

Euthanasia in the Context of Adult Psychiatry

Walking the Tightrope Between Life and Death

Monica Verhofstadt

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Faculty of Medicine & Pharmacy
Vrije Universiteit Brussel

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Promotors Prof.dr. Kenneth Chambaere (Ghent University)
 Prof.dr. Kurt Audenaert (Ghent University)
 Prof.dr. Koen Pardon (Vrije Universiteit Brussel)
 Prof.dr. Luc Deliëns (Vrije Universiteit Brussel)

Examination Committee

Chair Prof.dr. Marie-Anne Vanderhasselt
 (Ghent University)

Other Members Prof.dr. Tom Goffin (Ghent University)
 Prof.dr. Gwendolyn Portzky (Ghent University)
 Prof.dr. Frieda Matthys (Vrije Universiteit Brussel)
 Prof.dr. Johan Bilsen (Vrije Universiteit Brussel)
 Prof.dr. Peter-Paul De Deyn
 (Rijksuniversiteit Groningen)

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LIST WITH ABBREVIATIONS

DSM	Diagnostic and Statistical Manual of Mental Disorders
ICD	International Classification of Diseases
CHIME	Connectedness/Hope/Identity/Meaning/Empowerment
NIHDI	National Institute for Health and Disability Insurance
CGG	Centres for community mental healthcare
GDP	Gross domestic product
PH	Psychiatric Hospital
PDGH	Psychiatric department within general hospitals
CLP	Consultation-liaison psychiatry
VLESP	Flemish Centre of Expertise on Suicide Prevention
DALY	Disability-Adjusted Life Years
E/PAS	Euthanasia and/or physician-assisted suicide
PAS	Physician-assisted suicide
FCECE	Federal Control and Evaluation Committee on Euthanasia
BRCBE	Belgian Advisory Committee on Bioethics
EC	Spanish Control and Evaluation Committee on Euthanasia
RWS	The Flemish Right to Die with Dignity Association
LEIF	Life End Information Forum
Médecins EOL	The Walloon Right to Die with Dignity Association
APC	Adults with Psychiatric Conditions (other than dementia)
GUH	Ghent University Hospital
GDPR	General Data Protection Regulation
OSF	Open Science Framework
EOL	End-of-Life
BeNeLux	Belgium, the Netherlands and Luxembourg
HEC	Hospital Ethics Committee
NEOSi	Nature and Extent of Suffering indices
NOSi	Nature of Suffering indices
EOSi	Extent of Suffering indices

THIRD PERSON SINGULAR

Not the singular plural 'they' and 'them', but 'she' and 'her' is used throughout the manuscript to indicate a person of unknown or unspecified gender.

PREFACE

In debates about euthanasia and assisted suicide, it is rare to find an article that begins with an expression of neutral interest and then proceeds to examine the various arguments and data before drawing conclusions based upon the results of a scholarly investigation. Although authors frequently give the impression of being impartial in their introduction, they invariably reach their prior conclusions. Positions tend to be clearly dichotomized: either one believes that the practice of euthanasia or assisted suicide is totally acceptable or completely unacceptable in a just and moral society. Where there is some admission of a grey zone of uncertainty, authors attempt to persuade us that their beliefs (preferences) are the only sensible way to resolve outstanding dilemmas. The practice of vehemently promoting a “pro” or “con” position may be useful when societies must decide to either legalize certain practices or not.

Mishara & Weisstub^{1(p427)}

Mishara & Weisstub (2013) certainly made a good point on the value of position papers or argumentative essays. If the authors approach the topic of interest when they are crystal-clear about the purpose of their writing (e.g., to consider the topic from one specific stance or from opposing points of view), and the type and quality of their argumentative reasoning (differentiating between opinion, emotions, and facts), they contribute substantially to the debate. Even if the position paper is not based on evidence but is written from the heart or driven by an agenda, they contribute to the debate by raising an inventory or even a forecast of societal developments. For the readership, it can be helpful to know the author’s stance on the matter.

The fragment above also partly refers to the risk of ‘bias’ or the tendency to (unknowingly or deliberately) influence the argumentative process in a way that the author’s own prior beliefs or values are confirmed. This phenomenon also exists in scientific research. Bias can occur in each phase of the research trajectory: from the foetal phase of conceptualizing the research plan, which begins by choosing the questions on the topic of interest and setting the research context, to the phases of data collection, data analysis and data interpretation.

Research bias is one of the reasons for the poor validity of research outcomes. Science is supposed to be as objective as possible, as it concerns itself with finding out what there is, not what there should be or should have been. But science itself does not exist and does nothing – scientists make science and scientists are not value-free human beings. To a certain degree, bias is always lurking around the research corner. Hence, it is of utmost importance that researchers be aware of the risk of bias and do everything within their power to minimize it, by e.g., following the principles of good clinical practice and scientific integrity, and critically reflecting on the different types of bias in terms of the degree to which bias has been prevented as well as the degree to which bias might have influenced their research trajectory.

I will therefore start with some explanation of what has driven me to enrol in a PhD programme regarding euthanasia in the context of adult psychiatry, from a personal and newbie researcher perspective.

1.1. Motivation from a personal perspective

I might be good at explaining why euthanasia based on mental suffering is deemed problematic in my perspective. Until there is a patient standing in front of me. Or a psychiatrist asking me what I would do in certain circumstances. But that is part of the job.²

The quote is drawn from a magazine interview with prof. dr. Wim Lemmens, publicly known as strongly opposed to euthanasia in the context of psychiatry. On a personal note, I cannot assume a voice of authority in the debate, because I hold a clear and firm stance neither for nor against euthanasia in the context of psychiatry. This is (hopefully) not due to a wishy-washy character, but rather due to my own personal life story and experiences in the field of practice and the field of science.

Nor can I say that I hold a 'neutral interest' in the topic, as I am an expert in experience – e.g., struggling with mental illnesses and death ideation for decades. More than a decade ago, I applied for euthanasia, underwent the assessment procedure, and decided to withdraw. Therefore, the topic of euthanasia in the context of psychiatry is, and will remain, a topic close to my heart.

A few years after the withdrawal of my own request, when I started studying for a Bachelor's degree in Psychology, I was asked to help psychiatrist Lieve Thienpont and her colleagues in drafting a manuscript regarding her collected data on the first 100 patients who consulted her in one mental healthcare centre in Flanders for the clarification of, or a formal advice on, their euthanasia requests, which were predominantly based on psychiatric reasons. As *death ideation* is of personal interest to me, this seemed to be a once in a – prolonged – lifetime opportunity. It was then that I became aware of the sensitivity and contentiousness of the topic and the highly polarized debate surrounding it. A debate that was – at that time – dominated by strong voices and their outspoken stances in favour and against euthanasia.

Although I had applied for euthanasia as a patient, I experienced no radical stances as a human being, but positioned myself on multiple spots along the continuum of the spectrum 'pro', 'with reservation', 'critical of' and even 'against'. The last was experienced in my role as a volunteer at Vonkel, a non-profit end-of-life consultation centre in Ghent, (Flanders) Belgium. I was entrusted with registering the medical files and conducting intake interviews with patients applying for euthanasia. Those years were crucial to learning how diverse the patient group applying for euthanasia is and how complex the euthanasia assessment procedure can be, especially in the context of psychiatry.

1.2. Motivation from a newbie researcher perspective

Those years were also crucial to learning how much a more nuanced debate and the tackling of sacred cows were needed, on both sides of the 'pro' and 'con' spectrum. As in other highly polarized debates, proponents and opponents often talk past, or lock horns with, each other, often using ideology- or emotive-based arguments as a kind of kicking post.

One way to achieve a more nuanced debate is to set the research agenda and to examine euthanasia practice in a systematic and more objective manner, to finally add some facts and figures to the debate that has so long been deprived of 'factual evidence'.

In addition to the question 'where to start?', the question 'who should undertake the research?' emerges. Is it appropriate for an expert by experience to engage

as an executive researcher? Was I not way too involved in the topic due to my personal history and volunteering work? Would it be possible to reach the needed impartiality and achieve the needed credibility as a researcher? A suitable way to find the answers to these questions was to study for a Master's degree in Clinical Psychology, and to dedicate the master's internship and thesis to the first qualitative research study, under the supervision of two promotor's who had no experience or special interest in the topic. The fact that they not only held different stances towards the topic, but also introduced their own accents on how to do research, was rewarding. It's reassuring to find out that everyone faces the risk of bias, encounters mental and professional warfare, and needs others to have one's own stances and interpretations challenged. I also learned the value of being 'an insider', of having a feeling for the field of practice and of not being impartial from an emotional perspective. To paraphrase the work of Antonio Damasio (2005)³, emotions are the key element in decision-making and learning, and central to the process of rational thought. The existence of human intelligence is one thing and can work satisfactorily, but without emotions to guide intelligence, logical decisions and critical reflection cannot be made. Without emotions, one does not bother, one is not driven, to seek answers to the most pertinent questions. In an academic setting, the risk of being, and remaining, locked up in an ivory tower without any awareness of what is actually going on and of what is needed in practice lurks around the corner.

Hence, I learned the added value of exploring a certain fluidity in the roles of both insider and outsider. For me personally, to be allowed to gather quantitative and qualitative data in a systematic, uncensored manner, to analyse and reflect on this, and to exchange these reflections with individuals from both clinical practice and within the walls of the academic world, made it possible to regularly step outside my own framework. Nonetheless, I was also confronted with the possibility of dismissal from this PhD trajectory if my personal (hi)story were to come out into the open, as it would not only put my own credibility as a researcher in question, but also the credibility and the image of the research group. This made me realize once again how important it is to disclose the motives for doing research as well as to be surrounded by individuals holding different perspectives on the topic of interest, with different personal and educational backgrounds.

The more I immersed myself in the topic – by listening with an open mind to all possible perspectives on the continuum pro and contra, and many positions in between – the more I became convinced that there are no simple 'black and white' answers to this complex phenomenon.

To conclude, this PhD dissertation does not aspire to anything other than to contribute to the debate regarding euthanasia and psychiatry by providing scientific evidence, gathered in the most objective and structured manner, following the researcher's charter regarding good clinical practice and scientific integrity, and not being bounded by sacred cows.

CHAPTER 1 : INTRODUCTION

Author:

Monica Verhofstadt

“Someone once said that his favourite times in history were when things were collapsing, because that meant something new was being born. Does this make any sense if we apply it to our individual lives? To die when something new is being born—even if that something new is our very own self? Because just as all political and historical change sooner or later disappoints, so does adulthood. So does life. Sometimes I think the purpose of life is to reconcile us to its eventual loss by wearing us down, by proving however long it takes, that life isn’t all it’s cracked up to be.”

Julian Barnes (The Sense of an Ending)

The overarching objective of this PhD was to establish a more thorough understanding of the euthanasia practice in the context of adult psychiatry by means of (1) a critical reflection on how euthanasia is (to be) implemented in today's practice, (2) empirical research on the experiences and perspectives of patients and health care professionals. The research trajectory resulted in this dissertation, based on the papers submitted to, or published in, scientific journals during the course of my PhD (October 2017-December 2021). It is preceded by an Introduction and concluded by a General Discussion.

Before going into detail about the research aims and questions of the research trajectory, the concepts of psychiatry and mental illness, and the current state of adult psychiatry in Belgium, will be sketched to provide some framing of the research context. Then, the historical background of the euthanasia debate will be portrayed, as well as the road towards euthanasia legislation in Belgium and its implementation in clinical practice. The Belgian Law on Euthanasia will be described and briefly compared with the legal frameworks in other countries. The introduction concludes with an overview of past research studies on euthanasia in general and in the context of adult psychiatry, before zooming in on the research purpose, questions and methodology used in this PhD dissertation.

1. The Concepts of Psychiatry and Mental Illness

Today's concept of psychiatry refers to the medical science and practice of preventing, diagnosing, and treating mental illnesses. It is preceded by a long history of defining and distinguishing normality from abnormality, and the theories surrounding the aetiology of the latter to (for example) supernatural, somatogenic, psychogenic and/or sociocultural-genic factors. The history is encapsulated in the term 'psychiatry', which derives from ancient Greek and is composed of the words *psukhē* (mind, soul) and *iatreia* (healing).

With regard to the nosology of mental illnesses, the 'Statistical Manual for the Use of Institutions for the Insane' – published in 1917 by the American Medico-Psychological Association (today, the American Psychiatric Association) – categorized 21 disorders, 19 of which related to psychotic behaviours. This manual is the precursor to the first Diagnostic and Statistical Manual of Mental

Disorders (DSM), of which the updated version, DSM-V, is most often used in today's psychiatric practice and research.⁴ The initiative for the DSM-I was prompted by the existence of a diagnostic manual including all illnesses: the 'International List of Causes of Death'. The first edition was published in 1893 and listed mortality statistics. The List was further revised, which resulted in the classification of not only mortality but also morbidity, and thus also the listing of mental disorders. The sixth version of what was renamed the International Classification of Diseases (ICD) was published in 1948 and included a chapter with 26 categories of mental illnesses, each containing multiple diagnoses.⁴ Four years later, the DSM-I was published and captured, not just twenty-some, but 128 categories of mental illnesses that differentiated between physically detectable disorders (e.g., organic brain syndromes) and physically undetectable functional disorders (e.g., psychotic disorders, neurotic disorders and personality disorders). Following the societal restructuring leading to the deinstitutionalization of psychiatric hospitals, the DSM-II (1968) was designed to have more practical relevance to outpatients. It is important to note that the revised DSM-II had homosexuality – previously regarded as a sexual orientation disturbance – no longer pathologized but newly regarded as a deviation from socially accepted heterosexual behaviour.⁵

Notwithstanding the efforts made to better understand mental illness, the concept itself remains difficult to define, but deemed quintessential for (1) research purposes, (2) ethical reasons (e.g., to avoid societal concerns being psychiatrised), (3) legal purposes (e.g., to understand situations of legal imputability), and (4) financial issues (e.g., to allow for psychiatric treatment reimbursements).⁶

The first definition of mental illness was recorded by psychiatrist Robert Spitzer (1932-2015).⁶ Spitzer believed that the revised version of the DSM should include the most atheoretical and value-independent definition of what is deemed a mental illness in order to counter the arguments of antipsychiatry and to justify the removal of homosexuality.⁶ Therefore, Spitzer conceptualized a mental disorder as:

“a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is typically associated with either a painful symptom (distress) or impairment in one or more important areas

of functioning (disability). In addition, there is an inference that there is a behavioural, psychological, or biological dysfunction (...).^{7(p6)}

The definition of mental disorders has changed multiple times over the years,⁶ but generally speaking, a mental illness refers to all diagnosable disorders in the context of psychiatry, which are characterised by disturbances in cognition (reasoning), emotion (affect regulation), and/or behaviour, deviating from typical behaviour according to societal standards or from the expected/accepted deviant behaviour due to stressful life events (e.g., intense acute mourning after the loss of a loved one).⁸ The task of demarcating the line between normal mental struggles and a mental *disorder*, is entrusted to the profession of psychiatrists and psychologists, who are left to assess the epiphenomena of a psychiatric disorder when judging its degree of severity: mild, moderate or severe.

The DSM-III (1980) introduced the multi-axial classification system, following: (I) clinical psychopathology, e.g., psychotic disorders and mood disorders; (II) personality disorders and developmental delays; (III) physiological medical disorders that have relevance to psychiatric symptom presentation, e.g., impacting medication choices; (IV) psychosocial stressors in the environment; and (V) assessment of the patient's functioning ability in, e.g., work and relationships. The DSM-III comprised 265 classifications of mental illnesses.⁴

The DSM-IV (1994) introduced a variety of cultural diversity-related background characteristics for cross-cultural validity. The latest version, the DSM-5^a, was published in May 2013 and contained 317 classifications, structured in 20 main categories (Table 1). The changes made are largely informed by advancements in neuroscience, clinical and public health needs, and to ensure better alignment with the ICD-11.⁹

To date, the classification through both the DSM-5 and the ICD-10 is generally accepted^b. Notwithstanding the general acceptance of both classification

^a The shift from DSM-IV to DMS-5 has led to the discontinuation of the use of a Roman numeral.

