Euthanasia Case Studies from Belgium: Concerns About Legislation and Hope for Palliative Care

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About the Author

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He has published several studies on the meaning of life in the suffering person, with his most recent publications being chapters in two books: 'En Belgique: des médecins confrontés au sens de la vie et de la mort' in Prendre soin de ceux qui ne guériront pas. La médecine questionnée par l'incurabilité et la fin de la vie *(2016), and 'Fourteen years of euthanasia in Belgium' in* Euthanasia and assisted suicide *published by Cambridge University Press (2017).*

Summary

In examining the ethics of euthanasia and assisted suicide (EAS), it is common to focus on presenting arguments which either support or oppose the legalisation of the practice. As EAS is now legal in many countries (and in some cases, has been for many years) however, there is emerging evidence of the effect of EAS on patients, families, medical professionals, and wider society.

In Belgium, EAS was decriminalised in 2002, and there is now almost 20 years of important information on law and practice, which can make an important contribution to the ongoing debate **[1]**.

In this paper, Prof. Benoit Beuselinck presents a number of real-life example cases from the medical front line, and draws out some of the lessons that might be learned from those cases.

The lessons presented are that life expectancy is difficult to estimate; that euthanasia can be a cause for confusion and distrust in palliative care; that having major life-events to look forward to can result in patients living for longer than expected; that fear of being a burden can be alleviated through recognising that caring for another is often a source of happiness; that emphasising the autonomy of the patient requesting euthanasia can come at great emotional cost to the patient's family; that accepting a natural death can bring peace to the family and that the death can often be very smooth; and finally that doctors must accept death as a natural outcome of disease and resist therapeutic obstinacy.

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Case #1: Life Expectancy Can Be Very Difficult To Estimate

A 65-year-old woman with localised left-side breast cancer underwent surgery, followed by adjuvant chemotherapy and radiation therapy on the thorax. Several years later, she developed severe heart failure, as a consequence of chemotherapy and radiation therapy. The left ventricle ejection fraction (a measurement of the heart function) decreased to 10%, which is very poor (the normal value is around 55-65%).

As a consequence, she developed severe respiratory failure and had to be admitted to the coronary intensive care unit, where she remained for several weeks. With diuretics and supportive measures, the cardiologists tried to alleviate the patient's symptoms and recover cardiac function. After several weeks in the intensive care unit, the patient was discouraged and tired and the cardiologists could not find a way to improve the situation. The patient asked for euthanasia, given the hopeless situation. The cardiologists approved the demand and the palliative support team was called.

The doctor of the palliative support team accepted the advice of the cardiologists that it would be impossible to recover the heart function and admitted that they were very probably entering the palliative setting with short life expectancy and very reduced hope for improvement. Instead of simply agreeing to the request for euthanasia however, he proposed a transfer to the palliative care unit. The patient accepted the proposed solution and was transferred to the palliative care unit.

The change of setting from an intensive care unit without private rooms and with a lot of movement around the patient both night and day, to the peaceful environment of the palliative care unit, brought rest to the patient. Little by little, she recovered, and her cardiac function improved over several weeks. After three months at the palliative care unit, the patient was discharged and returned to her home. She lived for a further three years in good health and enjoyed her life. She was grateful for the opportunity she received to recover at the palliative care unit. Eventually, she developed metastases of the breast carcinoma, leading to her natural death.

This case shows that life expectancy is often difficult to estimate, because survival is based on a number of measurable and unmeasurable factors (physical, psychological, etc.). As certainty about life expectancy cannot be given, it is dangerous to decide for euthanasia based on this criterion. Transferring patients to a palliative care setting allows for life to follow a natural course, which may turn out to defy the expectations of even the most qualified and experienced clinical team.

Case #2: Introducing Euthanasia As An Option Of Palliative Care Can Lead To Confusion And Distrust

An 85-year-old man had suffered from prostate cancer for many years. He had been treated with hormone therapy with good results and he tolerated the treatment well. Over time, the hormone therapy became less effective and chemotherapy had to be added to his treatment regime. The patient was suffering from renal insufficiency however, and his overall condition was deteriorating. As a result, we estimated that it would be difficult to administer chemotherapy to this patient, and that the best option would be to go for supportive and palliative care.

The patient had been widowed for several years. He had no children. Every day, he went to the graveyard to greet his wife and afterwards to a restaurant to have dinner. In fact, his wife had always cooked, and he was unable to do so. It seemed likely that the best solution for this man would be to admit him to a palliative care unit, rather than organise palliative care at home with a nurse coming by every day. This was offered to the patient. The patient agreed that admission to a palliative care unit would be better than palliative care at home. When the time came however, he refused admission to the unit, because “that’s the place where patients are euthanised, and as a Catholic, I don’t want to be euthanised”.

