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First Do No Harm: Intentionally Shortening Lives of Patients without Their Explicit Request in Belgium

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Abstract: The aim of this article is to provide a critical review of one of the most worrying aspects of the euthanasia policy and practice in Belgium – the deliberate shortening of lives of some patients without their explicit voluntary request. Some suggestions designed to improve the situation and prevent abuse are offered.

Keywords: Belgium, end-of-life, euthanasia, abuse, competent patients, consent

Introduction

Since the enactment of the Belgian *Euthanasia Act* in 2002, biannual reports are published by the Belgian Federal Control and Evaluation Commission, established by the government in September 2002 and tasked to monitor the law's application. Euthanasia in Belgium is defined as the intentional termination of a patient's life by a physician at the patient's request, thus only voluntary euthanasia is legally sanctioned. Involuntary euthanasia which is the deliberate ending of life without the patient's explicit request is not legally permitted under the Belgian *Euthanasia Act*.

The aim of this paper is to raise concerns about the shortening of patients' lives in Belgium without the patients' explicit consent. First, background information is provided. The paper surveys the published data and explains why this practice is conducted in Belgium. It acknowledges a decrease of life-ending practices without the patient's explicit request and offers three possible explanations to this decrease. The paper criticises explanations provided by some Belgian physicians for carrying out this questionable practice. The paper also offers a critique of the Belgian Society of Intensive Care Medicine Council statement paper on 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".¹ Finally, some suggestions designed to improve the situation are offered. These proposals follow conversations with Belgian medical ethicists and clinicians as to what might be an acceptable practice at the present time, bearing in mind their own culture and medical practices. The Belgian legislators and medical establishment are invited to reflect and ponder so as to prevent potential abuse.

This paper is part of a research project on euthanasia in Belgium that commenced in 2003.² Its methodology is based on critical review of the literature supplemented by conversations, discussions and interviews that I have conducted in Belgium with leading professionals (scholars and practitioners) during the past eleven years (2003-2014). As I see little point in offering suggestions that would be ignored by the Belgian medical profession, the extensive fieldwork in Belgium during which I consulted relevant experts has both helped to formulate my claims and to devise some constructive suggestions for improvement. The claims that I report from my interviews have also been confirmed and verified by the existing literature reported in this paper.

The Belgian Law and Beyond

On 20 January 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 were met.³ On 25 October 2001, Belgium's Senate approved the law by 44 in favour, 23 against, 2 abstentions and 2 senators who failed to register a vote. In Belgian society at large, an opinion survey showed that three-quarters of those asked were broadly in favour of legalizing euthanasia.⁴ On 16 May 2002, after only two days of heated debate, the Belgian lower house of parliament approved the bill by 86 votes in favour, 51 against and with 10 abstentions.⁵ The Socialist-Liberal-Green 'Purple coalition' overcame the objections of the Christian Democrats. It is important to note that the euthanasia legalization was finalized without the broad involvement of and consensus among the medical professions.⁶ While many physicians in Belgium wholeheartedly applauded the *Euthanasia Act*, a considerable part of the medical profession remained silent and a minority expressed reservations. In 2009, sixty-six percent of the sampled Belgian physicians agreed that the euthanasia law contributes to the carefulness of physicians' end-of-life behaviour; 10% thought that the law impedes the development of palliative care.⁷

The legislation lays out the terms for physicians to intentionally end the lives of patients. At the heart of this legislation is the free will of the patient who asks for euthanasia. The physician who performs euthanasia is not performing an unlawful act if s/he has ascertained that the patient is an adult or an emancipated minor, capable and conscious at the time of his/her request;⁸ the request is voluntary, well-thought-out and reiterated, and is not the result of outside pressure; 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, and s/he has complied with the conditions and procedures prescribed by the present law.⁹ The law sets certain conditions in order to carry out euthanasia under terminal circumstances and defines extra conditions for cases in which non-terminal patients request euthanasia. For the latter group of patients (such as those who suffer from neurological conditions causing quadriplegia) who request to die, at least one month must elapse between the written request and the mercy killing, and the attending physician needs to consult a psychiatrist or a specialist in the disorder in question.¹⁰