^b Whereas the DSM-5 only comprises psychiatric disorders, the ICD also comprises a classification of somatic disorders. This may explain why the DSM is more often used in the context of mental healthcare research than the ICD. Whereas the more user-friendly ICD is more frequently relied on in developing countries, the DSM is used more in developed countries. As Belgium is classified as a developed country, the DSM classification system is used throughout this research trajectory and thus in the chapters of this dissertation concerning the research trajectory.

systems, they are frequently contested. The DSM is more subject to criticism due to its strong association with the American Psychiatric Association and its strong connection with the pharma-industrial complex.¹⁰⁻¹⁴ For instance, psychiatrist Allen Frances's book 'Saving Normal' (2013) expressed the need for more awareness and concern regarding diagnostic inflation and psychiatric epidemics flaws to please the pharmaceutical industry. Referring to his own first-hand experience as a taskforce chairman (!) during revisions of the DSM-IV, he concluded that it is 'a losing battle to protect normality from medicalization'.¹²

Table 1: DSM-5 Diagnostic Chapters

MAIN DIAGNOSTIC CATEGORIES	
1	Neurodevelopmental disorders
2	Schizophrenia spectrum and other psychotic disorders
3	Bipolar and related disorders
4	Depressive disorders
5	Anxiety disorders
6	Obsessive-compulsive and related disorders
7	Trauma- and stressor-related disorders
8	Dissociative disorders
9	Somatic symptom and related disorders
10	Feeding and eating disorders
11	Elimination disorders
12	Sleep-wake disorders
13	Sexual dysfunctions
14	Gender dysphoria
15	Disruptive, impulse-control, and conduct disorders
16	Substance-related and addictive disorders
17	Neurocognitive disorders
18	Personality disorders
19	Paraphilic disorders
20	Other mental disorders

In recent years, counter-reactions in favour of differential diagnostics, paying attention to sociocultural-related strengths and resilience in assessment and treatment, instead of simple problem-oriented classification diagnostics are made.^{15,16} These approaches fall beyond the scope of this introduction section.

The prevalence of mental illnesses and associated disease burden across the globe

According to the most recent figures of 2017, the Institute for Health Metrics and Evaluation estimated that at least 1 out of 7 (15%) of the global population is affected by one or more mental illnesses. This may be an underestimation, due to the under-reporting in low income countries, where little attention is paid to mental illnesses and their gathered data is scarcer.¹⁷ Most of these individuals live with an anxiety disorder (3.8%), followed by depression (3.4%), substance use disorder (2.3%), bipolar disorder (0.6%), schizophrenia and eating disorders (0.2%). There are differences with regard to gender: whereas depression, anxiety, eating and bipolar disorders are more prevalent in women, substance use disorder and schizophrenia are generally more prevalent in men.¹⁷

The disease burden is often measured in terms of mortality or the total number of deaths directly related to mental illnesses. The average direct mortality rate is considered to be low, and mainly resulting from eating disorders and substance use disorders.¹⁷ Nonetheless, mental disorders are also linked to a significant number of indirect deaths through suicide and other self-harm behaviours. Whereas in high-income countries, up to 90% of suicide deaths are ascribed to mental illnesses (mainly to depression and bipolar disorders), lower rates are reported in low- and middle-income countries. However, this can be due to underreporting.¹⁷ For instance, 68% of suicide deaths are noted in Asian countries (e.g., China and India), but they are ascribed to the 'dysphoric affect' and 'impulsivity' instead of being linked to a mental illness. In addition, the means for self-harm vary across countries. In these countries, a high percentage of reported deaths were carried out through poisoning (often through pesticides) and self-immolation, which can only be proven fatal but not, per definition, proven to be carried out with the clear intent of dying.¹⁷

The proportion of suicides based on psychiatric conditions in Belgium remains unclear. According to the Flemish Centre of Expertise on Suicide Prevention (VLaams Expertisecentrum SuïcidePreventie, or VLESP), this is probably due to physicians not being obliged to fill in the presence of mental illness in the administrative document on the patient's cause of death and hospitals'

emergency departments not being obliged to fill in the presence of mental illness in the administrative document surrounding suicide attempts.¹⁸ Nonetheless, the VLESP reported that, in a slight majority of cases, the presence of a mental illness was formulated, which confirms the link between suicides and psychiatric conditions.¹⁸ According to the VLESP, 5 people per day die by means of suicide, and 10 times more suicide attempts are registered. To put this in an international perspective: Belgium has one of the highest suicide rates in the European region.¹⁹

However, a narrow focus on suicide deaths shies away from the total picture of burden. Therefore, the disease burden is also measured through the Disability-Adjusted Life Years (DALYs) assessment. According to the most recent figures of 2017, DALYs account for around 5% of the global disease burden, and may reach up to 10% in several countries, with the highest contribution to overall health burden reported in Australia, Saudi Arabia and Iran.¹⁷

2. The current state of Mental HealthCare in Belgium

The financing of the Belgian healthcare system is regulated on a federal level and primarily funded through a combination of health insurance and social security contributions. The total amount of expenses made for healthcare in Belgium is estimated to be 10% of the gross domestic product (GDP), of which approximately 2.1% is paid by the patients themselves.^{20(p34)} The overall costs related to mental health problems was estimated to be about 5% of the GDP in Belgium, making Belgium one of the European countries with the highest overall costs related to mental health problems (only the Netherlands, Finland, and Denmark rank higher in this respect).^{20(p34)} Notwithstanding the efforts to shift from intramural towards extramural mental health, and a shift from a medical model towards both a holistic biopsychosocial and more tailor-made model of care, most of the mental healthcare budget (80%) still goes to residential care and thus to psychiatric hospitals.^{20(p50)}

The distribution of the expenses and the content of the area of 'health', including mental health, is covered to a different extent by each of the parliaments. For

instance, whereas the Federal government is responsible for paying psychiatrists and psychiatry services in inpatient hospitals, the federated entities are responsible for the funding of outpatient mental health services.²⁰ To encourage cohesion, the Inter-Ministerial Conference on Public Health, in which ministries from the different policy levels regularly meet, aimed to realise a reform in mental healthcare by means of generating different protocols for different targeted patient groups – e.g., the existing protocols for ‘adults’ and ‘children and young people’, and the upcoming protocols for the ‘elderly’. The following two main themes are the guiding principles: 1) ‘socialisation’ in the sense that as much care as possible should be provided by the patient’s own living environment, and 2) ‘network collaboration’ in the sense that, if a residential stay is deemed unavoidable, the stay should be as short as possible and follow-up care should be provided by extra-mural care providers as soon as possible.²¹

As adults with psychiatric conditions are the target group of this dissertation, only the organisation of mental healthcare for adults in Belgium will be sketched, with a particular focus on the situation in Flanders.

Hospital settings

Belgium has 118 hospitals that adult patients with psychiatric conditions can turn to, among them 51 psychiatric hospitals (PH) and 67 psychiatric departments within general hospitals (PDGH). Compared to the other regions, Flanders had more PH ($n = 29$) and PDGH ($n = 35$), which are more equally balanced over the whole territory and with more beds available to host more patients.^{21(pp6-7)}

In residential settings, there are different units according to the psychopathology and its particular treatment needs: (1) acute care, (2) chronic care, (3) specialised care services for psychogeriatric and chronically ill patients, (4) intensive care for patients with severe behavioural disorders, and (5) family placement or psychiatric family care, which is only provided in the atypical PH in the cities Geel (Flanders) and Lierneux (Wallonia).^{21(pp8-9)} More places for partial hospitalisation are provided in Flanders, which is also the only region that provides beds for acute care in night hospitalisation in their PDGH. Overall, there is a trend towards more acute treatment and day therapy^{21(p14)} but, at the same time, there is also a trend towards more stays in both PH and PDGH, with a more prominent increase of patients in the age range 19 to 40.^{21(pp16-17)} With regard to

the duration of the stays, whereas a reduction is observed, especially in the PDGH (almost 80% of stays last less than one month), the proportion of patients being readmitted the same year to the same hospital has increased, with frequent readmissions becoming more common. Also, and particularly in Flanders, the number of involuntary admissions has risen.^{21(pp19-20)}

Finally, there are several specialist hospitals, offering exclusively geriatric, palliative and rehabilitation services. During the 6th state reform, it was decided to transfer these specialist hospital services to the executive power of the federated entities. As a result, whereas some specialist-services were merged within general hospitals, some were expanded to additional service centres. To date, there are 8 specialised rehabilitation centres in Flanders.²² In addition, there is a trend towards implementing consultation-liaison psychiatry (CLP) services in hospitals to help patients suffering from both psychiatric and somatic comorbidities, with the use of a multidisciplinary and integrated care approach.²³

Psychiatric nursing homes and sheltered accommodation

Residential nursing homes and initiatives for sheltered living fall under the competency of the communities in Belgium. The reform of 1990 expanded the capacity of these residential care structures for patients with severe and persistent mental illnesses, who were no longer benefitting from curative treatment interventions but were in need of more intensive support and care interventions. To date, there are 38 facilities for sheltered accommodation and 23 psychiatric nursing homes registered in Flanders.²² These services made it possible to reduce the number of psychiatric hospital beds; but they also received criticism, as these residential settings are only partially reimbursed by the Belgian national insurance system, and partially by the patient or the patient's next-of-kin.²³

In recent years, initiatives are being made to provide a new type of care for the chronically ill. In reaction to the increased number of adult patients requesting, and approved for, euthanasia (see 6.1.2 and 6.1.4) , and in analogy to palliative care services for the (close to) terminally ill in somatic medicine, the concept of 'crustative' or 'oyster' care arose and is about to be further developed and expanded.^{23,24} Crustative or oyster care is a specialised, tailor-made 'palliative' psychiatric care for those patients for whom there are no therapeutic options left

in terms of alleviation of suffering, although their quality of life, perception of dignity, and connectedness need to be maintained.

Outpatient services

To date, there are 20 Centres for Mental Healthcare in Flanders,²² providing second-line psychiatric care by a cluster of multidisciplinary physicians and other professional care workers. These services are fully subsidized by the regional government and also offer help at lower initial costs to the benefit of the financially less well-off.²³

Private and group practices

Private and group practices that offer mental care and support for people struggling with mental difficulties or illnesses are widely spread over the country, also in Flanders.²³ Since 2016, it is legally regulated who may practice psychotherapy, e.g., masters in clinical psychology, orthopedagogy and medicine, resulting in the recent reimbursement model of a maximum of 8 sessions of psychological and/or orthopedagogic interventions per year.²⁵

Forensic Psychiatry

Among the specialised psychiatric care services, there are 10 forensic psychiatric care facilities for detained patients with mental illnesses affecting their mental competence and therefore not subject to criminal responsibility. As defined by the Belgian Law relating to Detention of 5 May 2014, these patients must not be punished but must be treated instead, and thus be hospitalised for an indeterminate period in time.²⁶ To date, there are 2 forensic psychiatric services in Flanders, providing care for internees with a high-risk profile. In addition, there are 8 specialised services in PH and psychiatric care homes to provide care: (1) 3 for internees with medium-risk profiles, (2) 3 for sexual delinquents, (3) 1 for female internees with high-risk profiles, and (4) 1 for male internees with high risk profiles.²⁷

THE PREVALENCE OF MENTAL HEALTH PROBLEMS IN BELGIUM

As explained, there is no uniform source of data on mental healthcare in Belgium. The *Minimale Psychiatrische Gegevens* (Minimum Psychiatric Dataset) is one of the few nationwide datasets in Belgium providing a short overview of: 1) the prevalence of psychiatric disorders in PH and PDGH, 2) the type of care provided by these residential facilities, and 3) the residential facilities' market share, based on the patient's domicile. As regards the prevalence of psychiatric disorders, residential stays are due to substance abuse in 1 out of 3 cases^c.²⁸ In the PDGH, depressive disorders and adjustment disorders were the second and third most common mental illnesses.²⁸ In PH, psychotic disorders and paranoid schizophrenia were the common disorders. In both of these care facilities, these disorders comprise more than half of the stays.²⁸

As data from private and group practices are lacking, one must rely on the quinquennial health reports from the Belgian Institute Sciensano to estimate the prevalence of psychiatric disorders. Their last official report (in 2019) revealed that one out 10 Belgian citizens would suffer from at least one psychiatric disorder, of whom 14% would also suffer from suicidal ideation, and around 4% would have attempted suicide.²⁹ Unfortunately, there is no single, standardised source of data covering the entire mental healthcare system in Belgium. Little is known about the mental healthcare landscape, especially as regards outpatient care. Therefore, it remains very difficult to assess the performance of the mental healthcare sector, the prevalence of the individuals making use of the sector, and for which psychiatric condition.

^c According to the Minimum Psychiatric Dataset, psychiatric hospital admissions of the 44,521 patients, ranging in age from 18 tot 64 years, were due to the following main mental illnesses: (1) substance abuse (29%), schizophrenia and other psychotic-related disorders (21%), depression (13%), adjustment disorder (10%), personality disorder (6%), bipolar disorder (5%), anxiety and stress-related disorders (3%), and a variety of other major disorders (12%).²⁸

3. An historical perspective on euthanasia

3.1. THE PREDOMINANCE OF THE PHILOSOPHICAL DEBATE

The concept 'euthanasia' was already debated centuries ago, in Hellenistic Greece. The word derives from the Greek 'eu-thanatos', literally meaning 'good death' in terms of a noble and painless death, but it was not used in the medical context. In antiquity, the concept was used in ample discussions among philosophers on the topic of suicide, a concept that derived from the Latin 'suicidium' (literally: 'to slay oneself'). The philosophical debates were related to the moral ethics of suicide, of which the outcome was related to the philosopher's attempt to distinguish between different types of suicide in terms of the different intentions preceding death by suicide.³⁰⁻³²

Suicide was generally disfavoured if it was considered to be an act of cowardice and as an injustice as it is forbidden by Law.³³ As for the latter, philosophers including Aristotle and Plato referred to the individual's legal duty towards oneself, towards society and towards the deity. However, suicide was considered ethically permissible in exceptional cases. Plato (427–347 BC), for example, argued that suicide deaths can be considered acceptable in individuals demonstrating an immoral character, immoral actions, or... when seriously afflicted due to a terminal illness, or grief when experiencing a traumatic loss.³⁰ Hence, in exceptional cases, suicide could be morally justified and thus seen as a good death. Important to note is that, not the individual's appeal to self-determination, but a more objective evaluation of the individual's moral and societal worth were deemed essential to the question.

