

Euthanasia and assisted suicide in the context of psychiatric disorders: sharing experiences from the Low Countries

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Summary

Euthanasia and physician assisted suicide (E/PAS) in the context of unbearable psychological or emotional suffering related to psychiatric disorders (psychiatric E/PAS) is a highly debated topic. In Belgium and The Netherlands, the law allows for psychiatric E/PAS since 2002. The aim of this article is to give an overview of the Belgian and Dutch experiences and the questions raised during the last decade of real-life experiences with psychiatric E/PAS. We use the available national data on psychiatric E/PAS to present a quantitative overview of the current situation. In addition, we identified different challenges; i.e. ethical, medical-psychiatric and legal, that increasingly impact and change the attitudes within the medical and psychiatric professional community towards psychiatric E/PAS.

Key words: euthanasia, physician assisted suicide, psychiatric disorder, mood disorder, ethics

1. Introduction

Euthanasia (a physician intentionally ends a patient's life at the latter's request by medical means) and physician assisted suicide (a physician prescribes lethal drugs at a patient's request with a view to self-administration; henceforth E/PAS) in the context of unbearable psychological or emotional suffering related to psychiatric disorders

(henceforth psychiatric E/PAS) is a highly debated topic. This is very understandable indeed, given that it touches upon the essence of both human and medical ethics. Luxembourg, Belgium and The Netherlands are among the very few countries where E/PAS in this context is legally possible [1]. However, in spite of a legal framework that has been in place for almost two decades, many questions remain in both countries as to the implementation in real life.

The debate has been strongly emotional, not only within the medical profession but also in the media and amongst the broader public. An example of this is a very recent and groundbreaking court trial in Belgium, where three physicians, involved in a case of euthanasia concerning a psychiatric patient, were put on trial for “murder by poisoning”. On 31 January 2020 these physicians were acquitted by a jury after a legal process that took almost 10 years and was initiated by the family. The media have covered this case extensively and reported that the patient had received euthanasia after a long trajectory with different psychiatric treatments with diagnoses including borderline personality, and, seven weeks prior to her euthanasia, a diagnosis of autism spectrum disorder.

The purpose of this article is to give an overview of the Belgian and Dutch experiences and the questions raised during the last decade of real-life experience with psychiatric E/PAS. This topic was recently discussed in a meeting of the Council of National Psychiatric Associations, within the framework of the European Psychiatric Association (EPA), Brussels, on 25 January 2020. For an overview of the current available data on euthanasia and physician assisted suicide within the scope of all medical diagnoses in Belgium, Luxembourg and The Netherlands we refer to a very recent overview [2]

2. Legal framework

Within Europe great differences remain between countries as to the legislation regarding E/PAS. Euthanasia is only legally allowed in the Benelux countries [3]. Laws on medical assistance in dying are implemented in Switzerland.

Both the Belgian *Act on Euthanasia* and the Dutch *Termination of Life on Request and Assisted Suicide* became effective in 2002. In both countries, physical and psychological unbearable suffering have been possible grounds for eligibility for euthanasia from the beginning.

The Belgian law distinguishes between foreseeable death (were the patient is expected to die within a relatively short term) and non-foreseeable death, were the point of expected death due to the disorder can be further into the future or unpredictable. In the latter case, the law requires fulfillment of additional due care criteria, including the consultation by the attending physician (i.e., the one who assesses the euthanasia

request) of a second, independent physician (specialized in the specific disorder or a psychiatrist), in addition to the consultation of one independent physician, which is always required by the Belgian law.

In Germany, the Constitutional Court (Germany's highest court) has very recently (on 26 February 2020) pronounced a sentence, resulting in a change of law, i.e., allowing for physician assisted life-ending (suicide). This verdict highlights the right of patients to choose the moment of death, both in the context of terminal and non-terminal disorders. Given the historical sensitivity of and reluctance towards E/PAS in Germany, specifically in the context of psychiatric conditions, this court verdict represents a groundbreaking change in attitude.