The fourth report to the legislative chambers (2008-2009), drawn up by the Federal Commission for Control and Assessment of Euthanasia, showed that 92% of the cases were concerned with lawful euthanasia practices with terminal patients while 8% of the cases concerned non-terminal patients. The most often declared illnesses mentioned to justify this latter type of request were primarily neuropsychiatric diseases, followed by degenerative neuromuscular diseases and a combination of non-fatal “multiple pathologies”.¹¹ In recent years, however, the practice of euthanasia has been extended to include people who were depressed, and who were tired of and/or unhappy with their lives.¹² In early 2014, Belgium became the first country to allow euthanasia for terminally ill children of any age. Whether or not children have the experience and wisdom to make a sound choice about such a grave decision is disputed.¹³ Research also indicates some physicians' confusion about and lack of understanding of the *Euthanasia Act*;¹⁴ a problem of inadequate consultation with an independent expert,¹⁵ and a problem concerning lack of notification of euthanasia cases.¹⁶ Smets *et al* found that in Flanders, only

one of two euthanasia cases is reported to the Federal Control and Evaluation Committee and that the unreported cases of euthanasia were generally dealt with less carefully than the reported cases: a legally required written request was absent in the majority of unreported cases; other physicians were consulted less in the unreported cases than in the reported cases; the life-ending act was more often performed with opioids, sedatives or both rather than with barbiturates and muscle relaxants. Furthermore, in the unreported cases the lethal drugs were often administered by a nurse alone, not by a physician.¹⁷ Whether deliberately or not, the physicians were disguising the end-of-life decision as a normal medical practice.¹⁸

A constant increase in registered euthanasia cases has been observed, predominantly in the Flemish (the Dutch-Flemish speaking part) of Belgium.¹⁹ 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.²⁰ A Flanders 2007 study (published in 2010) shows that euthanasia and physician-assisted suicide occurred in 2% of all *Flemish* deaths.²¹ This rate was higher than that in 1998 (1.1%) and in 2001 (0.3%).²² The annual figures are constantly rising at a rapid pace: 235 in 2003; 495 in 2007; 704 in 2008, and 1,133 in 2011.²³ In 2012, there were 1,432 cases and in 2013, 1,807 euthanasia cases were reported.²⁴

Shortening Lives of Patients without Their Explicit Request

In 2014, the Belgian Society of Intensive Care Medicine Council issued 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”.²⁵ 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”,²⁶ that suffering should be avoided at all times, and that avoiding futile treatment is not only acceptable but also necessary. The Statement further stipulates 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.²⁷

This paternalistic attitude is not reserved only to intensive care physicians. Studies conducted in Flanders, before the enactment of the 2002 euthanasia law, showed that decisions to end life without patients’ consent were common among general practitioners. A 1996 pilot study at the town of Hasselt in Flanders showed that the administration of lethal drugs in order to shorten the patient’s life without the patient’s request occurred in 3.3% of cases.²⁸ A 1998 study conducted in Flanders at large, where 60% of the Belgian population resides, more than 5% of all deaths in general practice resulted from the use of drugs with the explicit intention of shortening the patient’s life.²⁹ Bilsen *et al* wrote that during the studied period of time “an estimated 1,200 ELDs (medical end-of-life decisions) in general practice were made illegally”.³⁰ The administration of lethal drugs in order to shorten patients’ lives without their explicit request occurred in 1,796 cases (3.2 percent).³¹ Deliens *et al* noted that in Flanders the rate of administration of lethal drugs to patients with the explicit intention of shortening the patient’s life without their explicit request was similar to Australia, and significantly higher than that in the Netherlands.³²

In 2007, the use of life-ending drugs with the intention to shorten life and without explicit request occurred in 1.8% of deaths³³ and in 2013 it was 1.7% of deaths.³⁴ Three possible explanations to this decrease from 3.2% in 1998 to 1.7% in

2013 are (1) physicians have gained experience and confidence in the practice of euthanasia and involve the patients in the decision-making process; (2) physicians resort to practices such as terminal sedation which is different than euthanasia;³⁵ (3) physicians may not always be well acquainted with the labelling of all the medical practices at the end of life.³⁶ The ambiguity creates confusion and affect research results.