With regard to the context of medicine, Plato argued that no treatment should be provided to prolong the life of severely ill or disabled individuals as they represent a real burden to society. However, notwithstanding them not contributing to society, these individuals should be permitted to live.³³ This was enforced by the Hippocratic Oath prohibiting physicians from giving a deadly drug to 'anyone', not even upon the person's request. On a critical note, there is mention of a certain mistake in the translation of the sentence "And I will not give a drug that is deadly to anyone if asked for it." and, as a consequence, in its interpretation.³⁴ In the original Greek sentence, 'requested' goes along with the

subject 'I' and thus the one who swears in the 'nominative'. As the 'anybody' is written in the 'dative', the person who requests and to whom the fatal drug shall not be given are not referring to one and the same person. Hence, the individual requesting it does not *per definition* refer to the one to whom the physician shall not provide the deadly drugs.^{34(pp9-10)} The physician swearing the Hippocratic Oath would then be prohibited only to give the deadly drugs to the patient on the request of another individual, which can be interpreted as the equivalent of the prohibition of homicide. For someone who is not proficient in ancient Greek language and history, it is impossible to determine what the Hippocratic Oath intended to prohibit. Be it a violation of the Hippocratic Oath or not, it can be concluded that the ancient physicians did assist the severely ill with their pursuit to hasten death.³⁵

The Stoics of later eras placed more emphasis on individual decision-making, but solely in the event of 'wise men' (in contrast to the 'feeble-minded') seeking for 'a reasonable departure' when losing the ability to pursue the life that nature intended to have in store for them due to, e.g., a chronic illness or debilitating consequences of old age. Suicide would then be deemed a noble act, as the individual committing suicide sacrifices herself for the benefit of his/her relatives and of society in general. Seneca (4BC-65), for example, was regarded as a wise man to be praised for committing suicide, as it shows consistency of character and reflects an act of *dignitas*.³⁶

Suicide became taboo during the Middle Ages, under the ascendancy of the Judeo-Christian tradition.³⁷ For example, Thomas Aquinas (1225-1274) strongly disfavoured suicide, as it injures the societal system of which an individual is part and is responsible for, and it violates God's authority over life.^{38,39}

It was not until the 16th century that philosophers began to challenge the condemnation of suicide in all circumstances. Michel de Montaigne (1533-1592) wrote a critical essay on arguments in favour and against suicide, and concluded that suicide cannot be solely a matter of religious belief but also a matter of individual choice that can be acceptable in certain circumstances when the individual faces, e.g., pain and a gruelling dying process.³⁸ Suicide was discussed by many other philosophers, including Sir Thomas More (1478-1535) and Desiderius Erasme (1466-1536). This is not included in this sub-section, as their writings were distinguished by irony and satire respectively, which makes their

personal stances on the topic a matter of discussion.^{38,40,41} However, Thomas Moore deserves further mentioning, as the first reference on euthanasia in the Anglo-Saxon literature is ascribed to him.⁴² In his book, *Utopia* (1516), More describes the attitudes of the fictitious Utopian citizens regarding dying, death and the afterlife. As regards the terminally ill, the Utopians are convinced that everything should be done to make their lives as comfortable as possible (palliative approach). If the terminally ill suffer from torturous pains that cannot be sufficiently alleviated, they will be visited and encouraged by 'priests and magistrates' to alleviate their misery, and with warm reminders of the blessings promised in the future life (immortality is key in *Utopia*). In *Utopia*, a voluntarily hastened transition to the afterlife, with or without the assistance of others, is considered to be an honourable death.^{41,42}

It was Francis Bacon (1561–1626) who, in his work *The Advancement of Learning and the New Atlantis* (1623), contrasted the spiritual concept of euthanasia (sweet calm dying, when the soul prepares itself for the afterlife and separates itself from the dying human body) with the concept of 'euthanasia exteriori' (outward euthanasia) in the context of medicine. According to Bacon, the field of medicine should not only focus on cure but also gain knowledge and expertise to provide patients help in dying when recovery is deemed impossible.^{42–44}

In the 18th-century Enlightenment, or the so-called Age of Reason, religious authority was tackled, and ethical topics became the prominent subject of intellectual debate. The philosopher David Hume (1711-1776) argued that the suicide of an individual, plagued by (e.g.) tremendous suffering, may outweigh the loss for society.⁴⁵ Other philosophers, including Immanuel Kant (1724-1804), strongly opposed suicide due to its inconsistency with the value of life and the notion of individual autonomy, which is characterized by the subjugation of the individual's desire, including the desire to hasten death, to universal moral laws.

3.2. THE ENTRY OF THE PREDOMINANT VOICE OF ADVANCED MEDICINE TO THE CONTEMPORARY DEBATE

The philosophical debate on suicide continued and remained undecided, depending on the philosophers' stances on the value of life. Whereas philosophers such as Kant and Arthur Schopenhauer (1788 – 1860) strongly oppose suicide (Schopenhauer considered death by starvation as the one and only acceptable exception⁴⁶), other philosophers (e.g., Friedrich Nietzsche, 1844-1900) did not strongly defend it, but noted that the legitimacy of suicide should not be dictated by religious beliefs that do not acknowledge the fundamental value of individual autonomy and the relative value of life.^{47,48}

It was not until the late 19th century that the first essays on euthanasia in the context of modern medicine emerged, due to the rise of anaesthetics. In 1870, active euthanasia (by means of a physician administering chloroform to a patient, upon the latter's request) with the aim of conducting a quick and painless death, was unapologetically condoned.⁴² Attempts to legalise medical assistance in dying by means of euthanasia and/or physician-assisted suicide date back to around a century ago, culminating in 1906 in an Ohio Bill to legalize euthanasia 'to Mortally Injured and Diseased Persons', which was rejected the same year, based on strong concerns about the principles of social Darwinism and eugenetics.⁴²

A revival of the debate occurred in the UK, when the British Voluntary Euthanasia Society was founded in 1935 by a group of eminent scholars, including physicians, theologians and lawyers.⁴² This resulted in the proposal of a Bill to realise a change in the law to enable physicians to end the life of a terminally ill patient on the patient's request, without facing criminal charges. However, the concept of euthanasia was also used in the years around World War II, when the *Aktion T4 programme* was created to kill individuals on the grounds that they were physically and/or mentally disabled.⁴⁹

Although the term euthanasia was subsequently discredited, the debate on medical assistance in dying was not. The many advances in the field of medicine – e.g., the (further) development and greater use of antibiotics and anaesthetics

– made it feasible to both prolong life and to end life.^d It was, however, in the early 1980s that ‘medical assistance in dying’ was legally condoned in Switzerland^e and The Netherlands. In the mid-1990s, the first bills on medical assistance in dying passed in the American State of Oregon. In addition, the concept of individual patient autonomy entered the societal debate and led to a shift from medical paternalism to the patient-physician dyad, transforming the patient from a passive follower of the physician’s treatment proposals to an active partner in medical decision-making.^{50,51} Nowadays, the term euthanasia is predominantly used in the context of (one of the many more) medical end-of-life decisions, referred to as ‘a good death’ by some advocates of euthanasia legislation, and strongly contested by others.⁵² Be that as it may, Table 2 shows that the number of jurisdictions legally allowing euthanasia is steadily growing.

^d It is argued that the alleviation of pain became all the more important since aggressive disorders (e.g., cancer) affected many more individuals and became the main cause of death in the 20th century.^{400,401} Notwithstanding the increased capabilities to alleviate pain, the medications may lead to the unintended, albeit foreseen, consequence of hastening the individual’s death, which resulted in the theory (and the myths surrounding it) of the ‘double effect’ of pain medication.⁴⁰²

^e Note that the Swiss federal government already stated in its first federal penal code in 1918 that suicide is not a crime when being inspired by altruistic motives. However, this was not debated in the medical context, but in a time in which suicide deaths were condoned when motivated by honor and/or romance. Motives related to health were not subject to concern or debate.⁴⁰³

Table 2: Since when and where is Euthanasia and/or Physician-Assisted Suicide (E/PAS) legal and for whom?¹

Jurisdiction	Year of legislation	Euthanasia	PAS	Type of medical condition
Switzerland	1942		X	Not specified
Oregon USA	1997		X	Terminal, < 6 months
The Netherlands	2002	X	X	Not specified
Belgium	2002	X	Unclear ²	Minors: terminal Adults: Not specified
Luxembourg	2009	X	X	Not specified
Washington USA	2009		X	Terminal, < 6 months
Montana USA	2009		X	Not specified
Vermont USA	2013		X	Terminal, < 6 months
California USA	2015		X	Terminal, < 6 months
Colombia ³	2015	X		Terminal
Colorado USA	2016		X	Terminal, < 6 months
Canada ⁴	2016	X	X	Terminal and non-terminal somatic conditions
Columbia USA	2016		X	Terminal, < 6 months
Victoria ⁵ (Australia)	2018	X	X	Terminal
Hawaii USA	2018		X	Terminal, < 6 months
Maine USA	2019		X	Terminal, < 6 months
New Jersey USA	2019		X	Terminal, < 6 months
Western Australia	2021		X	Terminal Non-terminal somatic conditions: 12 months
Spain	2021	X	X	Not specified
New-Zealand	2021	X	X	Terminal < 6 months
Austria ⁶	2022		X	Terminal and non-terminal somatic conditions

1. The Northern Territory of Australia was the second jurisdiction to allow E/PAS in the terminally ill in 1996. In 1997 the law was overturned.
2. There is legal uncertainty on whether or not PAS falls under the Belgian Law on euthanasia, see subsection 4.3. of this Introduction.
3. Colombia allowed euthanasia in minors since 2018, be it under more strict conditions
4. Canada restricted regulated medical assistance in dying to the terminally ill in 2016 and expanded it to the non-terminally ill suffering from serious somatic disorders in 2021. Canada is about to expand their legislation to the non-terminally ill suffering from psychiatric conditions, the extended law is expected in 2023.
5. Victoria: in very rare circumstances, when the patient is physically unable to self-administer the drug, a physician may do so.
6. Austria: the first Law that decriminalises PAS for the terminally and non-terminally ill. According to the Explanatory Notes accompanying the Austrian Law, people suffering from psychiatric illnesses cannot be deemed eligible for PAS 'in principle' due to their perceived lack of mental competence.^{53,54}

3.3. ELUCIDATING CONCEPTS TO AVOID BABYLONIAN CONFUSION

In the Netherlands, people wear a different bracelet if you're elderly, and the bracelet says 'do not euthanize me.' Because they have voluntary euthanasia in the Netherlands, but half the people who are euthanized every year, and that's 10% of all deaths in the Netherlands, half of those people are euthanized involuntarily at hospitals because they are older and sick. And so elderly people in the Netherlands don't go to the hospital, they go to another country, because they are afraid, because of budget purposes, that they will not come out of that hospital if they go in with sickness.

The former Pennsylvania senator Rick Santorum, in one of his speeches during the American election campaign in 2012.⁵⁵ In his speech, Santorum presented a nightmarish vision of the Dutch euthanasia law and practice by falsely stating that, in the Netherlands, many of the elderly are *euthanized involuntarily* at Dutch hospitals and homes on grounds of being old and sick. The bleak picture painted in Santorum's propaganda ignores the fact that the voluntariness of the euthanasia request is a *conditio sine qua non*. If not based on the voluntary request of the individual patient herself, it is qualified as murder. The bleak picture also ignores the existence of more frequently used medical end-of-life options in the elderly used in the well-developed healthcare services (e.g., palliative care and nursing home care centres in the Netherlands).

This is just one example of the misunderstanding that can arise around medical assistance in dying. Therefore, an overview of the types of assistance frequently used in the international debates on dying in a medical context is given in Box 1. The difference between E/PAS and palliative sedation is thus based on 1) the intent of the medical act, and 2) the pace of death. Whereas the intent of E/PAS is the termination of the patient's life, the intent of palliative sedation is to alleviate the intractable suffering through sedation, with the possible risk of hastening death or the actual risk of hastening death, traditionally justified by the doctrine of double effect (the good intention of pain control for a patient to stay alive balances the less good effect of the patient's hastened death). Regarding the pace of death: whereas intensive palliative care scenarios offer slower ways of dying, the E/PAS path leads to a quick death.

Box 1: Ways of Dying in and outside the Medical Context

Dying with the assistance of physicians
<p>Euthanasia (<i>focus of this PhD dissertation</i>) The act of a physician intentionally ending the life of an individual by administering life ending/lethal drugs, upon the individual’s explicit request</p> <p>Physician-Assisted Suicide (PAS) (<i>focus of this PhD dissertation</i>) The act of a physician intentionally helping the individual to hasten death by providing or prescribing the individual with lethal medication, that the individual self-administers</p> <p>Active ending of life without explicit patient request The act of administering drugs with the explicit intention of hastening death, in the absence of the individual’s request (non-voluntary) or against the individual’s will (involuntary).</p> <p>Non-Treatment Decision The withholding or withdrawing of treatment, knowing that this may or will hasten the patient’s death:</p> <ol style="list-style-type: none"> 1) Withholding treatment (sometimes called passive euthanasia) the physician allows the individual to die by withholding life-prolonging treatment when believing that this serves the individual’s best interest and/or because the individual competently refused life-prolonging treatment 2) Withdrawing treatment (also referred to as passive euthanasia) the physician allows the individual to die by withdrawing life-prolonging treatment when believing that this serves the individual’s best interest and/or because the individual competently refused the continuation of the life-prolonging treatment 3) By allowing the individual to Voluntarily Stop Eating and Drinking and hence the refusal of all food and liquids, including those taken through a feeding tube. <p>Intensified pain and symptom alleviation Specialized medical care for individuals suffering from a serious illness. This type of care is focused on the alleviation of suffering due to, e.g., symptoms or the distress surrounding illness, aiming to improve quality of life for both the patient and the family, based on the needs of the patient, not on the patient’s prognosis. The most far-reaching form of intensified pain and symptom alleviation at the end of life is intermittent or continuous deep sedation until death: the act of using medications intended to induce a state of decreased awareness or actual unconsciousness to relieve the burden of otherwise intractable suffering.</p>
Dying without the assistance of physicians
<p>Suicide The individual intentionally hastens her death</p> <p>Assisted Suicide A non-physician helps the individual to hasten her death</p>

4. E/PAS legislation

Belgium is one of the states and countries in the world in which individuals – mainly adult patients suffering from a terminal illness – can apply for E/PAS and have it granted under certain conditions (see Table 2, page 26). In the context of psychiatry, this is legally allowed only in The Netherlands (2002), Belgium (2002), Luxembourg (2009) and Spain (2021), and it's legally 'condoned' in Switzerland. Canada is currently in the process of expanding its legislation on medical assistance in dying to this specific patient group, which is expected in 2023.

4.1. THE HISTORICAL BACKGROUND OF EUTHANASIA IN BELGIUM

As in other countries that have legalised medical assistance in dying, euthanasia was secretly practiced before it was decriminalized in Belgium.^{56,57} A survey study conducted in 1998, estimated that 1.3% of all deaths in Flanders, the Northern region of Belgium, could be considered an act of E/PAS. As it was illegal and thus potentially subject to prosecution, the need to make this practice lawful emerged.⁵⁷ At the same time, various group practices and patient associations emerged in the 1970s and 1980s in Belgium, aiming to move away from a strict hierarchical medical model, in which the physician imposed her medical vision on the patient in a rather patriarchal manner, and bore full responsibility for it. These various organisations advocated to move toward a different medical model in which the patient was given a voice and to have this voice reflected in medical healthcare decisions. In other words, they were fighting for the right to share decision-making, in which the physician has the responsibility to provide the patient with the most complete and professional advice possible about the patient's medical condition and all possible treatment options, after which the patient can decide for herself whether to begin or continue with (one or more of) the proposed treatment options. Regarding end-of-life decisions, these associations also wanted to give the patient the right to determine the process of death herself, in the manner and at the time of her choosing. At around 1980, Right to Die Organisations were founded in the Flemish and French-speaking

parts of Belgium: namely, the *Recht op Waardig Sterven* (Right to Die with Dignity) and *L'Association pour le Droit de Mourir dans la Dignité* (Association for the Right to Die with Dignity).⁵⁸ Their activism resulted in several legislative proposals in euthanasia from 1984 onwards⁵⁶, although their impact on the political debate was relatively small, mainly due to strong opposition from the Christian Democrats, who had been in government since 1958 and preferred to shelve this ethically-charged issue.⁵⁹

The public and political debate gathered steam in 1997, the year in which the Belgian Advisory Committee on Bioethics^f (BRCBE) formulated its advice on the desirability of a legal regulation of euthanasia on the request of the presidents of the Belgian federal parliament. Following the Dutch State Commission in 1985, in its advice of 12 May 1997⁶⁰ the BRCBE also defined 'euthanasia' as: "intentionally ending the life by another individual than the individual concerned, upon the latter's explicit request" and formulated 4 opinions on the desirability of euthanasia legislation (see Box 2).

