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Patient's Autonomy, Physician's Convictions and Euthanasia in Belgium

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I. Introduction

During the past few years, I published a series of articles concerning the policy and practice of euthanasia in Belgium.¹ These articles are critical and constructive, highlighting problems in the euthanasia policy and practice while offering some suggestions as to how to ensure that the patients' best interests are served. This paper builds on these articles and considers some other issues and concerns.

The Belgian definition of euthanasia follows the Dutch definition. Euthanasia is defined as practice undertaken by a physician, which intentionally ends the life of a patient at her explicit request. Since the enactment of the Euthanasia Act in 2002, biannual reports are being published by the Belgian Federal Control and Evaluation Commission, established by the government in September 2002, assigned to monitor the law's application. In 1998, four years before the legislation of the Belgian Euthanasia Act, a nationwide survey estimated that 1.3 % of all deaths resulted from euthanasia and physician-assisted suicide.² A constant increase in registered euthanasia cases has been observed, predominantly in the Flemish part of Belgium. The number of reported euthanasia cases increased from 0.23 % of all deaths in 2002 to 0.49 % in 2007.³ Approximately one of seven terminally ill patients dying at home under the care of a General Practitioner (GP) expresses a euthanasia request in the last phase of life.⁴ The annual figures are constantly rising in an rapid pace: 235 in 2003; 495 in 2007; 704 in 2008, and 1,133 in 2011.⁵ In 2012, there were 1,432 cases and in 2013, 1,816 euthanasia cases were reported.⁶ The most recent figures show that in 2015, more than 2,000 people died under the country's euthanasia laws, including children.⁷

In this paper I aim to show the inherent contradiction in the Belgian euthanasia practice. While stressing patient's autonomy, medical professionals exhibit paternalism in deciding the patient's fate. At the end of life, the autonomy of the patient is often less important than the physician's discretion. First, background information is provided. Then I will voice my critique of the 2014 Belgian Society of Intensive Care Medicine Council Statement Paper and raise concerns about euthanizing people who underwent unsuccessful sex change operation and blind people, euthanizing patients who did not give their consent, and euthanizing people with dementia. Finally, some suggestions designed to improve the situation are offered. The Belgian legislators and medical establishment are invited to reflect and ponder so as to prevent potential abuse.

II. The Belgian Law

On January 20, 2001, a commission of Belgium's upper house voted in favour of proposed euthanasia legislation, which would make euthanasia no longer punishable by law, provided certain

requirements are met.⁸ On October 25, 2001, the Belgium's Senate approved the law proposal by a significant majority. In society at large, an opinion survey showed that three-quarters of those asked were broadly in favour of legalizing euthanasia.⁹ On May 16, 2002, after mere two days of debate, the Belgian lower house of parliament endorsed the bill by 86 votes in favour, 51 against and with 10 abstentions.¹⁰ The legalization of euthanasia was finalized without the broad involvement of and consensus among the medical professions.¹¹

The legislation lays out the terms for physicians to end the lives of patients who are in a state which, medically, is without prospect of improvement and which is characterized by continuous and unbearable physical or psychological suffering which cannot be alleviated and which is the consequence of "a serious and incurable disorder caused by illness or accident."¹² Patients must be at least 18 years-old and have made specific, voluntary and repeated requests that their lives be ended. Chapter II, Section 3 of the Act speaks of patients who are adults or emancipated minors, capable and conscious at the time of their request. "Emancipated minors" is a legal concept referring to minors of a comparable legal status, i. e., autonomous people capable to make decisions.¹³ In early 2014, Belgium has become the first country to allow euthanasia for terminally ill children of any age. It is disputed whether children have the experience and wisdom to make a sound choice about such a grave decision.¹⁴ Many medical practitioners who support the extension of the euthanasia law think that since abortion is possible right up to the day before birth when the foetus is handicapped, euthanasia of newborns ought also to be allowed under the same conditions.¹⁵

Euthanasia requests are approved only if the patient is in a hopeless medical condition and complains of constant and unbearable physical or mental pain which cannot be relieved and is the result of a serious and incurable accidental or pathological condition. At least one month must elapse between the written request and the mercy killing.¹⁶ The one-month requirement is valid for only when the patient is not considered as "terminally ill" (i. e. neurological affections like quadriplegia). What we need to consider is whether people who are tired of life suffer unbearable physical or mental pain which cannot be relieved. Does a person who finds no meaning in life suffer unbearably? What about physically healthy persons who ask to end their lives because they may be tired of life?