Use of life-ending drugs without explicit request involved patients who were 80-year-old or older (52.7%), those with disease other than cancer (67.5%), and those in hospital (67.1%). The decision was not discussed with the patient in 77.9% of cases. Physicians explained that the decision was not discussed because the patient was comatose (70.1%), had dementia (21.1%) or because discussion would have been harmful to the patient's best interest (8.2%).³⁷ Similar reasoning was given in the Hasselt study two decades earlier: "because this was clearly the best for the patient" (28.2%); because of "diminished consciousness" (26.5%); because "the patient was unconscious" (18.5%), and due to dementia (13.6%).³⁸ However, the patient's best interest argument was far less significant in 2007 (8.2%) than it was in 1996 (28.2%). In contrast, the dementia argument was much more prevalent in 2007 (21.1%) than it was in 1996 (13.6%). It should also 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,"³⁹ thus lives of incompetent comatose and demented patients should not be shortened under the *Euthanasia Act*.⁴⁰ The *Act* does not apply to non-competent patients and it does not allow deliberate shortening of their lives. It should also be noted that deliberate ending the lives of patients without their request is taking place in Belgium more than in all other countries that document such practices, including the Netherlands (0.4% in 2005).⁴¹ It is worrying

that some physicians take upon themselves the responsibility to deliberately shorten patients' lives without a clear indication from the patients that this is what they would want.

Physicians were asked in what circumstances they ended the lives of patients without explicit request and described two types of situation: 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".⁴² Their aims were to shorten the length of misery considered to be futile, to ensure a relatively comfortable death and, most worryingly, to alleviate the burden of the next of kin.⁴³ Thus defenders of the euthanasia policy in Belgium argued that life-ending acts without explicit patient's request should be seen as "compassionate intended abbreviation of terminal agony".⁴⁴

Another study by Meeussen, Van den Block, Bossuyt *et al* found that the practice of explicitly and intentionally shortening lives of patients without explicit request to die involved some patients who suffered from incurable lingering diseases, and 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 involving "persistent suffering."⁴⁵ Most of the patients were "unconscious or in a coma."⁴⁶ 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.⁴⁷

Critique and Suggestions for Improvement

The practice of deliberately shortening patients' lives without explicit request and consent is ethically problematic and also illegal in most countries including Belgium. From physicians' testimonies, it appears that they acted out of compassion and chose what they believed to be the least bad option in futile medical situations. Yet the wishes of the patients were unknown to the physicians. Several questions are provoked by the forgoing account: Should physicians deliberately end the lives of patients who might still wish to continue living, despite all the odds? Should this issue be left to the discretion of physicians? Can physicians reliably estimate the length of time that patients have left to live? Belgian physicians who were involved in this problematic practice estimated life-shortening effect by one week or more for 6.4% of cases.⁴⁸ How precise is this estimation?⁴⁹ Furthermore, at what stage does treatment cease to be meaningful and become futile?

Reading the Belgian Society of Intensive Care Medicine Council Statement evokes nagging concerns. The word "consent" is not mentioned. The Statement asserts that a "consensus should be obtained for every end-of-life decision,"⁵⁰ that the decisions remain "the responsibility of the ICU physician",⁵¹ that once this consensus decision is made, "all members of the team must apply the plan that has been decided on,"⁵² and that while the plans for end-of-life care should be discussed with and understood by the patient's relatives or surrogate, this rather laconic statement emphasises again that "the final decision is made by the care team and not by the relatives".⁵³