After the federal elections in 1999, the Christian Democrats were – for the first time in 4 decades – voted out of the Belgian government. The new government consisted of Social Democrats, Liberal Democrats and Greens, who were willing to engage in the political debate regarding all sensitive ethical issues, including euthanasia.⁹

The new government formulated 7 different legislative proposals on euthanasia and reached a consensus on 20 December 1999, resulting in the Law on Euthanasia on 28 May 2002, which came into effect on 23 September 2002.⁵⁹ However, euthanasia remained the subject of intense debates and even of legal disputes.⁵⁹

^f The BRCBE is an ideologically and philosophically balanced committee that issues opinions on problems arising from research and its applications in the fields of biology, medicine, and healthcare. The committee examines problems in terms of their ethical, social, and legal aspects and with respect for universal human rights. Their advice must be issued after 6 months and must reflect the different points of view of all committee members.

⁹ Belgium enacted protections against discrimination based on sexual orientation in employment, housing, and public and private accommodations in 2003 with the inclusion of same-sex marriage in 2003 and same-sex adoption in 2006.

BOX 2: Four Opinions on the Desirability of Euthanasia Legislation, formulated by the Belgian Advisory Committee on Bioethics

1. To create legal certainty by means of an amendment in the Belgian Penal code that makes the act of euthanasia no longer punishable, provided that some strict regulations and conditions are fulfilled for euthanasia to be permissible.
2. To prohibit euthanasia in Belgian criminal law on the one hand, but also to provide the possibility for the performing physician to invoke 'the state of emergency' under certain conditions, e.g., the consultation of a colleague-physician. In addition, an *a posteriori* control procedure should be implemented. (= the current Belgian model)
3. The retention of criminality for all medical end-of-life decisions, including euthanasia, but also the possibility for the performing physician to invoke 'the state of emergency' under certain conditions and the implementation of an *a posteriori* procedure with the addition of an *a priori* procedure, which consisted of requiring the attending physician to consult a third person, a non-physician appointed by the local ethics committee, before the euthanasia can be performed.
4. Any form of euthanasia should be refused out of respect for the exalted value of the protection-worthiness of human life. To alleviate the patient's suffering, other means had to be sought, such as palliative care.

It is noteworthy that, almost simultaneously with the Law on Euthanasia, two other Laws were voted on and enacted, namely: the Law on Patient Rights and the Law on Palliative Care^h. The Law on Patient Rights⁶¹ entailed the right of every single patient to: 1) be free in their choice of a healthcare provider, 2) receive qualitative healthcare, 3) be informed of their current health status, prognosis and treatment options, 4) be free to consent, to refuse or to withdraw from the proposed treatment options, 5) be able to peruse and obtain a copy of a carefully updated medical health file, 6) be assured that their privacy and anonymity are protected by the physician, 7) be free (not) to inform relatives. The Law on Palliative Care⁶² aimed to grant all patients facing death the right to palliative care by means of increased medical, psychological, social and existential support through to the end of life, and the provision and further development of qualitative palliative healthcare services. The (combination of

^h Note that the Belgian Law on Euthanasia has a specific legal status. In contrast to e.g., the Law on Patient Rights, that provides a framework of good (medical) healthcare practices, the Law on Euthanasia is not about "healthcare" in the strict legal sense of the word but provides a set of legal conditions under which physicians who perform the act of euthanasia will not be held criminally liable.

these) laws clearly indicate the intention to establish an enduring relationship between the patient and the healthcare practitioner, based on shared decision-making in all health issues, including end-of-life decisions.

4.2. THE BELGIAN LAW ON EUTHANASIA: 4 REGULATED SCENARIOS

The Belgian Law on Euthanasia regulated two frameworks of dying: 1) by means of an advance directive, and 2) by means of an actual request. As regards the latter framework, the Belgian law distinguished three scenarios according to the patient's legal capacity and the nature of the main diagnosis. The following 4 scenarios can be distinguished: euthanasia upon 1) a written advance directive on euthanasia, 2) an actual request from a terminally ill adult or emancipated minor, 3) an actual request from a non-terminally ill adult or emancipated minor (the most prominent scenario in the context of psychiatry), and 4) an actual request from a terminally ill non-emancipated minor (regulated in 2014).

Before taking a closer look at the legal requirements that each of the 4 scenarios should cover, it is worth mentioning that there is no right to euthanasia.

Although every patient has the right to apply for euthanasia, no physician can be compelled to perform – and no other person can be compelled to assist in – the practice of euthanasia, on whatever grounds. This is clearly stipulated in Chapter IV, section 14 of the Belgian Law on Euthanasia. By doing so, the legislator follows the same logic as in the Law on the Patients Rights⁶¹, in which Section 8 stipulates, inter alia, that it is each patient's individual right to consent to the physician's proposed therapeutic options, but also to decline the proposed therapeutic options or to withdraw a previous consent. In both Laws, the legislator aimed to find a balance between the individual autonomy of the patient on the one hand, and the individual and professional autonomy of the physician on the other. The difference in both laws lies in the individual who is entitled as 'initiator'. According to the Law on the Patients' Rights, the physician – after thorough examination – is entitled to take the initiative to propose one or more treatment options to the patient, who then decides whether or not to give her consent. According to the Law on Euthanasia, the initiative lies with the patient who expresses the euthanasia request to a physician, who then decides whether to engage in it.

However, a minimum of physician engagement is legally required and made more stringent by the legislative amendment in 2020.⁶³ If the physician is confronted with an actual euthanasia request and refuses to practice euthanasia, this physician must inform the patient of this fact in a timely manner – no later than 7 days after the first time that the patient has explicitly expressed her euthanasia request – and she must substantiate the reasons for refusal. If the refusal is based on medical reasons, these reasons must be recorded in the patient’s medical file. Upon the patient’s (or her person in confidence) request, the contact details of a colleague-physician and/or an association or centre that is specialized in euthanasia legislation must be provided to the patient.⁶³ In addition, even if the physician does not want to be engaged, for whatever reason, she should provide the patient’s medical file to the physician of the specialized centre appointed by the patient, and this within 4 days following the patient’s request.⁶³

Scenario 1: Euthanasia upon an Advance Directive

By means of an advance directive, every adult patient (or emancipated minorⁱ) can request euthanasia to be performed once she would no longer be able to express her own will due to the condition of unconsciousness, caused by illness or accident, which is considered to be ‘irreversible’ given the current state of medicine. This framework of euthanasia is of little issue in the context of psychiatry and, therefore, will not be described in detail.

Scenario 2: Euthanasia upon an Actual rRequest from a Terminally Ill Adult

The Belgian Law of Euthanasia stipulates certain – in legal terms – ‘material’ legal criteria that the patient must meet to be deemed eligible for euthanasia (see Box 3) versus procedural criteria that the physician must fulfil in order not to commit a criminal offense.

With regard to the suffering, with the insertion of the coordinating conjunction ‘OR’ the Belgian legislator did not explicitly exclude patients with a psychiatric condition from the option to hasten death by means of euthanasia.

ⁱ A minor can only be considered ‘emancipated’ upon a judge’s decision to give the minor the legal status of an adult, and all the legal rights and duties that go with it. So-called ‘mature minors’, with capacity for discernment, are ruled out.

Box 3: Mandatory Material Criteria for a Patient to be deemed Eligible for Euthanasia

1. Attained the age of majority (i.e., 18 years) or is an emancipated minor,
2. Being legally competent and conscious at the moment of making the actual euthanasia request,
3. Voluntarily applying for euthanasia (not dictated by external pressure) and repeatedly confirming the euthanasia request as to ensure its sustainability,
4. Finding herself in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated,
5. The suffering underpinning the euthanasia request should result from a serious and incurable disorder caused by illness or accident

Although the Belgian Law clearly had been drafted with other patient groups in mind, the criteria included do not rule out adult patients who are predominantly suffering from psychiatric conditions, as they can be associated with the experience of unbearable suffering, may be considered as chronic and medically incurable (e.g., autism spectrum disorder) or may even be deemed to have a terminal condition in rare circumstances (e.g., the last stage of anorexia nervosa). Note that the tentative *mays* suggest that different opinions are held on the interpretation of the letter and spirit of the law.

Regarding the procedural criteria, the first task is the clarification of the patient's euthanasia request, which is entrusted to the 'attending physician'. This physician may be (but doesn't have to be) the treating physician of the patient's medical condition. This physician may also decide to assist with, or even to perform, the act of euthanasia herself. Either way, the attending physician must be independent from the patient in terms of blood ties.

In each case, the attending physician of the patient's euthanasia request must:

- 1) Inform the patient about her health condition and life expectancy, the potentially remaining therapeutic and palliative options, and their consequences.
- 2) Discuss the patient's euthanasia request and, together with the patient, come to the conviction that all the eligibility criteria are fulfilled. This entails several conversations with the patient, spread out over a

reasonable period (considering the progressive course of the medical condition).

- 3) Ensure that the patient consults one other physician. The attending physician should inform this 'advising physician' about the reason for consultation. The advising physician must then consult the patient's medical file and examine the patient about the characteristics of the disorder, the suffering resulting from it, and the (non-)alleviability of this suffering. Finally, the advising physician must report her findings to the attending physician, who then informs the patient about these findings.^j
- 4) Discuss the patient's euthanasia request with (some of the members of) the nursing team^k, if the latter is regularly in contact with the patient and upon the latter's request.
- 5) Discuss the euthanasia request with relatives appointed by the patient upon the patient's request to do so.
- 6) Ensure that the patient has had the opportunity to discuss her euthanasia request with all the individuals she wants to inform herself.

Note also that these are all minimal legal requirements. The Law's Section 3 clearly stipulates that the attending physician is free to impose additional conditions and may (e.g.) engage more than one advising physician.

Scenario 2 is highly unlikely to occur in the context of adult psychiatry, as most psychiatric conditions cannot be deemed incurable; but if so, the disorder is regarded as chronic rather than terminal.

^j The nature of the advice obtained from the advising physician, i.e., whether or not to (conditionally) approve the euthanasia, is not legally binding.

^k This concerns a consultation between the physician and (members of) the nursing team, whether or not in the presence of the patient, and in accordance with the terms of shared professional secrecy. Although the nurses' opinion or advice on the patient's euthanasia request is not legally binding, it can be of great influence. To exclude potential undue influence (e.g., prompted by financial interests), the Legislator refers to article 909 of the Belgian Civil Code. This article stipulates that 'nurses' should not receive any gifts or inheritance from their patient, neither in the event of the life of the patient nor in the event of the death of a patient they have treated. This article was further extended in 2003 to physicians, pharmacists and other so-called 'officers of health' (all professionals within the medical health sector in layman's terms).³⁶⁸

Scenario 3: Euthanasia upon an Actual Request from a Non-terminally Ill Adult

This scenario is more likely to occur in the context of adult psychiatry and, therefore, it is the focus of this PhD research trajectory. In scenario 3, all material and procedural criteria of 'scenario 2' must be fulfilled. Whereas the Belgian legislator did not distinguish between the nature of the patient's disorder and the suffering resulting from it, distinction was made regarding the life-limiting prognosis of the disorder. A distinction is made between those patients who are expected to die in the near future (the terminally ill) versus those who are not (the non-terminally ill).

If the attending physician is of the opinion that the patient is not expected to die 'in the near future', then she must:

- 1) Ensure that the patient consults an additional advising physician, who is a psychiatrist or a specialist in the disorder underpinning the patient's euthanasia request, and inform the second advising physician of the reasons for consultation. This additional advising physician is entrusted with the same tasks as in scenario 2, with the addition of the examination of the voluntary, sustained, and repeated character of the patient's euthanasia request. This second advising physician reports her findings to the attending physician, who then informs the patient of these findings.
- 2) Ensure a one-month waiting period between the patient's written euthanasia request and the performance of euthanasia.

Scenario 4: Euthanasia upon an Actual Request from a Terminally Ill Minor

The Belgian Law on Euthanasia was amended in 2014 so that 'factually capable' minors can also apply for euthanasia.⁶⁴ For a minor to be legally allowed to request euthanasia, more strict material and procedural requirements must be fulfilled. The legislator set no minimum age, but requires the attending physician to ensure that the minor has 'capacity for discernment', which means that the minor should have the mental ability to truly understand the implications of her euthanasia request and all its consequences.⁶⁵ This sufficient level of capacity of discernment should be certified by a child psychiatrist OR psychologist (the one and only route in which a member of the paramedical staff is entrusted with a formal role). The attending physician should also obtain the approval for

euthanasia from the minor's parent(s) or legal guardian(s). In addition, the minor's euthanasia request should be based solely on unbearable *physical* suffering, resulting from a *terminal illness*. Hence, unless the minor finds herself in the terminal stage of anorexia, a minor predominantly suffering from other psychiatric conditions cannot be considered eligible for euthanasia. According to the latest official figures, 3 cases of euthanasia being carried out in a minor were reported in the years 2016-2017, with conditions ranging from muscular dystrophy to cancer. This legal amendment is a subject of controversy, e.g., due to the fact that it was adopted after a shorter and simpler legislative procedure.^{65,66}

4.3. EUTHANASIA VERSUS PHYSICIAN-ASSISTED SUICIDE (PAS)

The Belgian legislator followed the BRCBE's definition of euthanasia, as Section 2 stipulates that euthanasia is the act of *intentionally ending the life by another individual than the individual concerned, upon the latter's request*. "Another individual" was in a later Belgian Royal Decree, in 2003, more clearly defined as 'the physician'.⁶⁷ Whereas in Luxembourg, the Netherlands and Spain, both euthanasia and physician-assisted suicide have been explicitly decriminalised,⁶⁸⁻⁷¹ the Belgian legislation does not explicitly cover PAS. However, both the Belgian Order of Physicians and the Belgian Federal Control and Evaluation Commission on Euthanasia (FCECE) have stated that, according to their opinion, PAS is also covered by Law, as the Law does not prescribe *how* euthanasia should be performed, as the physician, for instance, is required to be present when the patient self-administers the lethal drugs.⁷² This argument is strongly contested by others, who argue that these overarching bodies are only competent to control and evaluate the medical practice and the practice of euthanasia, respectively, and have no legislative power.⁶⁶ In addition, there is reason to believe that the legislator ruled out PAS deliberately on the grounds of the debates preceding the euthanasia legislation. Several amendments have been made to include both euthanasia as PAS and even the Council of State advised the Belgian government to do so, as there would be – in principle – little difference between the two practices, save a medical-ethical one.^{59,66} By not

explicitly mentioning both terms, but only mentioning euthanasia, one may assume that only euthanasia is legally regulated.⁶⁶

The legal uncertainty on whether or not PAS is covered by the Belgian Law flared up in 2015, when the first and only 'euthanasia case' was transferred to the Belgian Prosecutor because not all legal requirements were deemed to have been met. However, the Public Prosecutor decided that the case did not fall under the Law on Euthanasia, because the patient drank the lethal dose herself and thus dismissed the physician from further legal proceedings.