Also in Canada, where E/PAS was already legally regulated in cases of terminal illness (foreseeable death) [4], a proposal to change the law ("An Act to amend the Criminal Code (medical assistance in dying)") was tabled on Monday 24 February 2020, proposing to open up the current rules for E/PAS to patients with "non-foreseeable" death for patients with somatic or psychological suffering.

Taken together, it seems that an increasing number of countries is debating or considering the legalization of E/PAS also for indications relating to a "non-foreseeable" death, i.e., non-terminal conditions.

3. Putting things into perspective: data on the prevalence of E/PAS

3.1. E/PAS overall

According to the most recently published large scale physician questionnaire studies based on death certificates, the frequency of deaths following E/PAS was 2.9% of all deaths in the Netherlands (2010) and 4.6% in Belgium (2013). Moreover, the proportion of deaths following E/PAS has increased in both countries in recent years [5–7]. A follow up study in Belgium looking more closely into the euthanasia cases reported in the anonymous survey showed that only around 60% of them were reported to the Federal Control and Evaluation Commission for Euthanasia, suggesting a significant extent of underreporting [8].

Overall, data suggest that an increase in the numbers of actual cases can be expected the longer the practices have been legalized [3, 4].

3.2. Psychiatric E/PAS

In the Netherlands E/PAS is regulated by law since 2002. However, in the first decade only about two cases of psychiatric E/PAS per year were reported. Since 2012 the number of reported cases increased from two in 2011 to 83 in 2017 [9, 10]. This remains a very small fraction of the total number: i.e., 1% of all E/PAS cases ($n = 6,585$)

in 2017 in the Netherlands [9]. In a recent survey among Dutch psychiatrists, it was estimated that the total number of psychiatric patients explicitly requesting E/PAS was between 1,100 and 1,150 in a one year period (2015–2016), while an estimated 60 to 70 patients effectively received E/PAS in this period [11]. Only a minority of psychiatrists ($n = 9$) in this study reported cases in which they had granted an E/PAS request, with a majority ($n = 66$) describing cases in which they refused.

In Belgium, the most recent report of registered cases of euthanasia showed that in 2019 on a total of effectuated 2,655 cases (47.2% male; 77.3% of registrations coming from Flanders, i.e., the Dutch speaking region of Belgium), 49 were on the indication of the category “psychological and behavioral disorders” (1.8% of all reported euthanasia cases, making this the sixth most common indication). The evolution over the past five years of both the reported number of reported cases for this indication and its proportion of the totality of reported cases remains relatively stable (2014: $n = 61$; 2015: $n = 63$; 2016: $n = 37$; 2017: $n = 40$; 2018: $n = 57$; 2019: $n = 49$). Mood disorders remained the primary reason for requested (and effectuated) psychiatric euthanasia cases between 2014 and 2017 (Figure 1).

4. Psychiatric E/PAS – characteristics of patient cases

In spite of its seriousness and (terminal) finality, very little is known about E/PAS in psychiatric practice. Most of the available evidence and information are included in the reports of the Euthanasia Review Committees in the Netherlands and Belgium. A recent analysis of reported (and documented) psychiatric cases ($n = 35$) in the Netherlands between 2015 and 2017 showed that 77% was female and 74% was older than 50 years. The most prevalent diagnoses were mood disorders (66%), personality disorders (54%), anxiety disorders (29%), and eating disorders (20%). Most (71%) of the patients had more than one disorder and a history of suicide attempts was reported in 34% of the patients. No data were available on the severity of the disorders [10]. These findings are in line with an earlier Dutch study over the period 2011 to 2014, showing that patients receiving E/PAS were mostly women, of different ages (mostly above 60 years), with various chronic psychiatric conditions, most frequently depression (55%), accompanied by personality disorders (52%), significant physical problems and social isolation or loneliness. About half of the patients (52%) reported earlier suicide attempts [12]. The high prevalence of personality disorders is remarkable. In a recent analysis of Dutch cases with personality disorders, 97% had at least one, and 70% had two or more psychiatric comorbidities [13].

In an analysis of officially reported cases in Belgium ($n = 179$) between 2002 and 2013, with a psychiatric disorder or dementia as the sole diagnosis, mood disorder ($n = 83$) and dementia ($n = 62$) were the two most prevalent diagnoses.