This case shows that introducing euthanasia and, moreover, presenting it as one of the possibilities within palliative care, leads to confusion and distrust in palliative care. The lack of trust may create difficulties in convincing patients that a palliative setting is safe and respects their beliefs, thereby increasing anxiety surrounding the dying process.

Case #3: If You Have Something To Live For, You Can Bear Almost Anything

A 72-year-old man had been suffering from metastatic prostate cancer for many years, and had received many therapies to help him, including many years of hormone therapy. When the disease became resistant to hormone therapy, he was treated with docetaxel chemotherapy. By August, the docetaxel chemotherapy was no longer effective and his overall condition was deteriorating.

He asked us if there were still reasonable treatment options and that he would accept any outcome. His daughter, who was present at that consultation, was due to get married on the 26th of July of the following year, and he expressed a wish to be present for that significant event.

Although life expectancy and response on therapies is always difficult to estimate, it was thought that without therapy, life expectancy would be around six months. With therapy, it was estimated that his life expectancy might be extended some further months. To be present at his daughter’s wedding was not impossible with therapy, but could not be guaranteed.

The patient agreed to start a course of cabazitaxel chemotherapy, with the awareness that in case of poor tolerance, he could stop the therapy at any point. This chemotherapy was administered every three weeks. The patient took four courses of chemotherapy, but in October, he asked for a therapeutic pause, because he was feeling too weak.

In February, he made a new appointment, because he wanted to resume therapy. It was possible to administer three courses of cabazitaxel. From April on, he was not seen by the oncology team. Palliative care was organised by his general practitioner, since he lived some distance from the hospital.

Nothing more was heard about the man until a phone call was received from his daughter on July 28th. She told us that her father had attended her wedding on July 26th, felt weak on July 27th and entered the local hospital, and died on July 28th.

This is illustrative of a case type in which patients survive longer than expected because they have a future event as a worthwhile goal that they wish to pursue. Of course, this observation cannot be generalised to other patients. Nevertheless, oncologists in the Belgian setting often observe that demands for euthanasia occur less frequently in patients who are well-supported by their family, and who still want to witness a significant event such as a wedding or a birth. By contrast, patients who lack these perspectives can become more easily discouraged, an underlying factor in the request for euthanasia. Similar observations may have led Friedrich Nietzsche to write his famous sentence:

> *"If we have our own 'why' of life, we shall get along with almost any 'how'"* **[2]**.

Case #4: "Mum, Let Me Now Take Care Of You"

A 72-year-old woman, who had been suffering for many years from a metastatic breast carcinoma, attended the outpatient day clinic for trastuzumab chemotherapy treatment. A fellow went to see her before the administration of the therapy and reported that she had had enough of the therapy and was considering euthanasia. Upon further investigation, the patient reported that she did not feel any improvement with the ongoing therapy, that the transfers to the hospital were too tiring, and that she was afraid of becoming a burden for her daughter. The daughter was present and had to bring the patient in every three weeks for the therapy.

A closer look at the patient's medical file revealed that the patient had received many different forms of therapy previously, and that the current therapy would probably only bring a very limited benefit. It was agreed that this therapy could be stopped and that the patient could receive palliative care at home, thus sparing her the transfers to the hospital.

She was also afraid that she would become a burden for her family however, and specifically for her daughter. The patient was asked if she had ever taken care of someone else. She answered that she took care of her father, who was ill for five years. When he died, her mother became ill and she took care of her for six months, until she died. When asked if she considered this as a burden, she immediately replied that it was not, and that she had felt very happy when taking care of her parents.

This case is an illustration of the fact that patients are often afraid to be a burden, but that this can be contrasted with the perspective of the carer, who may see taking care of someone as a worthwhile and fulfilling task which brings a sense of joy. The case shows that we are replacing the care and solidarity framework for viewing the coming death of a loved one with a model based on autonomy.

The autonomy model places additional burdens on the dying patient.

Case #5: A Paralytic Patient Filling Her Days With Meaningful Activities

A 68-year-old woman was treated for metastatic kidney cancer. Unfortunately, the tumour had spread to the bones and caused nerve compression at several levels. It was possible that this compression could lead to paralysis.