4.4. THE REPORTING, CONTROLLING AND EVALUATING OF EUTHANASIA

The physician responsible for the performance of euthanasia is required to fill in an official registration form and to deliver this document to the Federal Control and Evaluation Committee on Euthanasia (FCECE) within four working days. There are no specific criteria concerning the capacity of the physician who performs the act of euthanasia. The performing physician does not have to be the patient's general physician, another treating physician, or the attending physician of the patient's euthanasia request. The physician does not even need to have specified knowledge on the medical end-of-life practice. This issue was subject to parliamentary debate and deemed redundant, as a physician is always bound by duty to provide and exercise due medical care.^{66(p12)}

The first task that the FCECE was entrusted with concerned the drafting and provision of a formal registration form that must be filled in by the 'performing physician'. The FCECE is also entrusted with the a posteriori controlling and evaluating of all euthanasia cases that are carried out. This document consists of two main parts. The first part must be placed under seal by the performing physician, as it includes identifiable information (e.g., contact details). 'Under seal' means that the document's first part is confidential in its essence and thus not to be used for evaluation purposes. The second part is also confidential but not placed under seal as it contains essential information for the evaluation of legal compliance. Based on the evaluation of this second part of the formal registration form, the commission can determine whether or not all legal

requirements have been fulfilled, whether additional information is needed, or a violation of the Law can be detected. A simple majority is needed to revoke the anonymity of the document's first part to invite the performing physician to disclose additional information. If the FCECE suspects a violation of the Law, a two-thirds majority is needed for the case to be sent to the Belgian Public Prosecutor of the jurisdiction in which the patient was euthanised.

The legislator allows the FCECE to establish its own internal regulations. However, the following requirements were set to safeguard the internal functioning. First of all, the FCECE should consist of a multidisciplinary team of 16 members: including 8 physicians (and at least 4 of them are professors at a Belgian university), 4 professors of law at a Belgian university or practising lawyers, and 4 individuals drawn from professional groups that are experienced in dealing with incurably ill patients.

The following three criteria are taken into account: 1) language parity, as half of the members are Dutch-speaking and the other half are French-speaking, because the commission must be chaired by a Dutch-speaking and a French-speaking member, and as both chairpersons are elected by the commission members of the respective linguistic group; 2) gender quota, as each linguistic group includes at least 3 members of the binary female/male based gender model; and 3) a pluralistic representation is ensured.¹

A second safeguard is that the membership in the commission cannot be combined with a mandate in one of the legislative bodies or with a mandate as a member of the federal, the regional or the community government.

Third, after anonymity has been revoked, and, as a result, the independence or impartiality of one of the commission members would turn out to be 'compromised', this member will be given the opportunity to explain or to be challenged during the discussion of this matter in the commission.

Finally, for the explicit benefit of the Legislative Chambers (and the implicit benefit of facilitating societal debate and external transparency), the FCECE must foresee in biennial reports the following: 1) a descriptive statistics report processing the information from the second part of the completed registration

¹ This is not further specified but, in practice, it is interpreted as follows: the FCECE must be composed of members holding different stances on the value of life.

forms; 2) a report in which the implementation of the law is indicated and evaluated; and, if applicable, 3) recommendations that could lead to new legislative initiatives or other measures regarding the Law's application.

4.5. OTHER COUNTRIES ALLOWING E/PAS BASED ON PSYCHIATRIC CONDITIONS

To date, E/PAS in the context of psychiatry can also be legally allowed in The Netherlands, Luxembourg and Spain, and legally 'condoned' in Switzerland. Their legal regulations will be briefly described in this subsection and – where deemed relevant – compared to the Dutch⁷³, Luxembourg⁶⁹ and Spanish Act. As for the latter, due to my lack of proficiency in Spanish and the current lack of an official English translation, the comparisons are not based on the reading of the original legislative text, but on a recently published article by Velasco et al.⁷¹

4.5.1. The Netherlands

In April 2002, the Netherlands was the first country in the world to legally regulate both euthanasia and assisted suicide. Contrary to the Belgian situation, the Netherlands could boast a history of three decades of 'condoned' experience with the E/PAS practice, interwoven with judicial cases, and the country had already published a guideline for physicians on how to handle E/PAS requests prior to the E/PAS legislation.

The Dutch Law entails less strict material and procedural criteria than the Belgian Law. As regards the material criteria, the patient should have attained the minimal age of 16 years and made a voluntary and carefully considered E/PAS request. A minor between 12 and 16 years may be deemed eligible if considered to have 'a reasonable understanding of her interest in the matter' and if approval from the minor's parents or legal guardians is obtained. Contrary to the situation in Belgium, the patient does not have to be conscious at the moment of the request, which means that patients suffering from (e.g.) dementia may be deemed eligible for E/PAS. The Law does not specify the characteristics of the patient's suffering other than being unbearable without prospect of improvement. Together with the patient, the attending physician must ensure that there is no reasonable alternative in the light of the patient's situation.

With regard to the procedural criteria, no distinction is made between the terminally ill versus the non-terminally ill. The attending physician must: 1) have informed the patient about her situation and prospects, 2) have consulted at least one other, independent, physician, 'who must have seen the patient' and have provided a written advice on the material criteria, and – if the case would be carried out – 3) ensure that the patient's life will be terminated with due medical care and attention.

Each case should be reported to one of the 5 regional Euthanasia Review Committees, which check whether all legal criteria are fulfilled. These Committees were already established in 1998 and composed of an uneven number of members, with a minimum of 3 members (and their substitutes): 1 physician, 1 ethicist and 1 lawyer (holding the chair). Another different aspect is that the Committee can obtain information from the coroner who examined (the cause of) the patient's death.

Finally, no physician can be compelled to practice euthanasia. A physician must also refer the patient after refusal, but that is explicitly noted in the Dutch parliamentary proceedings and not explicitly in their Law.⁶⁶

4.5.2. Luxembourg

The Luxembourg Law on Euthanasia and Assisted Dying⁶⁹ came into effect in 2009 and entails basically the same legal criteria as the Belgian counterpart. Contrary to the Belgian Law, it explicitly includes PAS and does not extend its law to minors by means of an amendment. Whereas the Belgian Law stipulates that, in the case of the attending physician's refusal, she should announce and substantiate the reasons for refusal no later than 7 days after the explicitly made euthanasia request, the Luxembourg Act requires the attending physician to do so within 24 hours.

The Luxembourg Law does not make a distinction between the terminally ill and the non-terminally ill. Irrespective of whether the patient is expected to die in the near future or not, the attending physician must only ensure that the patient consult one other physician to obtain their advice on the characteristics of the disorder, the suffering resulting from it, and the (non-)alleviability of this suffering.

4.5.3. Spain

The Spanish Law on Euthanasia⁷⁴ became effective in 2021 and covers both euthanasia and physician-assisted suicide. There are major differences with the Benelux Laws. First, only Spanish nationals or legal residents in Spain, or holders of a certificate that proves a stay of more than 12 months in Spain, can be deemed eligible for E/PAS. Similar to the Luxembourg Law, minors are ruled out for E/PAS.⁷¹ In contrast to the Belgian Law, the Spanish Law does not require different procedural criteria for the terminally versus the non-terminally ill.

Three major procedural differences with the Dutch, Belgian and Luxembourg Laws can be distinguished: (1) the requirement of an actual euthanasia request to be submitted twice in writing (to verify the sustainability of the euthanasia request), (2) the requirement of an a priori evaluation procedure, and (3) the procedural consequences following the outcome of each advising physician's formal advice on the request.

The procedure can be briefly sketched as follows. After the first expressed euthanasia request, the 'responsible physician' has about 7 days to make an initial decision. In the event of disapproval, the physician must inform: (1) la Comisión de Garantía y Evaluación (the Spanish Control and Evaluation Committee, or EC in short) involved on this initial decision, and (2) the patient on the possibility of appealing this decision to the EC within 15 calendar days. In the event of an initial positive decision, the patient must express a second euthanasia request in writing and submit this to the same responsible physician, at least 15 days after the first submitted request. Then, the responsible physician will consult a second advising physician, who has in turn 10 days to make a decision. Once the decision is made, the second advising physician has 24 hours to inform the patient and, by doing so, leave it up to the patient to continue with, to postpone or to withdraw the euthanasia procedure. In all cases, the physician has 3 working days to inform the EC.⁷¹ If both experts have agreed to approve E/PAS, the request can be carried out. If the two experts disagree with one another, the full EC is called on to make the final decision. In the event of a rejected request, the patient could appeal before the commission before appealing to the court of the patient's administrative jurisdiction. Hence, a major difference is that two members of the EC, one physician and one lawyer, are

entitled to verify all legal requirements prior to the procedure. They cannot consult only the responsible but also the advising physician.⁷¹ As in the other three countries, the Spanish Law also requires an a posteriori procedure by means of an Evaluation Commission. This Evaluation Commission operates in each autonomous community and is comprised of a minimum of 7 members, including medical staff and lawyers.⁷¹

Another major difference is the explicit mentioning of the duration of the whole E/PAS procedure, which could take up to 40 days between the initial request and the performance of euthanasia, unless the responsible physician expects an imminent loss of the patient's capacity. In the event of the latter, the time period can be reduced to a minimum of 15 days.⁷¹

Finally, the Spanish Law also acknowledges the healthcare professional's right to conscientious objection. However, and in contrast to the other Laws, this objection needs to be expressed in writing and officially registered in a confidential database in order to ensure professional replacement without undermining the quality of the service.⁷¹

4.5.4. Switzerland

Switzerland has a particular position on, and legal basis for, PAS. Article 115 of their Swiss Federal Criminal Code states that: "*Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty.*"^{75(p62)} In theory, not only a physician, but anyone can offer assistance in dying, provided that the assistance is granted without 'selfish motives'. However, when it comes to providing someone with a lethal medication (and that is what happens in Swiss end-of-life centres), at least one physician is involved because she alone can prescribe it. According to the Dignitas Swiss end-of-life centre brochure⁷⁶, the latter will prescribe the lethal dose of drugs only after an in-depth evaluation of the patient's written request and the information in her medical file, followed by at least two face-to-face consultations. Local pharmacists are not allowed to sell the lethal medication, as the financial gain may be considered to be 'selfish motives'.

There is mention of 'euthanasia tourism' in Switzerland. According to Statista's research database⁷⁷, the number of PAS deaths at Dignitas between 1998-2019, by country of residence in Europe, reveals that the largest number of individuals hailed from Germany, accounting for 1,322 individuals, followed by 457 individuals from Great Britain, 373 individuals from France, and 187 from Switzerland. Two years prior to its E/PAS legislation, Spain ranked 7th with 34 individuals. Despite existing E/PAS legislation, the Netherlands ranked 9th with 10 individuals, and Belgium shared 13th place with Finland with 5 individuals. Finally, 1 Luxembourg citizen was reported in the statistics.

On the other hand, there is mention of foreign patients applying for euthanasia in Belgium as well.⁷⁸ Anecdotal evidence revealed that this mainly concerns the terminally ill, mostly hailing from France, and the euthanasia is mainly practised in the French-speaking region of Belgium.^{79,80} Additional anecdotal evidence revealed that dozens of adults predominantly suffering from psychiatric conditions try to apply for euthanasia in Belgium, but there is a reluctance to have their request assessed due to the many juridical uncertainties and clinical challenges (e.g., the need for a solid patient-physician relationship).

5. Implementation of the Belgian Law on euthanasia in clinical practice

Contrary to the situation in the Netherlands, where the Royal Dutch Medical Association had published a written guideline on how to handle a patient's request for euthanasia or physician-assisted suicide *before* its legalization, the Belgian Order of Physicians did not undertake such an initiative until 2019. In 2003, they formulated a first formal advice on the impact of the legislation of euthanasia, palliative care and patients' rights on the physicians' medical profession and deontology. Noteworthy is their advice that "it should be avoided that the Law on Euthanasia results in the establishment of euthanasia teams and centres for euthanasia".⁸¹ The reality turned out differently.

5.1 EARLY INITIATIVES

As the legal due care criteria of the Dutch and Belgian law differ, physicians in Belgium could not totally rely on the recommendations of the Dutch guidelines on how to adequately deal with E/PAS requests. Therefore, inspired by the Dutch initiatives, and in close collaboration with some well-trained professionals in medical end-of-life care, the Right to Die Organisation RWS founded the Flemish organisation Life End Information Forum (LEIF) in 2003 in the region of Brussels.⁸² Among other things, LEIF provides training for physicians and nurses to increase their knowledge of end-of-life legislation and how to implement it in practice, and training for physicians to act as an advising or performing physician. LEIF also develops and publishes guidelines on how to handle euthanasia requests and how to perform euthanasia.⁸² Although more limited in scope, a similar organization was founded in Wallonia (Médecins EOL).

Notwithstanding, the Law on Euthanasia was almost immediately implemented in many public and private healthcare facilities, also in the Catholic inspired ones.⁸³ This is noteworthy, as the majority of the healthcare facilities fell under the Christian wing of Caritas Vlaanderen (now called Zorgnet-Icuro) and Christian inspired organisations had tried to reverse euthanasia legislation by means of legislative actions.⁵⁹

So as not to be caught short, Caritas Vlaanderen drafted the first mission statement on euthanasia, allowing the practice of euthanasia under the following three conditions^m:

- 1) The euthanasia request should clearly express the autonomous decision of a mentally competent patient. In the event of an advance directive of a mentally incompetent patient, the physician should hold a cautious and restrictive approach without gliding into therapeutic tenacity.^{83(p13)} Hence, in the event of an irreversible medical condition, one should opt for a complete phasing-out of the medical treatment.^{83(p13)}
- 2) Euthanasia is only allowed in the terminally ill who are expected to die within a maximum of a few weeks and only in the event of a terminal

^m The addition of more strict conditions is deemed legally allowed as the intro of section 3 of the Law on Euthanasia states that 'the physician can – without prejudice – impose any additional conditions to his/her own action'.²³¹

illness that cannot be sufficiently alleviated by means of palliative care.^{83(p11)} The mission statement explicitly rules out patients with progressive degenerative and/or psychiatric illnesses.

3) In contrast to the Law on Euthanasia, in which euthanasia and palliative care are not considered equivalent medical end-of-life options, the mission statement expressly introduced the 'palliative filter'.^{83(pp4-5)} At first, the physician should intensify symptom management, as this may impede patients in applying for or persisting in their wish for euthanasia. The option of palliative sedation should only be considered in the event of one or more 'refractory symptoms' hindering a dignified death.

As regards the population of adults predominantly suffering from psychiatric conditions, the mission statement pointed to society's duty to care for, and thus to find means to sufficiently alleviate, these patients' suffering.^{83(p12)}

In 2006, the Belgian Congregation of the Brothers of Charity formulated their first vision statement on how to handle euthanasia requests in the context of adult psychiatry.⁸⁴ Whereas it was clearly stated that the euthanasia could not be carried out within their healthcare facilities, it was also recommended not to neglect the patient's euthanasia request but to take it seriously, to guarantee the continuity of the clinical trajectory and the physician-patient relationship, and to explicitly express the value of the protection-worthiness ('*beschermwaardigheid*') of life. Only in the event of an impasse may the caregiver refer the patient to another healthcare centre that is willing to clarify the euthanasia request and possibly also to perform the act of euthanasia. In any case, the patient should not be dismissed for reasons of applying for euthanasia. The patient may even stay in the Brothers of Charity's healthcare setting until the performance of the euthanasia, which should be carried out elsewhereⁿ.