III. Statement of the Belgian Society of Intensive Care Medicine

In 2014, the Belgian Society of Intensive Care Medicine Council developed a statement paper about the administration of sedative agents with the direct intention "of shortening the process of terminal palliative care in patients with no prospect of a meaningful recovery".¹⁷ The Statement holds that shortening the dying process by administering sedatives "beyond what is needed for patient comfort can be not only acceptable but in many cases desirable",¹⁸ that suffering should be avoided at all times, that avoiding futile treatment is not only acceptable but also necessary, that shortening the dying process with use of medication may sometimes be appropriate, "even in the absence of discomfort", and can actually improve the quality of dying, that the final decision lies in the hands of the medical care team, and that the document applies to children as well as to adults.¹⁹

Reading the Belgian Society of Intensive Care Medicine Council statement paper evokes nagging concerns. The first is that the word "consent" is not mentioned. The Statement asserts that a "consensus should be obtained for every end-of-life decision"²⁰ but the consensus includes all members of the intensive care team, not the patient and her loved ones. Second, the tone is paternalistic, manifesting a belief that the intensive care physicians are capable to discern when patients have no prospect of a "meaningful recovery" (the term "meaningful" is not explained),

when treatment becomes “futile” (the assumption is that we all know what “futile” means), and when patients “are arriving, irreversibly, at the end of their life” (no indication is given regarding patients’ longevity). Furthermore, relatives should be informed of prognosis and plans for end-of-life care but it “must be made clear that the final decision is made by the care team”.²¹ The Statement is said to uphold the principles of beneficence and nonmaleficence. Respecting patient’s autonomy and her wishes are not mentioned. The decision as to which life is no longer “worth living” is not in the hands of the patient but in the hands of the doctor. Jean-Louis Vincent, a former president of the Society, wrote in a newspaper op-ed that advance directives are worse than useless and that doctors need to be able to give lethal injections to shorten lives “which are no longer worth living”, even if the patients have not given their consent.²² Vincent, who is unafraid to take upon himself immense responsibility, is not aware just how problematic his beliefs and conduct are from an ethical point of view.

Traditionally, the term ‘paternalism’ has been used to refer to practices of treating individuals in the way that a father treats his children. The two assumed features of the paternal role are the father’s beneficence, i. e., the father is assumed to hold the interests of his children paramount; and the father’s authority, that is, that he makes certain decisions for his children and controls certain affairs rather than letting them make the decisions or take control.²³ Most physicians, however, are not perceived by their patients as father figures nor physicians wish or capable to assume such a role. Physicians often guard themselves against becoming too close to their patients and expressing close sympathies to them. Therefore, they should be very careful in applying paternalistic treatment. They should remain professional in attempting to serve the patient’s best interests. They should do this through consultation with all concerned people around the patient’s bed and, when possible, with the patient as well. Decisions should be made involving a circle of people: medical staff, patient’s beloved people, and medical experts who specialise in the particular medical condition of the patient. At the end-of-life, quite often palliative care specialists can contribute to improving the patient’s condition.

A few years ago I had a discussion with two senior physicians at a busy Intensive Care Unit (ICU) in a large Belgian hospital. I asked them whether they customarily consult with palliative care specialists. The answer was an unequivocal “No”. I asked why and the answer was: There is no need. The two physicians claimed they know how to take care of patients and were quick to dismiss the idea that palliative care specialists may provide insights that they do not have.

