapporteur to the Commission for regulation of euthanasia) advances the arguments of Dr. Marc Cosyns (GP in Ghent), in favour of the euthanasia.

Objective: To minimize the risk of suffering due to a failed suicide attempt (euthanasia is a gentle death ...): 'I consider it very important that these folk have shown that one can die and that the one who survives in despair need not procure a rope or a gun but that a legal solution is possible when, like this woman, one is suffering from incurable ailments that can be demonstrated. "[12]

In response to the loneliness of the elderly: 'We know that the number of suicides of people over 80 years is particularly high. This is certainly among those who are left alone and who wish to die because of this. It is not incomprehensible. There are people who have had a very deep union with their partner, as expressed so well in Jacques Brel 'The song of old lovers.' [...] But at the same time, we need to let those whose suffering cannot be relieved really that euthanasia is possible ... "[13]

The express wishes of a couple gives them all the rights: 'While it is rare, it is not unique.' Dr. Cosyns cites five similar recent cases, including two euthanasia deaths he did himself. He thinks that nevertheless that the history of this couple is special because the patients explained in their obituaries that they died on the same day and they thanked the doctor who helped them. He believes they have broken a taboo and says he admires for doing so. [14]

So the wife, who 'could not imagine life without her husband' [15], was euthanized on the grounds of age-related diseases such as rheumatoid arthritis. Recall that under Belgian law, it is not necessary to be terminal for the right to euthanasia and that the suffering is unbearable is enough. Is the deterioration in the quality of life and reduced autonomy due to old age a justification of euthanasia? Because of the number of incurable diseases (diabetes, osteoarthritis, osteoporosis, deafness, Alzheimer's, etc. ..), the restrictions of the law on euthanasia are a fiction.

Euthanasia Practice in hospital

For my part, I can expound the concrete case of euthanasia in the past that I attended. This story shows both:

- The lack of solidarity of an entire society;
- The pressure on caregivers;
- Physicians become more militant than therapists.

This is a lady of sixty year whose cognitive faculties and the ability to move deteriorated due to the effects of chemotherapy. It was also in remission from her cancer. She said she made an early request for euthanasia and reiterated her request in view of her loss of autonomy and her significant loss of memory.

Faced with this request for euthanasia, the difficulty for caregivers was threefold, due to:
1. Her cognitive losses. One day she asked me, 'but in reality have [agreed to] euthanize me or not?', like it was an ordinary treatment. She did not seem to

remember what it meant. But for the doctors, it was a good thing, she had finally uttered the word ‘euthanasia’! This was the first time in years, she had spoken about it spontaneously. To revive a request, the challenge was for her to say ‘I want euthanasia’ without seeming to propose it to her, as in law, the request must be voluntary and repeated.
2. The fuzzy nature of her suffering (no pain or refractory symptoms to be treated). Physically she has no pain and is in remission from cancer. So no incurable disease, death is not imminent. The only solution was to find how her mental suffering was unbearable. When caregivers would sit beside her to talk, she smiled again and asked that we stay close to her. For weeks, she no longer asks for euthanasia. However, when she felt lonely, she'd speak of it again in a pretty vague way.
3. The worrying influence of her entourage. The entourage, consisting of friends and some family due to conflict, seemed totally unprepared. They kept harassing caregivers demanding euthanasia for this lady. The Care team felt uncomfortable because they understand that despite the request of the patient there is another reality: that of feeling abandoned because of a lack of solidarity. Her companions were undoubtedly sincere, seeking [her] well-being. But their kindness was devoid of empathy, the perspective necessary for real solidarity. The whole time she was in hospital, the asked for a toothbrush. Instead of a toothbrush, they bring her what they believe to be good according to them: wine, cakes, but never meeting the lady’s request.

Also, the majority of the care team feel frustrated because lots of measures have been put in place to improve her comfort and her desire to be more surrounded. Initially, she agreed appropriate structures to her needs, and then under the influence of her environment, she rejected them. Those close to her are locked in the emotion of seeing their friend disabled. They cannot bear to see her different. Any other solution than euthanasia seems unimaginable to them. In a small notebook where they leave her messages while she’s sleeping, the question of euthanasia is on every page. You can read words such as: ‘Do not forget your euthanasia, it is your right, you have to ask the doctors or they’ll never do it for you…’

It is in this context that the doctors who were in favour of this euthanasia, found arguments. To circumvent each of these difficulties, and legally meet the demand for euthanasia, ‘solutions’ were found:
1. Because it was impossible to properly assess her request for euthanasia due to cognitive loss, it was decided to accept her beliefs and requests prior to her memory loss, (supported by the advance directive), rather than a change of mind which could be due to her memory loss.2. Moreover it was necessary to determine the nature of her mental distress. The diminution of her autonomy was irreversible, which is what gave rise to her emotional suffering unbearable.3. Finally, as regards the failure of perspective influencing their choices, the argument in favour of euthanasia was: her entourage was part of well-being, even if the influence on her personality and her decisions were harmful, it is not for us to judge. Similarly, it is not for the care team to compensate for the lack of perspective.