5.2 EVIDENCE ON THE IMPLEMENTATION OF THE LAW ON EUTHANASIA

The above-mentioned mission statements only concern the professionals from healthcare institutions that are housed under the Christian umbrella. It goes

ⁿ For instance, in 2008, a vision text was published for spiritual care workers on how to communicate with and provide spiritual support to in-home patients with a euthanasia request.⁴⁰⁴

without saying that other private and public healthcare institutions were also responsible for the proper implementation of the law within their walls. A survey study in the years 2005-2006⁸⁵ gauged the presence and content of a euthanasia protocol within their specific walls. It appeared that 91% of the surveyed hospitals had been prompted to draft such a protocol, of which 63% had already done so. Most of the hospitals allowed euthanasia to be practised in their institutions if the patient suffered from a terminal illness (98%) or in the event of an advance directive (78%), mostly with the use of the palliative filter as an additional safeguard. Half of the hospitals also exceptionally accepted euthanasia regarding the non-terminally ill, though under more strict conditions than required by law. The same trend was observed in the nursing homes in Flanders.⁸⁶

Another survey study, part of a larger medical end-of-life care (MELC) research project, examined (among other things) the presence of euthanasia protocols in 37 contacted 'psychiatric healthcare centers'.⁸⁷ The results revealed that 70% of the 28 responding psychiatric institutions had a euthanasia protocol, in which it was stated that euthanasia was forbidden in their walls (81%), allowed under stricter conditions than legally required (12%), or allowed in conformance with the legal rule (6%). As no information was given on the main characteristics of these centres and to what extent they covered all psychiatric healthcare centres in that specific year, it can be questioned whether these results are drawn from a representative sample.

Notwithstanding the fact that several hospitals and nursing homes allowed the practice of euthanasia for their non-terminally-ill patients, their protocols mainly concerned patients suffering from severe somatic disorders. Anecdotal evidence revealed the rare occurrence of euthanasia being practiced in patients predominantly suffering from psychiatric disorders.⁸⁸ However, even the Catholic inspired psychiatric institutions allowed these patients to be referred to other centres willing to handle, and eventually also to carry out, these euthanasia requests. Some university hospitals in Brussels, Ghent and Louvain had drafted protocols on how to manage these patients' euthanasia requests.⁸⁹

Anecdotal evidence from pioneering physicians revealed that some euthanasia requests continued 'to fall on deaf ears', mainly the euthanasia requests from adults with psychiatric conditions. Therefore, LEIF established three end-of-life

consultation centres (ULteam in 2011, LEIF Western-Flanders in 2013, and LEIF.Ghent in 2015) with the aim of effectively engaging in euthanasia assessment procedures, especially for those patients confronted with a neglected euthanasia request.^{90,91} These consultation centres consist of an interdisciplinary team of physicians, psychologists, (psychiatric) nurses, ethicists and legal experts, with extensive expertise in the management of complex euthanasia cases.

In the past decade, LEIF also established several other LEIF centres. When a patient expresses an actual euthanasia request, rather than engaging in the handling of these requests, these centres provide low threshold information about, and assistance in, end-of-life care issues, and refer to regional LEIF physicians, the central LEIF or the end-of-life-consultation centres.

On the other hand, different approaches exist on how the euthanasia requests are or should be handled. One international media article has given rise to a great deal of debate and much concern about euthanasia practice in the context of adult psychiatry by pointing to the dissension about how (not) to handle these cases.⁹² This resulted in the discontinuation of LEIF.Ghent as regional LEIF centre and its transition from LEIF.Ghent to the Centre of End-of-Life Questions Ghent (publicly known as Vonkel). The media article also prompted many physicians, ethicists, etc. to write open letters back and forth, arguing for a profound evaluation of the euthanasia legislation and practice in the context of psychiatry.^{93,94}

6. Research studies regarding euthanasia in Belgium

In Belgium, aside from the FCECE's biennial reports, there is a considerable amount of empirical scientific research into the topic of euthanasia, mainly (but not only) relating to the prevalence rates (see *infra*) and the implementation of euthanasia legislation from a practical-clinical point of view – e.g., on the mandatory consultation of colleague-physicians,^{95,96} the training, role and experience of LEIF-physicians⁹⁰ and their functioning and involvement⁹¹, the

quality of consultations between the attending and advising physicians⁹⁷, and the (in)appropriate drugs used.⁹⁸

Although a relatively extensive body of empirical evidence emerged in the years after euthanasia legislation in Belgium, it mainly emphasised the patient population suffering predominantly from somatic disorders. No empirical study that strictly focused on the euthanasia practice in the context of adult psychiatry in Belgium was published until 2015. This may seem striking, because, by definition, these are the cases that caused tempers to flare most between opponents and proponents of euthanasia legislation.

In the early years of euthanasia legislation, media articles had mentioned euthanasia requestors in the psychiatric context, but this concerned patients who were denied euthanasia and died by means of suicide.⁹⁹⁻¹⁰⁶ This lack of scientific attention may also be due to the fact that, contrary to the Netherlands, there had been no Belgian case law precedents on this issue on which psychiatric practice could fall back as 'additional guideline'. In other words, until 2019, physicians (willing to be) involved in euthanasia assessment concerning this patient group did not know how judges would interpret (some of the) legal criteria. Moreover, no euthanasia case reached media attention until 2013, when the first official complaint was lodged with the Belgian Order of Physicians against a physician who carried out euthanasia in a woman who would – according to media articles – have suffered predominantly from psychiatric conditions.^{107,108}

6.1. DANCING THE DATA: ATTEMPTS TO MAP THE E/PAS PRACTICE

6.1.1. The prevalence rate before E/PAS legislation

As mentioned earlier, survey data collected in 1998 showed that euthanasia had been practiced in Flanders, Belgium, years before its legislation, albeit to a very limited extent.⁵⁷ A few years later, a nationwide study was conducted in 6 European countries,¹⁰⁹ based on their death certificates in the period June 2001 and February 2002, revealing a prevalence rate of reported practiced E/PAS of 0.1% in Italy, 1.82% in Belgium, and 3.4% in the Netherlands. Focusing on euthanasia deaths in particular, the prevalence rates were 0 to 0.6% in Belgium,

Denmark, Italy, and Sweden, around 0.3% in Switzerland, and 2.6% in the Netherlands. In addition, the results revealed that the practice of physicians ending the patient's life without the latter's explicit request (involuntary euthanasia) occurred more frequently than E/PAS in all countries *but* the Netherlands and was the only medical end-of-life act reported in Sweden.¹⁰⁹

6.1.2. The prevalence rate since E/PAS legislation

A first trend analysis compared the main characteristics of the euthanasia cases reported to the FCECE. Results revealed an increased proportion of the number of deaths by means of euthanasia, from 0.2% of all deaths in 2003 to 1.7% in 2013.¹¹⁰ However, additional empirical evidence by means of a mortality follow-back study revealed an underreporting of euthanasia deaths.⁹⁸ According to the findings, 4.6% (instead of the 1.7% reported to the FCECE) of all deaths in 2013 could be classified as euthanasia deaths. Regarding the reporting rates, whereas in 2007, it was calculated that slightly more than half of all 'estimated' euthanasia deaths were reported to the FCECE in Flanders, approximately two-thirds were reported in 2013.^{98,111} The missing one-third was ascribed to the existence of a grey zone between euthanasia and palliative sedation, with the latter used with the intention to hasten death but not interpreted or reported by the performing physician as such.⁹⁸ Note also that, whereas the reporting of euthanasia deaths to the FCECE are mandatory in Belgium, the reporting of other medical end-of-life interventions is not^o. To date, no follow-up research initiative has been undertaken, but the more recent trends can be drawn from their biennial reports, especially as these reports make use of the ICD classification system since 2014. According to these reports, the number of euthanasia deaths, and its proportion related to all deaths, continues to rise.¹¹²⁻¹¹⁴ As for the latter, euthanasia deaths make up for 2.5% of all deaths in 2019¹¹² and 1.9% of all deaths in Covid-year 2020.¹¹⁵

^o On top of this, there are regional differences in the proportion of euthanasia cases between the Dutch-speaking Flemish community of Belgium, and the French-speaking Walloon counterpart. The majority of reported cases in the period 2002-2007 in the Dutch-speaking region was approximately 80/20⁹⁶ and, according to the latest official FCECE report, this ratio has remained constant.¹¹² Two survey studies among physicians suggest ascribing this skewed ratio to cultural differences in the practice, the knowledge and attitudes regarding euthanasia, and the extent to which the legal criteria were fulfilled.³⁴²

With regard to the Belgian prevalence rates of E/PAS in the context of adult psychiatry, no clear evidence can be derived from the FCECE's biennial reports dated prior to 2014. The year 2004/05 was the first year that neuropsychiatric disorders were specified¹¹⁶, and the year 2014 was the first year in which a further distinction was made between the patient group suffering from psychiatric disorders versus those suffering from degenerative neuropsychiatric disorders, such as (the early stages) of dementia. Thus, before 2014, the reports did not mention the occurrence of euthanasia cases predominantly based on psychiatric disorders (other than dementia).

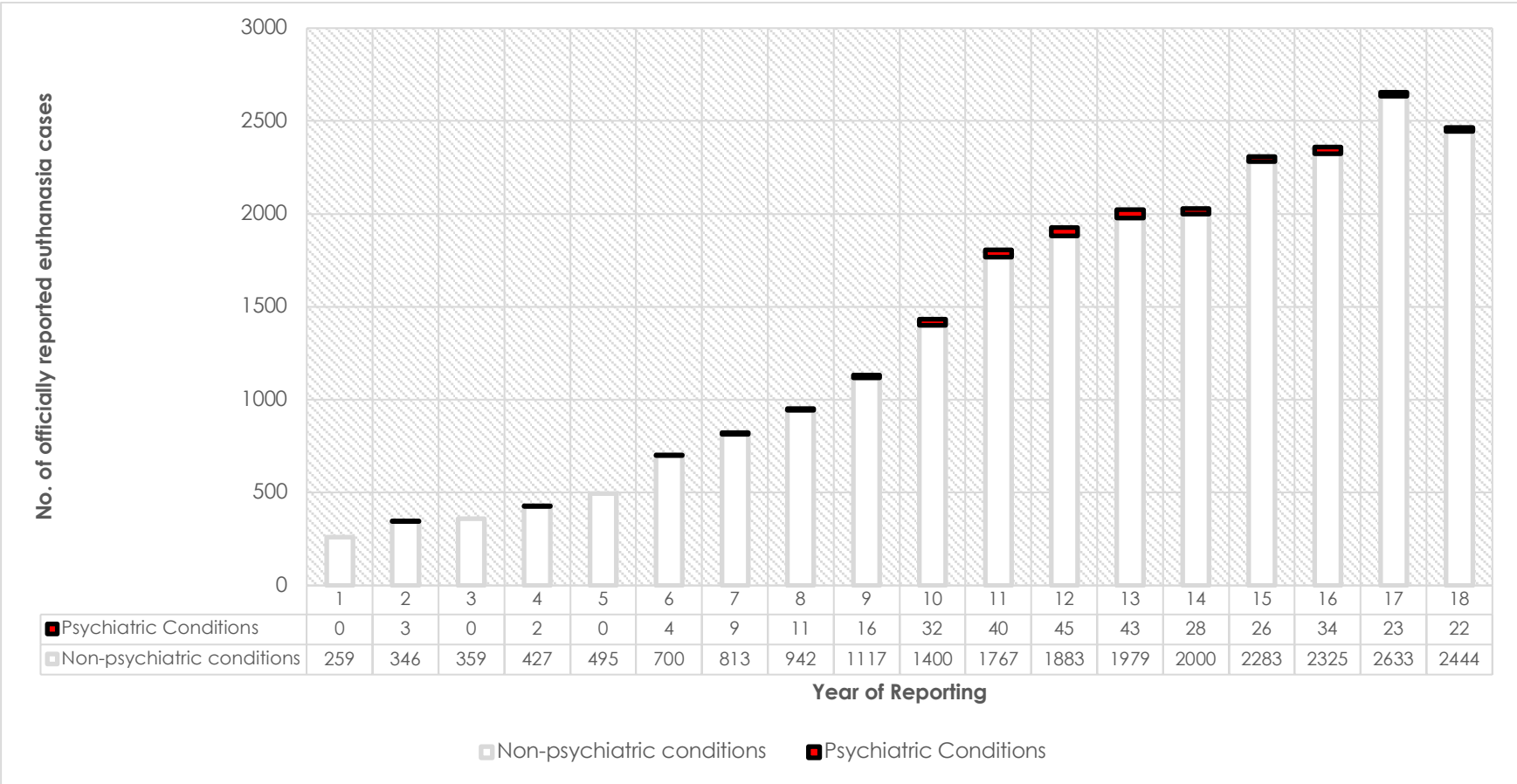
The first empirical study that strictly focused on these cases made a clear distinction between the cases based on psychiatric disorders versus the cases based on dementia, with data drawn from the FCECE's database over the 2002 – 2013 time frame.¹¹⁷ The results showed that the prevalence of euthanasia practiced in patients predominantly suffering from psychiatric disorders was extremely rare until 2008, after which the numbers increased to 40 cases in 2013.¹¹⁷

From 2014 onwards, the FCECE used a different form of classification and reported on the number of euthanasia deaths based on psychiatric disorders, and specifying the main underlying diagnosis. This allows for a further tracking of the number of carried out cases until 2020, showing a further increase of the number of these cases to 43 reported E/PAS deaths in 2015, and a decrease in the following years to 22 E/PAS deaths in 2020, as shown in Figure 1.¹¹²⁻¹¹⁴ A similar trend was seen in the Netherlands, with numbers increasing from 0 euthanasia deaths based on psychiatric reasons in 2008¹¹⁸, 56 cases in 2015¹¹⁹, 83 cases in 2017¹²⁰, followed by a decrease to 67 and 68 cases in the years 2018/19.^{121,122} The numbers increased again to 88 cases in 2020.¹²³

In Switzerland, there is no central register for reporting E/PAS deaths. However, the Swiss federal Statistical Office started to collect reported E/PAS deaths from 2011 onwards¹²⁴, and a recent study on death certificates from 1985 to 2014 revealed that patients with psychiatric disorders as sole diagnosis, or with comorbid somatic disorders, make up for 3.7% of all E/PAS deaths in total.¹²⁵ To date, no E/PAS deaths predominantly based on psychiatric conditions have been reported to the Luxembourg and Spanish Control and Evaluation Committees.

Figure 1

Reported euthanasia deaths in Belgium since its legislation in 2002, predominantly based on psychiatric versus non-psychiatric reasons



6.1.3. Main patient, clinical, and decision-making characteristics in carried out EAS cases

The study of Smets et al. (2010) was the first that showed some insight into the proportion of euthanasia cases carried out in Belgium and their main characteristics.⁹⁶ This study was based on the FCECE's database of collected data between 2002 and 2007 and showed that most patients suffered from cancer (85%). 0.7% of all the reported cases concerned euthanasia in non-terminally ill, who were reported not to have suffered physically.⁹⁶ A following trend analysis (2002-2013) revealed that the increase of E/PAS deaths is mainly seen in the elderly, aged 80 or older (from 17% to 35%), the patients suffering from a disorder other than cancer (from 15% to 31%) and the non-terminally ill (from 8% to 15%).¹¹⁰ The most recent FCECE reports revealed that, while the ratio of the terminally ill versus the non-terminally ill did not differ significantly, and cancer remains the most reported condition underpinning the E/PAS death, the (newly applied) diagnosis of polyopathy (or the coexistence of multiple chronic diseases) ranked second.^{112,113}

With regard to the share of E/PAS deaths in the context of psychiatry, a first study revealed that in the first lustrum of E/PAS legislation, 18 of the 1,917 the reported E/PAS deaths in total concerned more patients who suffered from (neuro-) psychiatric disorders.⁹⁶ Whereas 12 patients suffered from degenerative neuropsychiatric disorders (e.g., Alzheimer's and Huntington's disease), 6 other patients suffered from 'depression' (5) or 'psychosis' (1).⁹⁶ The first Belgian empirical study that attempted to gain more insight into the main demographic, diagnostic and decision-making characteristics of these cases from a broader time range (from 2002-2013) showed fewer cases based on degenerative neuropsychiatric disorders, e.g., dementia (34.6%).¹¹⁷ In the majority of these cases (65.4%), patients suffered from mood disorders (53.1%), whether as single underlying psychiatric condition (46.4%) or combined with another psychiatric disorder (6.7%).