The tone of the Statement 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 agree what "futile" means), and when

patients “are arriving, irreversibly, at the end of their life”⁵⁴ (no indication is given of how this potentially self-fulfilling diagnosis is to be reliably made). Furthermore, relatives should be informed of prognosis and plans for end-of-life care but it is emphasised yet again, that it “must be made clear that the final decision is made by the care team”.⁵⁵ The Statement is said to uphold the principles of beneficence and nonmaleficence. Respecting a 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, explained in a newspaper op-ed that because at intensive care units death usually follows after a decision is made to stop treatment, and because this decision is often accompanied by an increase of tranquillizers, “euthanasie non demandée” (“euthanasia not asked for”) exceeds considerably the few thousand cases of “euthanasie demandée” (“euthanasia asked for”) that are registered in Belgium annually.⁵⁶ Vincent explicated that increasing drugs to relieve all pain or providing tranquillizers to prevent agitation or anxiety were not at issue; rather his focus was on hastening death when the patient’s quality of life has become insufficient. Vincent maintained that patients in such a condition are not conscious enough to express an explicit demand, and that these active interventions to shorten life are not reported to the Federal Control and Evaluation Commission. Vincent maintained that Belgium needs a law that clearly condemns “therapeutic stubbornness” and he invited an open and collegial discussion about the possibility of offering drugs that shorten life of too mediocre quality. This is even when the patient did not sign a consent paper. Vincent concluded by saying that the first goal of medicine is to restore or maintain health,

that is to say restore or maintain the well-being of the individual. The first goal of medicine is not to maintain life at all costs.⁵⁷

In 2008, I asked Vincent whether he was in favour of the law. Vincent's answer was: "The law may serve some who deal with slowly progressing diseases, but is more deleterious than helpful in the majority of cases, i.e. in patients who are not fully conscious towards the end of their life. In the ICU we often increase the doses of sedative agents at the end of life, but the person has not signed any document, so that this may become unlawful."⁵⁸

At the very least it seems that these concerns should be opened for a public debate. As Chambaere *et al* rightly note, the use of life-ending drugs without explicit request of the patients occurred predominantly among groups of vulnerable patients: 80 year-old patients or older who were mostly in coma or suffered from dementia.⁵⁹ The Belgian population should be aware of the present situation and know that if their lives may 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 put to death.

To clearly mark the difference between treatments administered to relieve pain and suffering, and treatments aimed to shorten the patient's life, transparency and proper documentation are vital. Records should be kept of the timing and doses of the drugs in use, and the physician's intention at each step. Such documentation may reduce the use of inappropriate doses of medication given in the guise of relieving pain and suffering but actually intended to bring about the death of the patient.⁶⁰

The medical staff should be made aware of the differences between voluntary and involuntary euthanasia, relating to patient's consent and autonomy, the performance of the two practices, and the explicit legal directives for euthanasia. Ethical education in medical schools and in hospital rounds should include discussions about the requirements of the *Euthanasia Act*, and about the medical requirements of due care. Open discussions are recommended relating to the decision-making process and who should be involved in it: physicians, the patient and all the people around the patient's bed: her loved ones and friends, nurses, palliative care professionals, social workers, psychologists and others. Physicians may also benefit from discussion on decision-making processes and the appropriate use of opioids and other medications that might shorten life.

Guidelines and adequate control mechanisms are necessary to prevent abuse of power and to facilitate trust conferred on physicians to heal, support and provide care for people when they are most needy and helpless.⁶¹ Medical records should include documentation relating to the medical condition, patients' expressed wishes, the decision-making process, discussions with the patient and/or her loved ones, the palliation medication that was administered, the use or lack of use of artificial hydration and nutrition, and the effects of the intervention.

Conclusions

Although the legalization of euthanasia was finalized without the broad involvement and consensus among the medical profession, the acceptance of euthanasia among Belgian medical professionals has increased from 78% in 2002 to more than 90% in 2009.⁶² 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 difficulties have been recorded in the Netherlands following the legislation of the Dutch euthanasia law.⁶³ 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 (euthanasia, intensified alleviation of pain, withholding or withdrawing life-prolonging treatment, and continuous and deep sedation until death) with the exception of the use of life-ending drugs without explicit request.⁶⁴

The use of drugs with the explicit intention to shorten life and without the patient's volition still continues to linger on and should be addressed adequately. The liberal state has an obligation to protect the vulnerable. Given that ending patients' lives without request is more common than euthanasia,⁶⁵ it is suggested to urge the Belgian medical profession to put this issue high on its agenda. The lives of many patients are still shortened involuntarily. Even Chambaere *et al* who are not critical of life-ending acts without the patient's explicit request implicitly acknowledge that in 31.9% of the cases they studied the practice was problematic.⁶⁶ The Belgians are researching the way their dying patients are being handled in a medical context. Their culture of self-searching is certainly necessary. The Belgians should ensure that their policy is not abused.