IV. Should all Euthanasia Requests be Accepted?

In 2013, Nathan Verhelst was euthanized on the grounds of “unbearable psychological suffering” following a botched sex change operation. Nathan, born Nancy, was 44 year-old. He had hormone therapy in 2009, followed by a mastectomy and surgery to construct a penis in 2012. But “none of these operations worked as desired”.²⁴ Nathan was quoted saying: “I was ready to celebrate my new birth ... But when I looked in the mirror, I was disgusted with myself. My new breasts did not match my expectations and my new penis had symptoms of rejection. I do not want to be... a monster”.²⁵ Verhelst did not wish to continue his life in the present form and he was disillusioned with the unsuccessful attempts to change then.

Professor Wim Distelmans, who carried the euthanasia of Verhelst, said that “The choice of Nathan Verhelst has nothing to do with fatigue of life ... There are other factors that meant he was in a situation with incurable, unbearable suffering. Unbearable suffering for euthanasia can be both

physical and psychological. This was a case that clearly met the conditions demanded by the law. Nathan underwent counseling for six months".²⁶

Verhelst had difficult life. He felt that his life were not worth living. He grew up as an unwanted child. He said: "I was the girl that nobody wanted ... While my brothers were celebrated, I got a storage room above the garage as a bedroom. 'If only you had been a boy', my mother complained. I was tolerated, nothing more".²⁷ His mother was quoted saying: "When I saw 'Nancy' for the first time, my dream was shattered. She was so ugly. I had a phantom birth. Her death does not bother me ... For me, this chapter is closed. Her death does not bother me. I feel no sorrow, no doubt or remorse. We never had a bond".²⁸

Verhelst tried to change his gender in order to be accepted, to be liked, to be what his mother wanted him to be. When he realised that his mother will never accept him, he decided to die. What he needed was a holistic treatment to relieve his physical pain, and to heal his tormented soul. Verhelst needed care, investment, compassionate treatment, love, being appreciated for what he was, as he was. Verhelst never received such treatment. Instead, he was put to death. The relatively quick and less expensive way is not always the right way. Most often, it is not the right way.

Professor Distelmans also euthanized the twins Marc and Eddy Verbessem, who were 45 year-old. The two brothers were born deaf and asked for euthanasia after finding that they might also both go blind. After having their request to die refused by their local hospital, Prof. Distelmans accepted on the grounds of "unbearable psychological suffering".²⁹ Distelmans, the champion of euthanasia who also heads the Federal Control and Evaluation Commission that is supposed to monitor and inspect all cases of euthanasia, has no qualms killing deaf and blind people who decide to give up on their lives. He tagged them as "suffering unbearably" and respects their autonomy to the utmost. As he is also the person who inspects all cases of euthanasia, no further official review was conducted.

In 2009, Amelie Van Esbeen asked her doctors for euthanasia after she indicated that she had ceased appreciating her life. Her physicians did not believe that she was suffering from a "serious terminal illness" and "constant and unbearable pain that cannot be relieved" as the law stipulates, hence they refused her request. The 93-year-old woman began a hunger strike and after ten days a different physician helped her die. The controversial case re-launched the debate as to how life should end; about quality of life, and whether such requests should be honoured. Wim Distelmans said that euthanasia can only be performed when there is a question of "unbearable suffering".³⁰ This sounds like a restrictive view of euthanasia. But Distelmans maintained that older persons often suffer from many illnesses: poor sight, poor hearing, poor verbal skills and dependence on others: "Put together this could amount to unbearable suffering. I don't believe it's wrong to request euthanasia in such situations".³¹ Distelmans voiced his belief that the Euthanasia Act should be changed to enable seniors who are "tired of life" to be able to request euthanasia.³²

In Belgium, the role of medicine has received a horrible and most disturbing twist. Physicians like Distelmans are saying to patients like Nathan Verhelst, Marc and Eddy Verbessem and Amelie Van Esbeen: "Are you unhappy with your life? Come to us and we will terminate your life for you". The patient's age does not matter. The medical condition does not have to be terminal (in many parts of the world "terminal" means that the life-expectancy of the patient is no longer than six months and the medical condition is incurable). In the focus is patient's autonomy. People are entitled to wish to die and the physicians should provide them assistance. In other parts of the world, physicians are saying to such patients: "Are you unhappy with your life? Come to us and we will help you find new meaning in your life". Physicians should resist becoming desensitized to the gravity of taking life.