In the remaining 12.3%, there was mention of 'another psychiatric disorder', with autism spectrum and personality disorders as the most common ones.¹¹⁷

Regarding gender and age, results showed that E/PAS deaths primarily concerned women (68-77%), and at least 4 out of 5 patients who suffered from

comorbid psychiatric diagnoses, or another psychiatric diagnosis, were younger than 60.^p

A similar trend was observed in the various quantitative research studies that were conducted in the Netherlands.¹²⁴ A recent systematic review summarised the Dutch findings as follows: the carried out EAS deaths that were studied also concerned mostly women (70-77%) and people mainly suffering from mood disorder (55-70%).¹²⁴ However, the majority of these concerned patients suffering from at least two psychiatric disorders (56-97%), with personality disorders as the most common comorbid psychiatric condition (52-54%). In addition, 37-62% suffered from at least one comorbid somatic condition (a condition that was excluded in the abovementioned Belgian study), and in 34-52% a history of suicide attempts was reported.

The results from research studies in Switzerland were less detailed in these respects.¹²⁴ One Swiss study compared data from a longitudinal mortality study, with the assisted suicide cases reported by 3 right-to-die associations between 2003/08, and focused more on other socio-demographic factors, e.g. the gender and education ratio of unassisted suicide (higher in men and negatively associated with higher education) versus assisted suicide (no significant gender differences but positively associated with higher education). In addition, determinants as living alone, not having children, or not having a religious affiliation were positively associated with both assisted and unassisted suicide.

6.1.4. Main personal, clinical, and decision-making characteristics of E/PAS requestors

The (reported) E/PAS death rates represent but the tip of the iceberg, as there are more patients applying for euthanasia than having their request carried out. Prior to this PhD trajectory, there was only one Belgian study: on 100 consecutive patients requesting euthanasia in one mental healthcare practice in

^p Note that in this study, 3 broad age ranges were distinguished: (1) patients younger than 60 years, (2) patients between 60 and 80 years of age, and (3) patients older than 80 years. The breadth of these age ranges complicates the comparative analysis with the findings in other Belgian and Dutch studies.

the years 2007-2011.¹²⁶ The study revealed that 48 cases were considered eligible for euthanasia and 35 were carried out. Whereas 6 of those patients died by means of suicide – because family resistance to euthanasia was strong, or the procedure was perceived as being too arduous – around 1 out of 10 patients decided to withdraw their euthanasia request, some of whom declared having found sufficient peace of mind to give treatment, and thus life, another chance⁹. Compared to the study of E/PAS cases that were carried out¹¹⁷, this study confirmed a preponderance of women (77%), more detailed information regarding age (an average of 47 years, with a range of 21 to 80 years of age), and a high prevalence of mood disorders (58%), with personality disorders and – often formerly undiagnosed – autism disorders ranked second and third respectively – but it revealed a higher prevalence of comorbid disorders (90%)¹²⁶ than reported in Dutch studies (52-54%).¹²⁴ According to Vonkel's most recent annual report, 107 euthanasia requestors were registered in the year 2020, of which 88 (82.3%) predominantly requested euthanasia for psychiatric reasons.¹²⁷

In the Netherlands, a survey study among psychiatrists in 1996 (and thus years prior to E/PAS legislation) showed that 37% of the responding psychiatrists reported that – during the course of their career – they had received at least one E/PAS request based on psychiatric conditions.¹²⁸ A follow-up study, based on the same survey data, estimated the annual number of psychiatric consultations to be 400, making up about 4% of all E/PAS requests.¹²⁹ A recent retrospective report from the Dutch Centre of Expertise on Euthanasia (EE) revealed that the number of E/PAS requests based on psychiatric reasons showed an increase from 222 in 2012 to 696 in 2018.¹³⁰ Most E/PAS requests concern women (60%) suffering from mood disorders, and the gender ratio of granted and withdrawn requests is 64% and 69%, respectively, for females. When not distinguishing by gender, the requests primarily concern people suffering from comorbid disorders (80%) between 41-50 years of age. In addition, the report showed an increasing proportion of young E/PAS requestors (21 to 30 years) over recent years, and even an increase in the 16 to 20 age range. The E/PAS requests based on psychiatric reasons are less likely to be granted (10%). Whereas 60% of E/PAS

⁹ Although not supported by numbers, the latter effect was also confirmed in another, non-private clinical practice.²⁰⁴

requests end up being rejected, 20% end up being withdrawn, and another 4% of the E/PAS requestors commit suicide.¹³⁰

A recent Dutch survey study estimated the number of psychiatric E/PAS requestors between 1100 and 1150 in the period 2015-2016 for all surveyed psychiatrists, of whom 60 to 70 patients received E/PAS.¹³¹ Of the 207 responding psychiatrists, 54% had received, and 4% had carried out, at least one psychiatric E/PAS request during their career.

6.2. TO ENGAGE OR NOT TO ENGAGE IN E/PAS REQUESTS AND PROCEDURES

6.2.1. Medical-ethical and policy-implementation considerations

E/PAS in the context of psychiatry is not only considered highly complex but also extremely contentious, especially since Dutch review articles on a proportion of reported E/PAS cases revealed that some of the legal criteria are often 'presumed' met, and at times insufficiently documented and/or subject to dissension between physicians.¹³²⁻¹³⁴ A recent systematic review (2019) collected the main ethical and policy challenges surrounding the E/PAS practice in the context of psychiatry.¹³⁵ In this review, the majority of the 42 selected articles have been published after 2013 and showed a more or less equal distribution between 'pro' versus 'contra', with most of the so-called 'pro' articles being lengthy articles written by non-clinicians and most of the 'contra' articles being commentary-type, reactive articles written by clinicians.¹³⁵

When categorized^r into 4 overarching domains, the reasons in (dis)favour concern: 1) the nature and course of mental illnesses and related suffering; 2) the underpinning principle of autonomy in E/PAS legislation and how the concept relates to (a) the mental capacity of the mentally ill, and (b) the self-determination and authenticity underlying their E/PAS request; 3) the main goals of psychiatry (e.g., how allowing E/PAS relates to suicide prevention); and 4) the consequences of E/PAS on mental healthcare in general.

^r Nicolini et al. (2020) categorised their findings in 8 categories, some of which I have merged for perceived global consistency reasons.

First of all, regarding mental illness and related suffering, disagreements occur regarding (1) the (un)justified distinction between mental versus somatic illnesses and related suffering, and (2) whether the legal key criteria – irremediability and unbearable suffering – can be met and adequately assessed in the context of psychiatry. Regarding the first, most articles made use of parity arguments to argue against the exclusion of the mentally ill for E/PAS. Doing so is deemed illogical as, for example, there is no strict cut-off line between somatic and mental illness and related suffering, and some of both of the patient groups can be deemed terminally ill from the moment that they seriously consider ending their lives themselves.^{136,137} In addition, when based on their so-called ‘vulnerability’, it would be discriminatory and stigmatising, as it would lead the mentally ill to suffer much longer than the physically ill.¹³⁸⁻¹⁴³ As regards the illness-related suffering, physical and mental suffering are considered to be entangled,^{136,144} with mental suffering being the most decisive reason for all patients requesting E/PAS¹⁴⁵ and deemed to be as bad as – or even far worse than – mere physical suffering.^{136,137,139-141,144,146,147} Arguments against parity mainly concern clinicians pointing to insufficient knowledge of the aetiology of the mental illness¹⁴⁸⁻¹⁵⁰, and non-clinicians turning the parity argument upside down when pointing to the unfairness of not acknowledging the evidence for differences, as mental illnesses are more multifactorial in nature, more prone to diagnostic uncertainty¹³⁵, and more prone to the risk of diagnostic errors.^{146,149,151,152} The latter argument is undercut as it was also deemed to be present, but not sufficiently acknowledged, in somatic medicine,^{136,138,140,142,144,145} it can be countered by the adoption of additional safeguards and more cautious approaches¹³⁸⁻¹⁴⁰, and there is no justified reason for letting this clinical issue of higher uncertainty and error be at the detriment of the mentally ill.^{137,145,146} Regarding the key criterion ‘irremediability’, this is disputed in 3 respects: (1) whether or not incurability or treatment-resistant symptoms do exist in psychiatry, as spontaneous recovery can occur, and whether or not this can be reliably assessed by means of statistical tools, 2) whether or not the judgement should only be entrusted to physicians’ opinions and statistical tools, or should also include the patient’s voice, and 3) whether or not future treatment potentials – e.g., the promising effect of ketamine in chronic depressive patients that are treatment-resistant to classic psychopharmaceuticals and ECT should be waited for. As regards the assessment of the criterion ‘unbearableness of

suffering': less disagreement was found in the literature, with most articles leaving this up to the patient, regardless of whether the suffering is physical or mental.^{136,139,144,153}

Second, the general concept of autonomy, one of the core principles of medical ethics and law in Western democracies and also underpinning E/PAS legislation, is often disputed. It was questioned whether the legal requirement of 'mental capacity' can be present in the mentally ill, because: (1) it may be impaired due to the mental illness, and (2) it may be difficult for physicians to have it reliably assessed. Although most of the papers conclude that mental capacity is not lacking in (all of) the mentally ill per definition^{139,141,144,145,154}, different opinions arise on whether this is sufficient reason for including or excluding these patients for E/PAS. Whereas some argue that physicians should be able to properly assess it (as it is no different from other capacity assessments),^{137,138,144,146} others emphasise that higher assessment thresholds should be applied in psychiatry due to the higher margin of error^{149,154}, or they are convinced that mental capacity cannot be reliably assessed, or that it is even lacking, in this particular patient group^{152,155-158}. Contentions also occurred regarding (1) whether or not the mentally ill can express an authentic E/PAS request based on a rational wish to die, and, if not, (2) whether or not the irrational wish to die should be respected under the medical-ethical principle of autonomy.^{137,138,144-146,154,159,160} For instance, whether depression compromises¹⁶⁰, or can be part¹⁴⁵ of, the patient's authentic self.

Third, disagreements occurred concerning whether or not E/PAS requests should be included in the physicians' toolbox^s and how this relates to the physician's

^s This is subject to dissension in the legal literature as well. In Belgium, legal experts disagree on the correct qualification of E/PAS as: (1) 'a normal medical act' and, more specifically, an extension of palliative care, (2) a societal normalised 'standardised medical act in extenso', or (3) a 'societal normalised and standardised act, carried out by physicians'. Some legal experts consider euthanasia to be a normal medical act because, inter alia, 1) it is 'exclusively' entrusted to doctors and therefore falls within the doctors' monopoly, 2) it was explicitly categorised as a medical act during the preparatory parliamentary discussions, 3) it is in line with Dutch law, which considers euthanasia to be a private matter between doctor and patient and subjects it to professional secrecy, and 4) it is an extension of palliative care, which has already been recognised as a medical act in Belgium. Other legal experts point to the differences from 'standard' medical acts, as euthanasia has no diagnostic or therapeutic aspect. An act such as euthanasia is not performed with the aim of maintaining or improving the patient's state of health. However, the legislator has specifically entrusted this act to physicians because euthanasia is preceded by an assessment procedure that is part of a therapeutic process. The social importance of supervision and control is, however, of such importance that the standardisation of this (and other medico-ethical acts, such as abortion) cannot be left merely to the professional autonomy of physicians, but requires a specific legal (con)text. The latter view holds that euthanasia cannot be called a medical act

duty to treat (and not kill) patients and relieve their suffering.^{137,141,144,147,149,151,156,161,162} With regard to the first, disagreements arise as to whether physicians are needed to provide assistance to people who have other ways to end their lives^{149,151,163} – assuming that (all of) the mentally ill are deemed physically able to do so¹⁴⁰ – and whether acknowledging the limits of the physician’s toolkit to sufficiently relieve the burden of suffering and compassion can justify E/PAS.^{137,139,141,144}

In addition, the crucial factors of a good patient-physician relationship and ‘hope’ as key element towards rehabilitation are often a subject of dissension. Critical concerns are expressed that E/PAS may lead to the impression of giving up on the patient and may jeopardise the learning of better coping strategies^{150,152,155}; which is counter-argued by statements on the potential beneficial therapeutic effect of the E/PAS option^{141,142,164}, and that there is already mention of physicians giving up on their patients, irrespective of E/PAS¹³⁸. In addition, dissensions appeared regarding the tension of allowing E/PAS and preventing suicide, and more specifically: (1) whether E/PAS may prevent the mentally ill from, or drive them into, considering and committing (violent or lonely) suicide (attempts)^{139,140,142,145,146,160–162,164}, (2) whether it’s the physician’s duty to preserve life at all, or at reasonable, costs^{139,152,154,162,164}. Finally, dissension appeared regarding the tension between the patient’s legal right to refuse (life-sustaining) treatment and the (non-) justification of E/PAS. Whereas for some, there is only a relatively small moral distinction as treatment refusal is – even after a suicide attempt – legally allowed^{137,139,142–144}, others point to a larger moral difference between a physician’s act versus a patient’s omission^{151,154,165}. Finally, the overarching impact of E/PAS legislation on mental healthcare in general is often disputed. Whilst arguments not in favour of E/PAS point to the need to tackle access barriers to the underfunded field of psychiatry first^{155,163} (as the option of E/PAS may potentially yield to even poorer than the already poor mental healthcare expectations^{150,152,155,157,162,166}), arguments in favour do not consider this sufficient reason for excluding this patient group^{138,140,142,144,167}. Another argument of dissension relates to the *slippery slope* argument.

because ending someone's life in no way contributes to their health, as it has no diagnostic or therapeutic purpose. ^{405(pp128-132),406(pp31-55)}

According to this type of reasoning, a particular initial course of action will inevitably lead to a chain of many more related courses of action, which will eventually culminate in undesirable consequences that were initially unforeseen and unintended. In the context of E/PAS legislation, the slippery slope would – over time – result in an increase of E/PAS requests and deaths, mostly affecting the vulnerable patient population (the mentally ill and the elderly) to an extent that is no longer acceptable (E/PAS as means to resolve society’s failures) or even legal (increased risk of error and abuse when not properly assessed and monitored).^{156,163,168} Arguments in favour do not consider such potential expansions necessarily bad per se, and point to poor empirical-based evidence for the concerns to be substantiated^{136,139,143,146}. Tanner (2018) warns against a one-sided interpretation of ‘vulnerable persons’ and how to best protect them, and points to the different types of external pressure, including the familial and/or social pressure on these patients to stay alive, which might not always be in the patient’s best interest.¹⁴⁴ Finally, disagreement occurred regarding whether or not E/PAS automatically and undeniably negatively impacts the patient’s relatives.^{138,140,155}

In sum, most articles made use of parity arguments – and when they did not, they primarily concerned conceptual disputes about the feasibility to adequately implement E/PAS in clinical practice.