In his critique of this paper, Dan Callahan asks the following: If Belgium has been unable to control abuse -- and does not seem to have tried very hard -- what reason is there to believe it will be controlled in the future? Indeed, the situation in Belgium presents a true challenge. It is not easy to control abuse. At the same time, opinion polls indicate that the majority of the Belgian public, 85% to 93% of them, support euthanasia⁶⁷ 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.

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¹ **Vincent J-L.**, “Piece” (sic) of mind: End of life in the intensive care unit Statement of the Belgian Society of Intensive Care Medicine, *J of Critical Care* 2014; **29**(1): 174-175.

² Other research products include: Belgian Euthanasia Law: A Critical Analysis, *JME* 2009; **35**(7): 436–39; Euthanasia Policy and Practice in Belgium: Critical Observations and Suggestions for Improvement, *Issues in Law & Medicine* 2009; **24**(3): 187-218; First Do No Harm: Pressing Concerns Regarding Euthanasia in Belgium, *Int. J. of Law & Psychiatry* 2013; **36**: 515-21; First Do No Harm: Euthanasia of Patients with Dementia in Belgium, *J. of Medicine & Philosophy* (2015, forthcoming).

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⁶ **Smets T.**, Cohen J., Bilsen J. *et al.*, Attitudes and experiences of Belgian physicians regarding euthanasia practice and the Euthanasia Law, *Journal of Pain & Symptom Management* 2011; **41**(3): 581.

⁷ **Smets T.**, Cohen J., Bilsen J. *et al.*, Attitudes and experiences of Belgian physicians regarding euthanasia practice and the Euthanasia Law, *Journal of Pain & Symptom Management* 2011; **41**(3): 581.

⁸ Freddy Mortier, professor of ethics at Ghent University, explained that emancipated minors relate to "boundary cases of 16-17 year old patients." Mortier argued that there were very few cases of emancipated minors who received help to die by doctors. Interviews with F. Mortier, Ghent (6 February 2003 and 14 February 2005). See **Cohen-Almagor R.**, Belgian Euthanasia Law: A Critical Analysis, *JME* 2009; **35**(7): 436–39.

⁹ **Belgian Act on Euthanasia**, Chapter II, Section 3, no. 1, <http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59>. One referee commented that the line between lawful euthanasia and other end-of-life practices is blurred and creates confusion.

¹⁰ **Belgian Act on Euthanasia**, Chapter II, Section 3, no. 3(2).

<http://www.ethical-perspectives.be/viewpic.php?LAN=E&TABLE=EP&ID=59>

¹¹ **Euthanasia in Belgium: 10 years on**, *Dossier of the European Institute of Bioethics*, http://www.livinganddyingwell.org.uk/sites/default/files/LDW%20-%20Research%20-%20Belgium%20-%202010-Year%20Review_0.pdf

¹² **Cohen-Almagor R.**, First Do No Harm: Euthanizing People Who Are "Tired of Life" in Belgium, paper presented in *Euthanasia and Assisted Dying: Lessons from Belgium*, The Anscombe Bioethics Centre, Oxford and St Mary's University, Twickenham (1 November 2014).

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²⁰ **Meeussen K.**, Van den Block L., Bossuyt N. *et al.*, Dealing with requests for euthanasia: interview study among General Practitioners in Belgium, *Journal of Pain & Symptom Management* 2011; **41**(6), p. 1068.

²¹ **Chambaere K.**, Bilsen J., Cohen J. *et al.*, Physician-assisted deaths under the Euthanasia Law in Belgium: a population-based survey, *Canadian Medical Association Journal* 2010; **182**(9): 896.

²² **Bilsen J.**, Cohen J., Chambaere K. *et al.*, Medical end-of-life practices under the Euthanasia Law in Belgium, p. 1119.

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