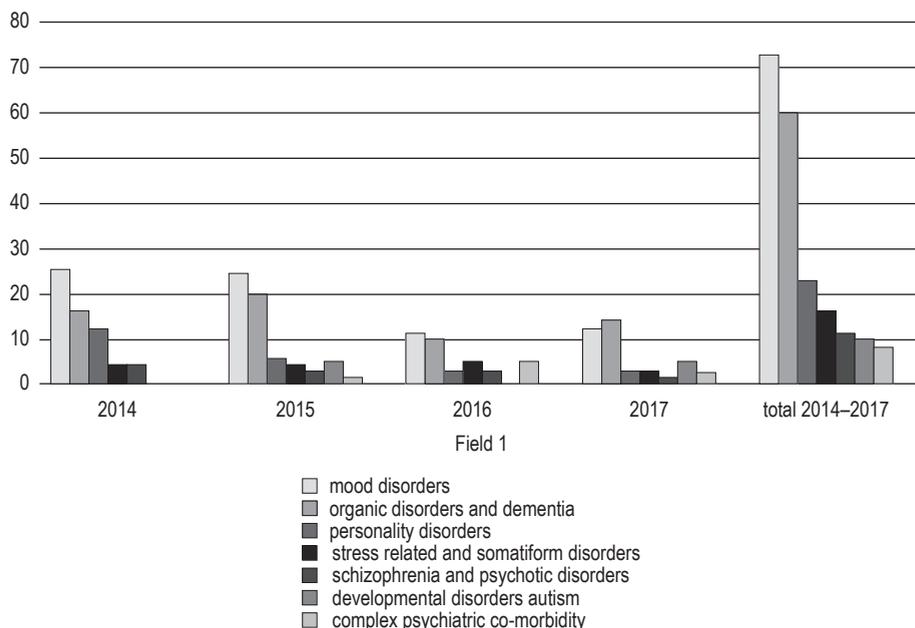


Figure 1. Number of Belgian cases per year by disorder type (source 8th report to the legislative chambers, years 2016–2017, Federal Control and Evaluation Commission for Euthanasia)

Of importance, a clear increase over the years is clear from the data. The proportion of euthanasia cases for mental reasons by all reported cases increased from 0.5% over the period 2002–2007 to 3% between 2008 and 2013. Given the overall increase in euthanasia, this also reflects a substantial increase in the absolute number of cases, specifically for mood disorders (4 cases in 2008 increasing to 30 cases in 2013) [14].

A retrospective Belgian study analyzed 100 cases referred for evaluation of possible euthanasia for psychological suffering between 2007 and 2011. The evaluations were performed by a single unique psychiatrist. The majority were female patients (77%), the mean age was 47 years, and the most prevalent diagnoses were depression ($n = 58$) and personality disorder ($n = 50$), with a majority of cases carrying more than one diagnosis. Ultimately, 48 euthanasia requests were approved and 35 carried out [15].

The biannual report on registered euthanasia cases in 2016 and 2017, submitted to the Belgian Parliament by the Federal Control and Evaluation Commission for Euthanasia, showed that depression was the most frequent and personality disorders the second most frequent psychiatric diagnosis (Figure 1) in the reported euthanasia cases in that period. 63% of the patients was older than 50 years. Remarkably, for patients younger than 40 years personality and behavioral disorders were the most frequent

diagnosis. In these cases, severe psychological trauma was frequently reported. However, interpretation of these Belgian data remains difficult. Indeed, current registration systems specifically on psychiatric diagnosis (i.e., the different co-morbidities) and treatment history provide only limited data, making in depth analysis difficult.

Taken together, patients who receive E/PAS for psychological suffering do seem to have some shared characteristics: most patients are female, they all have a severe mental illness, most frequently depression, they report more personality disorders (specifically younger patients), about half have attempted (multiple times) suicide, and are socially isolated or lonely [16]. Typically, patients received treatment in different settings and different intervention types over many years. However, also a substantial portion (56%) of patients have refused some types of treatment [12].