Therapy with an angiogenesis inhibitor was initiated in order to try to control tumour growth, which resulted in eight months of tumour control, and the patient was able to enjoy good quality of life. The patient was seen regularly at the outpatient day clinic, where she revealed her plan to ask for euthanasia. When asked why she was asking for euthanasia. she revealed that she was afraid that at a certain moment, she would be admitted to the intensive care unit and receive cardiac and respiratory assistance and would continue to live like a ‘vegetable’. She was reassured that this would not occur, because patients with severe underlying diseases who show no possibility of improvement are not admitted to the intensive care unit, since such treatment provides no benefit. Having heard this, she immediately started smiling again and expressed the wish to continue treatment. After the first treatment with an angiogenesis inhibitor, a second course was attempted, but this proved to be ineffective and was stopped. She was then treated with immune therapy and received three injections. There was increasing pressure on the nerves, however, and the patient became paralytic. As she could not live alone anymore at her house, she was admitted to a hospice. She received frequent visits from her daughter. During that period, she was able to fill her life with meaningful activities: the daughter organised outside trips, and even a birthday party with 100 participants. After some weeks at the hospice, her general condition worsened as the disease progressed. At the very end, she asked again for euthanasia and the doctors who were treating her, accepted her request. The euthanasia was scheduled for the following week, however the patient died three days later, several days before the scheduled euthanasia.

This case illustrates many typical features of euthanasia. It shows that patients are often afraid of therapeutic obstinacy, but also that they may have inaccurate ideas about what will or will not be offered (in this case, intensive care). It also shows that patients (especially when there are helped by family members), can fill their days with meaningful activities, even if their underlying condition has a significant impact on their quality of life. Finally, this case also illustrates something which often occurs: namely, that patients request (and are approved for) euthanasia at a point when the natural dying process is already ongoing. In such cases, a mild sedation with low dose morphine or benzodiazepines can be sufficient to relieve the suffering of these patients, making euthanasia surplus to requirement.

Case #6: Family Despair

A 42-year-old woman had suffered from depression for 20 years. Nevertheless, she got married and gave birth to two children. She was diagnosed with Ewing sarcoma located in the spine. Such tumours need to be treated with chemotherapy and radiotherapy, though surgery was not possible in her case (due to tumour location). In her case, the chance of recurrence was high, however, we estimated a life expectancy of more than two years and good quality of life after the administration of the chemotherapy.

Before starting the therapy the patient asked for euthanasia. The clinical team did not judge that she was in a situation of unbearable suffering without prospects or alternative possibilities. The suggestion was made that she go ahead with the proposed therapy, but because of her uncertainties, she declined. Subsequently she consulted another hospital where she underwent euthanasia two weeks later.

The husband of the patient had talked to the psychology unit about the demand for euthanasia. He told the psychologist that he was aware of the demand of his wife, but that he 'hoped that she would not go for euthanasia, but for therapy'.

This case illustrates the consequences of a euthanasia law which is centred on autonomy. The decision to opt for euthanasia is based on the patient's autonomous request, but without regard for the voice of family members. In cases such as the one above, this can be very challenging for the family. The husband, as next of kin and a person whose life would be deeply affected by the manner of his wife's death, had no voice, no means of raising concerns about her decision to opt for euthanasia. Moreover, the case illustrates that, in all probability, long-lasting depression had influenced the patient's decision; an example of the complex interaction between mental health problems and physical disease. A patient without a significant history of depression may well have chosen to accept the proposed treatment for the Ewing sarcoma. The case also shows that the decision to approve euthanasia or not will be largely dependent of the attitude of the treating doctors towards euthanasia.

Case #7: Accepting Natural Death

A 74-year-old patient was diagnosed with a very aggressive metastatic kidney cancer. The disease spread to the liver and the patient's life expectancy was short. After the decision was made to start therapy with an angiogenesis inhibitor a consultation was set up every two weeks to monitor the tolerance of the therapy and severity of symptoms of the disease.

After four weeks of therapy, the tolerance seemed to be fine, but the patient's general condition did not improve, probably due to disease progression. The patient and his wife reported that they wanted to continue the therapy because it had only recently been started, but at the same time, he was considering euthanasia.

The natural course of the disease was explained to the patient: due to progressive liver metastases, the patient would enter into hepatic failure and thus in a coma and pass away smoothly. This process could take some days, but not more than two weeks. The medical opinion was expressed that the suffering would not be unbearable and without perspective, because a natural and smooth death would follow shortly. The patient, who had a son in another country, was also told that this was the moment to gather the family and to spend as much time as possible with them. It was explained that being accompanied by family in his last days, till natural death, would probably ease the mourning process, especially when compared with the sudden death that results from euthanasia. At the end of the discussion, the patient and his wife nevertheless repeated that they would prepare everything for euthanasia in case of further deterioration. The patient went home continuing his pills against the disease. It was arranged to see him again two weeks later for follow-up of the therapy.