V. Conflict of Interest

Before moving on to consider other problematic aspects of the Belgian euthanasia policy and practice I wish to digress and need to say something about the physician whose name is repeatedly mentioned in all these cases: Wim Distelmans who is the face of euthanasia in Belgium, the relentless champion of euthanasia who celebrates the patients' autonomy to terminate their lives with his help. Distelmans is the Belgian version of the American Jack Kevorkian and the Australian Philip Haig Nitschke. Kevorkian was and Distelmans and Nitschke still are physicians who campaign for people self-determination and free will to end their lives. In their uncompromising campaigns to provide death to those who wish to die, the three physicians became ideologues. It is extremely risky for patients when physicians become ideologues as ideology might obscure good judgment and patients might transform from being ends in themselves into mere means to a higher end. Ideological physicians become rigid and robust in their judgment as they become purveyors of their euthanasia campaign. Distelmans and Nitschke believe that truth and justice reside with them; they have little respect or patience for counter-argument. They are authoritarian physicians who celebrate patient's autonomy to bring their life journey to an end and, ipso facto, surrender autonomy. Their decisions should be closely scrutinized and monitored.

For these reasons, Distelmans needs to decide whether he prefers to euthanize people, or to inspect cases of euthanasia. He cannot do both. Distelmans fails to see the inherent and blatant conflict of interests between his two positions: the physician who performs euthanasia and the inspector who evaluates his own conduct. Regrettably for him, he must address the ethical and professional requirement to forego one of his most important tasks. History has shown unequivocally, time and again, that the assured path to corruption is to enable people to be the judges of their own conduct. People find it most difficult to be impartial about themselves. We may try, but as we humans are prone to err, we need to acknowledge our weaknesses and accept them.

Furthermore, about half the voting members of the Commission are collaborators or members of the Association for the Right to Die in Dignity, an association which openly fights in favour of euthanasia and the expansion of legal conditions.³³ As long as Distelmans continues to head the Federal Control and Evaluation Commission, and as long as the composition of this commission is so pro-euthanasia, Belgium is conveying a clear message that its decision-makers do not truly care to have a viable and trustworthy system of checks and balances. As we are talking of life and death, this attitude is unprofessional and irresponsible. Control mechanisms are required for any conduct that concerns human life. They are essential on matters concerning the termination of life. No wonder that the Federal Control and Evaluation Commission has found until now that the euthanasia policy and practice in Belgium is working extremely well. Such a clear conflict of interests should not take place.

VI. Euthanizing Patients with Dementia

In 2008, Belgian author Hugo Claus died by euthanasia while suffering from Alzheimer. Jacqueline Herremans, president of the Belgian association for the right to die in dignity, said that all the guarantees provided for in the law, including a visit to a psychiatrist, were "certainly respected."³⁴ According to a member of the official committee evaluating euthanasia cases, it was likely that Claus "still in the early stages of Alzheimer's, made the decision while he still had his faculties."³⁵ Bert Ancaux, culture minister for Belgium's Dutch-speaking Flanders region, explained the timing of Claus' death by saying that he wanted to leave with pride and dignity.³⁶

Death with dignity should always be sought. But euthanizing demented patients is morally problematic. The Euthanasia Act (Chapter II) speaks of *competent* patients. Euthanizing patients who do not suffer from somatic illnesses is highly controversial due to the complexity of the situation. Such decisions require taking into account the psychological needs of the patients, the influence and psychological situation of their intimate caregivers, the susceptibility of patients to depression and demoralization, the patient's ability to understand and to process information as well as their emotional state.