5. Challenges regarding psychiatric E/PAS

In contrast to E/PAS for patients with somatic conditions and foreseeable death, psychiatric E/PAS raises many concerns regarding the assessment of the due care criteria as outlined in the law [17]. First, the patient's mental competence might be affected by the psychiatric condition. For example, some might argue that a death wish is to be considered as a symptom of severe depression. Moreover, there is still a lack of consensus about the evaluation of the decision-making capacity of a patient. No criteria for evaluation are specified in the Belgian Law.

A second concern pertains to the concept of the incurability of the disorder. Given the highly variable course of psychiatric disorders, which is often determined by other, not strictly disorder-related factors (e.g., negative life events, financial and social problems) deciding on incurability is very difficult [18]. In addition, also from a scientific perspective, we need to acknowledge that psychiatric assessments currently still perform very poorly as to the prediction of course and outcome of psychiatric disorders for an individual patient. This is clear from the sometimes unexpected recovery or response to treatment [19]. Third, the unbearable nature of psychological suffering remains highly subjective and much more difficult to assess "objectively" compared, e.g., with unbearable suffering in somatic disorders. Fourth, questions remain concerning the requirement of a lack of prospect of improvement of the medical situation. Indeed, given the wide variety of treatment options, the highly personalized response typical for psychiatric treatments (e.g., the importance of a good personal bond with a therapist [20]), it remains very difficult to decide at one point that all treatment options have been exhausted. Furthermore, the law allows for any psychiatrist to evaluate these complex psychiatric conditions, whereas it can be doubted that he or she is an expert and up to date regarding all new treatment options for different disorders (e.g., mood disorders, personality disorders, eating disorders, autism). Moreover, at least in

Belgium, a very real danger exists that patients consult many doctors (“shopping”), until they have enough ‘positive’ psychiatric evaluations.

Finally, a majority of the patients receiving E/PAS refuse available treatments (e.g., electroconvulsive therapy for depression). A key question here is whether the incurability criterion refers to the mere existence of possibly effective treatments or to the existence of possible effective treatments acceptable to the patient. If patients are the only reference for judging the acceptability of side effects or administration methods of treatments, the medical criteria of non-alleviability of suffering and of incurability, explicitly mentioned in the Belgian Euthanasia Law, could stealthily be turned into the patient-subjective criterion of unbearableness.

Patients could then be deemed to be experiencing suffering that cannot be alleviated or they could be considered to be incurable despite there being treatments which could provide improvement or alleviation, simply because they refused such treatments on the ground that they consider them to be unbearable. We believe that there are good reasons for resisting this patient-subjective interpretation of incurability. Physicians are involved in euthanasia as both medical experts and moral agents. Indeed, euthanasia and physician assisted suicide create a conflict for physicians between their role as “life-saver” versus “terminator” of life [21, 22]. Their role, in our view, should not be reduced to merely meeting patients’ demands. Of course, we are not arguing that it would be permissible to interfere with patients’ rights to refuse treatment, which is a fundamental moral right of any patient. Patients can always refuse treatment, without having to justify this decision. However, such refusal should never automatically make a patient qualify for receiving euthanasia.

6. The response of the medical profession

6.1. Attitudes

Public attitudes towards E/PAS in general differ widely between countries. Remarkably, public attitudes indicate a broad support for E/PAS in the Western European countries, while being much more limited, and decreasing, in the Central and Eastern European countries [4]. Of interest, globally, attitude surveys of physicians are traditionally showing a smaller portion of professionals in support of E/PAS as compared with the general public [4]. Specifically, for psychiatric E/PAS, these differences seem more outspoken. A recent survey among the Dutch general public and physicians showed that of the general public 53% supported the idea that people with psychiatric disorders should be eligible for E/PAS. Among physicians this ranged between 20% (among medical specialists), 47% (among general practitioners) and 39% (among psychiatrists) [23]. These data are in line with an earlier study showing that only 34% of the physicians supported psychiatric E/PAS [24].