Ten days later, on a Monday, a phone call was received announcing that the patient would not attend the scheduled consultation on the Friday because he would die on that day; leading to the conclusion that euthanasia was scheduled on that day. On the day before this was due however, a phone call was received from his wife, who reported that her husband had died naturally, surrounded by his children who were with him in the last three days. She told me that all happened as had been foreseen and that they were happy that it went that way, and that they did not have to make the difficult choice of euthanasia.

This case shows that in many instances, despite understandable fears and anxieties about how the process of dying may unfold, natural death can in fact be very smooth. It also illustrates that the acceptance and accompaniment of loved ones during the process of natural death can be a positive experience which helps bring peace to the family as they deal with their loss.

Case #8: A Terminal Coma: Unbearable Suffering Without Perspective?

A 75-year-old man was diagnosed with an aggressive cancer. As he had avoided consulting doctors because of a fear of what his symptoms might indicate, the disease was widespread and his general condition was very poor. An attempt was made to ascertain which was the primary tumour and a biopsy was performed. Before the results were received however, the patient was already entering into coma. Life expectancy at that moment was very short, probably some days. The patient was quiet, only sometimes a little bit agitated, but the agitation could be managed using morphine. There was no way anymore to reverse the disease. The only solution was to go for the best supportive care. Moreover, it was impossible to ask the patient about his opinion.

Some family members started to ask for euthanasia, however. They could not bear to see the patient in such a condition, and they estimated that this kind of life was not worth living, and that it made no sense that the patient would remain in this situation for several days. The requirements of the law on euthanasia were not fulfilled in any way, since the patient had not formulated any demand; it was only the family who were asking for euthanasia. Moreover, the suffering was not unbearable and natural death would follow in the coming days. The family disagreed with the medical position, and were upset that euthanasia was not performed, stating that what was happening to him was inhuman.

This case shows that occasionally family members or patients can be upset when doctors decide not to opt for euthanasia, because the conditions of the law are not fulfilled. Where the family's position differs from that of the doctor, and therefore their wish for euthanasia cannot legally be granted, this places the doctor in a position of conflict with the family. This is a source of enormous emotional stress for the doctor.

Case #9: Therapeutic Obstinacy, Common Sense And Euthanasia

A 93-year-old man was suffering from metastatic bladder cancer. Despite his age, he had received chemotherapy some months previously, but now his general condition was deteriorating quickly. He was hospitalised due to his poor condition and asked for euthanasia. There was no reasonable therapeutic option anymore, given his age and the previous low response to chemotherapy. It was decided to talk to the patient on the following day, with a view to recommending best supportive care.

The following day it was reported that the patient was weak, but that he was waiting for a consultation on the therapeutic plan. Performance of a blood analysis had revealed many abnormalities, and amongst them a very low potassium level which could lead to fatal heart rhythm problems. This deficiency was corrected immediately.

In consultation with the patient it was decided he should receive the best supportive care, and the patient died in the following days. The decision to correct potassium levels was not the right one, however. In this case, the patient was dying due to the disease. At that moment, doctors should have accepted the natural death of their patient as a consequence of a severe, untreatable disease. The correction of potassium levels was a form of therapeutic obstinacy.

The lesson of this case is that acceptance of death is not only an issue for patients. Doctors have to accept death as a natural outcome of a disease, and make sure that they recognise that the process has started – that certain treatments might be futile, and therefore of no benefit to the patient.

Conclusion

The cases outlined above provide real life examples from Belgium, where euthanasia and assisted suicide have been legal for almost 20 years. On the negative side, some of the cases above show how the availability of euthanasia can have significant negative consequences for individual patients, for their families, and for the medical teams who care for them. More positively, however, the cases also show that when patients are shown understanding, given support, communicated with clearly; where family are involved, where goals can be enabled, and when medical teams are prudent and realistic in their approach, the process of dying can be managed appropriately without need for recourse to euthanasia.

Endnotes

The picture on the title page is ‘Palliative Care’ by Prachatai, retrieved 10 December 2021: https://www.flickr.com/photos/prachatai/48917684353
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[1] See Raus *et al*, ‘Euthanasia in Belgium: Shortcomings of the Law and Its Application and of the Monitoring of Practice’, The Journal of Medicine and Philosophy 46 (2021): 80–107, https://doi.org/10.1093/jmp/jhaa031; see also Jones, D., Gastmans, C., & MacKellar, C., eds., Euthanasia and Assisted Suicide: Lessons from Belgium, Cambridge Bioethics and Law (Cambridge: Cambridge University Press, 2017), https://doi:10.1017/9781108182799.

[2] Nietzsche, *Twilight of the Idols* (1889) ‘Maxims and Arrows’.

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