Conclusion: an unrestricted interpretation of the law prevents any ethical reflection

The media coverage of these ‘beautiful deaths’ seems to induce the idea that euthanasia is the most dignified, most humane death. She became a model of how to die well according to some criteria of beauty and dignity. In this sense, guilt to go on living can be established in patients. Euthanasia become an exemplary human act. The mental dichotomy between ‘good’ and ‘bad’ death distorts the links of solidarity in a community and finally, makes death taboo.

On the other hand, the interpretation of ‘psychological suffering’ is so broad that it seems not to have any legal limits in the practice of euthanasia (reduced autonomy due to old age, fear of being alone, fear of future suffering, weariness of life , etc. .) .

It is the same for the criterion of ‘incurable disease’. The law allows euthanasia for diagnoses of diseases where death is not expected in the short term: Alzheimer’s, asthma, diabetes, osteoarthritis, arthritis, blindness, etc.

Finally, that it is not necessary to be in the terminal phase of an illness, provides the possibility of anticipating future suffering, which is not current reality, but which generates an ever greater fear of death.

Do these corruptions of the law not hide a reality of ever greater desertion? Isn’t this state of affairs symptomatic of a society prey to loneliness, fear of bad company, and a lack of trust in caregivers?

The opening now for euthanasia of children is just the result of a gradual progressive normalization of euthanasia attitudes and reveals more and more the facture between campaigners and doctors in the field. One hundred and sixty paediatricians sent an open letter to members of parliament saying that there was neither emergency nor value in the extension of the law to children. The paediatricians argued, expressing their opinions as experts in the field. They have not yet been included in the debate. It has taken place, but, it seems, between advocates only.

The question of support at the end of life appears therefore, as raising a question about the particular values of a society: what place we give to sick people? What image do we have them? What humanity belongs to a person? These questions being so much more primal than the ideas and the choices of a family are influenced by the image that the healthcare team reflects back to the patient, of themselves and their situation.

Today, it seems urgent for caregivers to reclaim a vision of the common good, if only to ensure the sick person appropriate care and dignity until the end of their existence.

---

[1]Lossignol D., Damas, F., « Sédations continue : considérations pratiques et éthiques », *Rev. Med Brux.*, 2013, p.27.
[2]Rapport aux chambres législatives de la Commission fédérale de contrôle et d’évaluation de l’euthanasie, tous les deux ans depuis 2004.
[3]Dardenne L., *La Libre.be,* « Euthanasie: unis, à la vie. Et à la mort. », 14 janvier 2013.
[4]*Ibid*.
[5]Dardenne L., *La Libre.be*, « La demande d’euthanasie répondait aux conditions légales », 14.01.2013.
[6]Herremans J., « Christian de Duve, merci ! » in *Bulletin de l’ADMD*, n° 128, juin 2013, p.8.

[7]de Decker C., Colart L., « Décès de Christian de Duve : Une personnalité scientifique exceptionnelle», *Le Soir,* 6 mai 2013.
[8]Propos recueillis par Delvaux B., « Si on continue comme cela, ce sera l'apocalypse, la fin », *Le Soir*, 10 avril 2013.
[9]Rebillat C., « Un transsexuel euthanasié après avoir changé de sexe », *Paris Match*, 02 octobre 2013.
[10]*Le Monde.fr*, « Après un changement de sexe raté, un Belge obtient le droit à l'euthanasie », *Le Monde*, 02 octobre 2013.
[11]D'après « La Libre » du 28.03.2011, Englert M., « Mourir ensemble par euthanasie : une première ? », in *Bulletin de l'ADMD Belgique*, n° 120, juin 2011, p.11.
[12]D'après « De Morgen » du 28.03.2011, Englert M., « Mourir ensemble par euthanasie : une première ? », in *Bulletin de l'ADMD Belgique,* n° 120, juin 2011, p.11.
[13]*Ibid*.
[14]*Ibid*.
[15]*Ibid*.