Psychiatric E/PAS remains controversial within the psychiatric practice field, both in Belgium and the Netherlands, and the acceptability of E/PAS and the conditions under which it should be allowed are still debated. As the number of psychiatric patients requesting E/PAS is increasing, Dutch psychiatrists are becoming more reluctant to consider E/PAS [25]. A recent qualitative study showed that, irrespective of their own position in the debate, most Dutch psychiatrists consider reasons for and against E/PAS, including moral (justice and equality, professional responsibility, compassion), epistemological (how can one ever know whether the suffering is without prospect of improvement), practical, and contextual (mental health care provisions) reasons.

The variation in views on E/PAS in psychiatry seems to be related to a difference in views on the nature of psychiatric illnesses [25]. Also, in Belgium attitudes seem to be changing within the psychiatric professional bodies. A first surprising finding is the quasi absence of registered psychiatric E/PAS cases and subsequent public discussion on the topic in the French speaking part of the country. In the Dutch speaking part of Belgium, it seems that, along with the increasing numbers of cases over the last years, fundamental questions are being raised by a growing number of professionals. Within this respect a new initiative by psychiatrists and psychologists, looking critically to E/PAS, the “Review Belgian Euthanasia Law for Psychic Suffering” (REBEL; www.rebelpsy.be) group is gaining some momentum.

6.2. Professional regulations and practices

In response to the legalization of E/PAS in 2002 in both Belgium and the Netherlands, physicians’ (and pharmacists’) professional bodies have developed guidelines (e.g., the Belgian Medical Council in 2005) providing guidance on both the due criteria and safety of medical procedures. In more recent years, guidelines have been developed specifically for psychiatric E/PAS in both countries. Indeed, the need was felt to develop specific guidelines that go beyond the requirements of the law and try to take into account the specific challenges (cfr *supra*) that need to be addressed in cases of psychiatric E/PAS. Guidelines have been developed on several levels: e.g., by national medical councils, psychiatric associations and hospital organizations. Many of these guidelines incorporate elements from the guidelines issued by the Dutch Psychiatric Association (2009 and 2018). An overview and critical analysis of the different guidelines can be found in Verhofstadt et al. [17]. These authors conclude that, notwithstanding some minor differences, the different guidelines contain many similar aspects and procedures. These concern the nature of the assessment (multidisciplinary, repetitive over time, longer reflection time), the involvement of other parties (family, caregivers, other professionals), the control procedures and bodies, and the treatment (disorder specific guidelines versus focus on recovery-oriented approach).

Overall, it looks like a consensus is growing on the use of a two-track approach in the handling of a psychiatric E/PAS request. This approach is characterized by focusing on the ‘avenue of life’ by continuing treatment of the patient (often from a more recovery-oriented point of view), in parallel by a separate health professional with a focus on death (‘avenue of death’) by way of assessing the patient’s euthanasia request [26, 27]. As to the latter, experience shows that being heard and taken seriously in their request often relieves suffering and deepens relationships with caregivers [28].

7. Future directions and conclusions

Although the Benelux countries currently remain in an isolated position as to psychiatric E/PAS, in some countries (e.g., Canada and Germany) attitudes are shifting. Indeed, in the jurisdictions that have legalized psychiatric E/PAS, psychiatric patients are increasingly aware that they can request E/PAS and that their request may be eligible. Moreover, since mental disorders are among the most disabling illnesses, requests for psychiatric E/PAS may increase in many countries [26]. In line with this hypothesis, in countries with a legal framework for psychiatric E/PAS we see an increase over the last decades, of both requests and effectuated E/PAS cases.

The Belgian and Dutch experiences of the last decade illustrate the enormous complexity on a scientific, ethical and practical implementation level. In the Netherlands, the trend towards a broader use of euthanasia has led some commentators to conclude that the boundaries of the Dutch law are being extended or even stretched [29–32]. The call for a much more rigorous evaluation of psychiatric E/PAS requests and a subsequent stricter legal framework is growing in Belgium and the Netherlands [28]. The last two decades have enabled the emergence of a large body of experience and suggestions for improvement regarding this most delicate matter. The different experiences and guidelines developed in the last decade may be of relevance for other countries to build upon their own professional guidance and vision, adapted to their own (possibly changing legal and social) contexts. With respect to the psychiatric profession we think there is a clear need to open this up and work towards a European guidance that captures the best possible practices while at the same time leaving room for country specific contexts and considerations.

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