The Federal Control and Evaluation Commission had on various occasions endorsed euthanasia cases of patients who suffered from depression and dementia.³⁷ Also in the Netherlands there were cases in which demented patients were killed with the help of a physician³⁸ but some of these cases are very problematic even in the eyes of Dutch experts who condone euthanasia for demented patients in particular circumstances.³⁹ Tomlinson et al. argue that health workers should be mindful of the holistic experience of dementia at the end of life.⁴⁰ The psychological and existential aspects of suffering should be addressed, as well as relief of physical pain. Further research is required. The Belgian and the Dutch are willing to condone euthanasia in the earlier stages of dementia because then patients are capable to take such a decision. The problem here is that patients are killed prematurely, when they can have months of quality life. Euthanasia in the later stages of dementia is considered wrong because then patients who do not know what is happening to them are killed, and this contravenes the competency and autonomy considerations.

VII. Euthanizing Patients who did not Grant Consent

In 2009, it was decided not to prosecute Dr. Marc Cosyns after he euthanized a 88-year-old woman who asked to die but was not terminally ill. She was not fully lucid and had not given written consent. The patient's own physician had opposed the euthanasia request.⁴¹

In 2010, the use of life-ending drugs without explicit request occurred in 1.8 % of deaths.⁴² It should be reminded that the law specifically stipulates that "the patient is an adult or an emancipated minor, capable and conscious at the time of his / her request,"⁴³ thus lives of comatose and demented patients should not be terminated under the Euthanasia Act. It should also be noted that ending the lives of patients without their request is taken place in Belgium more than in all other countries that document such practice, including the Netherlands (0.4 % in 2005).⁴⁴ Physicians were asked when they end the lives of patients without explicit request and the answers were in two situations: Shortening the length of the patient's final phase of agony during the last phase of the dying process, and facilitating the death of the "terminally ill, demented and inhumanly deteriorated patient".⁴⁵ Their aims are to shorten the length of misery considered to be futile, ensure a relatively comfortable death and, most worryingly, alleviate the burden of the next of kin.⁴⁶ Another study found that the practice of terminating lives of patients without explicit request to die occurred among patients who suffered from incurable lingering diseases, whose quality of life was perceived to be poor by the medical teams. The patients were all bedridden and incapable of self-care in what was estimated as the last phase of their lives. Their medical situation was mainly characterized as "unbearable" and of "persistent suffering."⁴⁷ Most of the patients were "unconscious or in a coma."⁴⁸ All but one patient had lost the capacity to assess their situation and to make an informed decision about it. One patient was considered competent but was unable to express himself well.⁴⁹ It appeared that the physicians acted out of compassion and chose what they believed to be the least bad options in futile medical situations. Yet the wishes of the patients were unknown to the physicians. Should physicians end the lives of patients who might still wish to continue living, despite

all odds? Should this issue be left to the discretion of physicians? Can physicians estimate the length of time that patients have to live? Meeussen, Van den Block, Bossuyt et al. wrote that the estimated life-shortening effect was for all but one patient “less than one month.”⁵⁰ How precise is this estimation? Furthermore, at what stage does treatment cease to be meaningful and become futile? Is one-month estimate commonly agreed upon framework of time?

At the very least it seems that these questions should be opened for a public debate. The Belgian population should be aware of the present situation and know that if their lives come to the point where physicians think they are not worth living, in the absence of specific living wills advising physicians what to do then, they might be euthanized.

VIII. Suggestions for Improvement

Building on the experience of Belgium and other countries, I would like to suggest the following: Research has shown that the major reasons which drive patients to ask for death are despair, mental anguish, feelings of hopelessness, loss of autonomy, the fear of losing one’s dignity, and physical discomforts such as pain, nausea and exhaustion.⁵¹ In a survey conducted in Washington State, losing autonomy, lack of ability to engage in enjoyable activities, loss of dignity, and inadequate pain control or concern about it were mentioned as the most common reasons that brought patients in to ask for assistance in dying during 2010.⁵² Similarly, the Oregon 2011 survey showed that the most commonly expressed concerns of those dying from physician-assisted suicide were, as in previous reports, lack of ability to engage in activities making life enjoyable, losing autonomy, and loss of dignity. One third of patients had inadequate pain control or concern about it.⁵³

There is a need to involve palliative care consultants so as to enhance the general knowledge and experience of physicians in palliative care.⁵⁴ Many patients’ concerns can be addressed with comprehensive care that seeks to improve the patient’s mental, spiritual and physical condition. I suggest a combined effort of palliative care and involving the patient’s loved ones in treatment. By palliative care it is meant a holistic treatment that is designed to help the patient resume her will to live, helping her to rediscover meaning in life. Palliative care aims to relieve suffering and improve the quality of life for patients with advanced illnesses and their families through specific knowledge and skills, including communication with patients and family members; management of pain and other symptoms; psychosocial, spiritual, and bereavement support; and coordination of an array of medical and social services.⁵⁵ Indeed, the Belgian Euthanasia Act stipulates that the physician needs to inform the patient the possible therapeutic and palliative courses of action and their consequences,⁵⁶ but it does not require consultation with a specialist palliative care team prior to the act of euthanasia as the Flemish Palliative Care Federation recommended.⁵⁷ A recent study shows that only 55.4 % of GPs had followed a training programme in palliative care or were members of a palliative care team.⁵⁸ It is suggested that GPs who provide euthanasia to their patients should all undergo such training.

Coping with pain and suffering can drain all of the patient’s emotional strength, exhausting the ability to deal with other issues. In cases of competent patients, the assumption is that the patient understands the meaning of end-of-life decision. A psychiatrist’s assessment can confirm whether the patient is able to make a decision of such ultimate significance to the patient’s life and whether the decision is truly that of the patient, expressed consistently and of his / her own free will. The qualified psychiatrist must always meet with the patient to confirm that s / he was not clinically depressed. It is worthwhile to hold several such conversations, separated by a few days. The

patient's loved ones and the attending physician should be included in at least one of the conversations.

IX. Conclusions

The Belgian public has accepted the practice of euthanasia and has made it part of the duties of the medical profession.⁵⁹ Social and peer pressure makes it difficult for those who oppose euthanasia to uphold their position in the liberal culture that has been developing. Similar phenomenon has been recorded in the Netherlands following the legislation of the Dutch euthanasia law.⁶⁰ Johan Bilsen and colleagues found that the enactment of the Euthanasia Act was followed by an increase in all types of medical end-of-life practices with the exception of the use of life-ending drugs without explicit request.⁶¹

Opinion polls indicate that the majority of the Belgian public, 85 % to 93 % of them, support euthanasia⁶² and it would be coercive to deny them what they perceive as a fundamental right. The good news is that the history of the euthanasia in Belgium is young. The Euthanasia Act was passed only in 2002, and the country is still in the early learning stages. We can hope that the Belgians learn from their experience and will devise ways to address the concerns. Having said that, looking at the short history of the euthanasia laws, policy and practice, in Belgium and also in the Netherlands may lead us to think that there is something intoxicating about the practice that blinds the eyes of decision-makers, leading them to press forward further end-of-life practices without paying ample attention to caution. In both countries, one cautionary barrier after the other are removed to allow greater scope for euthanasia. The logic of the 2002 Euthanasia Act that spoke of adults or emancipated minors lost its grounds in 2014 when the Belgians extended the law to all minors. Although some patients are euthanized without explicit request (1.8 % of all deaths in 2010)⁶³ the Belgians are not hard-pressed to push for more stringent control mechanisms. Quite the opposite. A careful review of the euthanasia policy and practice is called for. After all, human lives are at stake.

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