6.2.2. Evidence regarding engagement in the Dutch and Belgian practice

A recent Dutch survey study also aimed to examine more detailed information on the characteristics and reasons for granting or refusing these requests. In total, 66 refused cases were described in more detail, with 59% of these patients suffering from a personality disorder and 19% from somatic comorbidity. Most E/PAS requests (75.4%) were refused on the grounds that the legal criteria had not been met^t. In addition, 1 out of 3 reporting physicians mentioned personal

^t For instance, reasonable treatment alternatives (e.g., with psychopharmaceuticals, psychotherapy or ECT) were deemed available in 53% of the surveyed cases, and the criteria ‘suffering without prospect of improvement’, ‘voluntary and well-considered request’, and ‘unbearable suffering’ were not deemed to be sufficiently met in 30%, 28% and 11% of the cases, respectively.¹³¹

objections to approving E/PAS^u.¹³¹ Finally, 1.5% of the refused cases were ascribed to the patient's family opposing the E/PAS request being carried out.¹³¹ In addition, the majority of the patients who were denied E/PAS were still alive (69%), or died by means of suicide (16%) or other means (3% died of natural causes, 3% received E/PAS via the Dutch End-of-Life Clinic, and 1.6% via VSED). Finally, 9 granted cases were reported in more detail, with 5 patients suffering from a mood disorder and 3 patients from somatic comorbidity.¹³¹ Moreover, a comparative analysis of survey studies revealed a growing reluctance among psychiatrists to provide E/PAS, from 47% in 1995 to 37% in 2016.¹⁶⁹ Additional Dutch survey and qualitative studies among physicians also confirmed a higher reluctance to assess and grant these requests, mainly due to the complexity of the E/PAS assessment procedures.^{88,170-172}

In Belgium, no research focused on psychiatrists' or other physicians' (un)willingness to engage in these E/PAS requests, at least not in the years prior to this research trajectory. Only one survey study (2021) was conducted in 2017 among 111 psychiatrists and their trainees from one University Psychiatric Centre in Louvain. This study examined their opinions and experiences regarding euthanasia in general and euthanasia in the context of adult psychiatry in particular. The results showed that most psychiatrists were in favour of E/PAS legislation, especially concerning the terminally ill (94%) and to a lesser extent in the context of psychiatry^v (64%). Significant differences in opinion were found among psychiatrists (not) being religious and those with less or more years of work experience. 77% of the religious psychiatrists were of the opinion that E/PAS can only be considered an acceptable end-of-life option in the event of a terminal illness. Psychiatrists with more than 20 years of working experience were more open towards euthanasia than their younger colleagues, but less so than psychiatrists in training. Finally, the majority (62%) had been confronted with an E/PAS request in the 5 years prior to the survey. The majority took the E/PAS seriously into account, one-third of whom decided to start the E/PAS trajectory. One out of 5 psychiatrists were asked to engage as advising

^u Whereas close to one-quarter (23%) did not further specify the reasons behind their objection, 12% expressly ascribed this to the perceived absence of a (good) therapeutic relationship.

^v Interesting detail: in the questions testing the psychiatrists' knowledge of E/PAS, one physician (2%) appeared to think that E/PAS was not legally allowed for patients predominantly suffering from psychiatric conditions in Belgium.

physician. Only 5 psychiatrists reported not to have taken the E/PAS request seriously. Important detail: their opinions on E/PAS in the context of psychiatry did not differ significantly from the other psychiatrists.¹⁷³

6.3. PATIENTS' REASONS FOR REQUESTING EUTHANASIA

The reasons underlying the patients' E/PAS request is less studied and were mainly gathered from physicians' second-hand accounts. One nationwide physician survey revealed that not only the burden of pain, but also the patient's perceived suffering without prospect of improvement, the loss of dignity, and not wanting to be a burden as the main reasons for a patient to apply for euthanasia.¹⁷⁴

Research on patients' first-hand accounts regarding the suffering underpinning their E/PAS request was not only limited but also overlooked the complexity^{175,176} The research topic itself was set from 2010 onwards, mainly in the Netherlands. A literature review in 2010, provisionally defined unbearable suffering in the E/PAS context as 'a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind'.^{177(p350)} Note that this definition is predominantly based on scientific studies on the suffering experiences of patients predominantly suffering from somatic conditions.¹⁷⁷ In addition, most studies measured the extent of unbearable suffering using quality-of-life scales or well-being surveys, subsequently interpreting low scores as suffering indicators.¹⁷⁸ As low rates on perceived well-being or quality-of-life do not necessarily resemble the experience of unbearable suffering, a first measurement instrument – the State Of Suffering-Five (SOS-V) – was developed from 2009 onwards and directly addresses the extent of suffering in terminally ill cancer patients by measuring the frequency and intensity of their suffering experiences.^{179–181} Moreover, cultural differences in the reasons why patients request E/PAS were suggested in a recent Canadian study, in which loss of autonomy or the ability to enjoy activities were less commonly reported than in the Netherlands.¹⁸² Overall, evidence on unbearable suffering experiences of both the terminally and the non-terminally ill is too limited to be integrated in a

general definition of unbearable suffering, let alone to be measured by means of a golden standard instrument.

Few studies delved into the reasons why adults who suffer predominantly from psychiatric disorders apply for euthanasia. When they are studied, then this is mainly based on surveyed psychiatrists', and thus second-hand, accounts, with a strict focus on 'unbearable suffering' when pointing to 'depressive feelings', 'suffering without prospect of improvement' and 'desperate situations in several areas of life' as the main reasons.¹³¹ Prior to this PhD trajectory, only one Dutch study focused on unbearable psychological suffering from patients' first-hand accounts, but only in patients with primarily somatic disorders and only a few patients with psychiatric co-diagnoses.¹⁸³

As the earlier mentioned definition on unbearable suffering^{177(p350)} had been predominantly drawn up on studies based on the suffering experiences of the terminally ill, and to a lesser extent of the non-terminally ill, suffering from somatic disorders, this definition has a generic nature that might not clearly distinguish between the suffering experiences of patients suffering from somatic and mental disorders. However, the scarce available evidence suggested that this distinction may be important. The abovementioned qualitative study on patients' first-hand accounts found that unbearable suffering was, in general, the result of an intensive process that often found its origin in the medical symptoms of the patients' disorders. In addition, psychological, socio-environmental, existential, and biographical aspects affected the suffering experience, with hopelessness as a critical element. Not only does this characterization of the process imply that there may be fundamental differences between the unbearable suffering experience of patients with somatic and/or psychiatric illnesses, the results also showed that only patients with a psychiatric diagnosis, or with both a psychiatric and physical diagnosis, 'suffered unbearably all the time'.^{183(p727)}

7. Research Aim and Outline of this Dissertation

7.1. MAIN OBJECTIVES AND RESEARCH QUESTIONS

The overarching research aim is to set a firm research agenda in order to establish a more thorough understanding of the E/PAS practice in the context of

adult psychiatry in Belgium. In doing so, the following 3 main objectives can be distinguished, each consisting of several research questions to be answered.

Objective 1: to describe the first written guidelines on how to deal with euthanasia requests in the context of adult psychiatry

Contrary to the situation in the Netherlands, no written guideline on how to implement E/PAS in psychiatric clinical practice was published until late 2017 (exactly when this PhD trajectory commenced). Also, contrary to the Dutch situation, not just 1 but 4 guidelines on this issue were published within a short period of time (2017-2018). In line with the Dutch guideline, criteria were set that were stricter than required by law. As these guidelines differed slightly from one another, we deemed it necessary to undertake a descriptive review study. In addition, we also reviewed the step-by-step management protocol of the Ghent University Hospital to sketch a broader picture of the E/PAS practice in adult psychiatry. The following research questions were set:

1. What are the added value and potential shortcomings of the Flemish written guidelines on how to adequately deal with euthanasia requests and procedures in the context of adult psychiatry?
2. What are the added value and potential shortcomings of Ghent University Hospital's step-by-step protocol on how to deal with euthanasia requests from external facilities?

Objective 2: to provide the first insights into why adults, predominantly suffering from psychiatric conditions, request E/PAS in Belgium.

Prior to this PhD dissertation, no empirical study (neither in Belgium nor in another country legally allowing E/PAS in this patient group) has been published that directly addresses the motives for requesting E/PAS. Moreover, nothing has been known about these persons' perceptions on how the E/PAS trajectory has affected them, their current clinical trajectory, and their relationships with their closest inner circle. Therefore, we decided to set the research agenda on evidence gathered through these patients' first-hand accounts and the following research questions:

3. How do these people phrase the nature and extent of their suffering experiences, and what renders their suffering unbearable?
4. What are their motives for requesting euthanasia, how does it relate to suicide, and what would have prevented them from considering a hastened death?
5. How do they phrase the impact of the euthanasia procedure on their mental state, their clinical trajectory, and their social relationships?

Objective 3: to provide the first insights into psychiatrists' attitudes and engagement regarding E/PAS in the context of Psychiatry, as well as the first insights into their, and other care workers', concrete experiences, and support needs regarding these E/PAS trajectories.

Prior to this PhD dissertation, only the Netherlands has provided (quinquennial) research that (among other things) has addressed the attitudes and experiences of psychiatrists regarding E/PAS in general and E/PAS in the context of psychiatry in particular.^{131,169} No study has yet been published that examines the attitudes, experiences and support needs of psychiatrists working in Flanders, Belgium. This is striking, as the Belgian legislator requires at least one psychiatrist to be engaged in the E/PAS trajectory in the context of adult psychiatry. Therefore, we decided to roll out the first survey study among a representative sample of psychiatrists working in Flanders as well as the first qualitative in-depth study to learn more about their concrete experiences and potential support needs.

Although the formal roles in the E/PAS trajectory are legally entrusted to the patient and their physicians involved, the patient nursing team should at least be informed about the E/PAS request, if (and only if) that nursing team is in close contact with the patient. To date, only one survey study (2015) has been published that aimed to gain insight into the attitudes and experiences of psychiatric nurses regarding E/PAS in the context of psychiatry in a non-specified research period.¹⁸⁴ Therefore, a survey was sent to 11 psychiatric hospitals in the Flemish part of Belgium. Regarding attitudes, the vast majority (86%) were in favour of E/PAS legislation. The following confounding factors were distinguished: (1) the psychiatric diagnosis, with nurses working with patients suffering from psychosis and personality disorders being more likely to agree with the E/PAS

request than nurses working with patients suffering from substance addiction, and (2) the type of work setting, with nurses working in acute settings being more likely to agree with the E/PAS request. In addition, 13% of the surveyed psychiatric nurses reported that E/PAS had been performed in their psychiatric facility.¹⁸⁴

Results also showed that 53% of the responding psychiatric nurses were frequently and directly confronted with a request for euthanasia and 69% were indirectly informed about the E/PAS request through 'another mental healthcare worker colleague'. Hence, not only physicians and psychiatric nurses, but many other mental healthcare workers are confronted with E/PAS requests and procedures – and, therefore, much can be learned from these care workers' concrete experiences and support needs.

The following research questions were set:

6. What are psychiatrists' attitudes towards, and readiness to engage in, euthanasia assessment procedures and/or performance concerning these adults with psychiatric conditions?
7. To what extent have these psychiatrists been confronted with, and engaged in, psychiatric euthanasia practice?
8. What can be learned from their latest experience with a completed euthanasia case (irrespective of its outcome)?
9. How do healthcare professionals and volunteers phrase their concrete experiences and support needs regarding the euthanasia trajectory concerning this patient group?

7.2. OUTLINE OF THIS DISSERTATION

Following this introduction, this dissertation comprises 4 main parts, with chapters based on articles that have been published, accepted, or submitted for publication in full in scientific journals during the period of this PhD trajectory (October 2017-December 2021).

Part One is dedicated to the written policies on how to adequately address euthanasia requests based on psychiatric conditions. As most of the Belgian

advisory texts on 'how to adequately address euthanasia requests based on psychiatric conditions' were published during the first semester of this PhD trajectory, Chapter 2 is dedicated to the critical point-by-point analysis of these advisory texts. Chapter 3 addresses a more detailed description of one of the Flemish University Hospital's written policies in circulation: namely, Ghent University Hospital's step-by-step protocol on how they, inspired by their pluralistic stance on euthanasia, deal with euthanasia requests from outside patients.

Part Two addresses the euthanasia practice from a patient perspective. Chapters 4 and 5 focus on the legal criterion 'unbearable suffering', the most subjective criterion in its essence, whose evaluation is mostly considered to be best judged by the patient herself. Whereas Chapter 4 provides deeper insight into the determinants that can render the suffering unbearable by means of a qualitative study on 26 spontaneously written or audio-recorded 'testimonials', Chapter 5 provides the means to map the patient's suffering experiences by means of a new assessment instrument: the NEOSi (the Nature and Extent of Suffering indices), which is tested on cognitive validity. As evidence revealed that there is more to the story than the experience of 'suffering' alone, Chapter 6 maps the reasons that these patients request euthanasia, including their perspective on how euthanasia relates to suicide and what could have prevented them and their peers from thinking about ways to hasten death. Chapter 7 focuses on the impact of the euthanasia procedure and its provisional and/or final outcomes on the patients' mental state (which also, but not only, includes death ideation), clinical trajectory and social relationships. Chapters 6 and 7 are based on the results of a qualitative in-depth interview study with 16 adults.

Part Three addresses the euthanasia practice from a psychiatrist perspective. The chapters present the results from a survey study among psychiatrists affiliated with the Flemish Association of Psychiatry. Whereas Chapter 8 focuses on the responding psychiatrists' attitudes regarding euthanasia in general and euthanasia in the context of psychiatry in particular, Chapter 9 reveals their concrete experiences in psychiatric euthanasia practice. Chapter 10 provides more detailed information on 46 unique cases, based on the psychiatrists' latest experience with a completed euthanasia assessment procedure, irrespective of its outcome (i.e., whether euthanasia was performed or not).

Part Four addresses the euthanasia practice from a mental health carer perspective. Chapter 11 zooms in on their (un)favourable concrete experiences and their reported support needs regarding euthanasia requests and procedures in the context of psychiatry. Chapter 11 is based on the results of an in-depth interview study with 16 physicians and 14 other mental healthcare professionals or volunteers (other than the patients' relatives acting as family caregivers).

PART ONE

Toward the adequate management of euthanasia requests and procedures concerning adults with psychiatric conditions

Chapters are based on the following publications:

Chapter 2

Verhofstadt M, Van Assche K, Sterckx S, Audenaert K, Chambaere K. Psychiatric patients requesting euthanasia : Guidelines for sound clinical and ethical decision making. *International Journal of Law and Psychiatry*. 2019;64(May-June):150-161.
doi:10.1016/j.ijlp.2019.04.004

Chapter 3

Verhofstadt M, Audenaert K, Van Assche K, Sterckx S, Chambaere K. Ghent University Hospital's protocol regarding the procedure concerning euthanasia and psychological suffering. *BMC Medical Ethics*. 2019;20(1):1-7.
doi:10.1186/s12910-019-0400-z

CHAPTER 2 : PSYCHIATRIC PATIENTS REQUESTING EUTHANASIA : GUIDELINES FOR SOUND CLINICAL AND ETHICAL DECISION MAKING

Verhofstadt M, Van Assche K, Sterckx S, Audenaert K, Chambaere K.
Psychiatric patients requesting euthanasia : Guidelines for sound clinical and
ethical decision making. *International Journal of Law and Psychiatry*.
2019;64(May-June):150-161.
doi:10.1016/j.ijlp.2019.04.004

“Why linger, why turn back, why shrink, my Heart?
Thy hopes are gone before: from all things here
They have departed; thou shouldst now depart!
A light is passed from the revolving year,
And man, and woman; and what still is dear
Attracts to crush, repels to make thee wither.
The soft sky smiles,—the low wind whispers near:
’Tis Adonais calls! oh, hasten thither,
No more let Life divide what Death can join together.”
Percy Bysshe Shelley (Adonais)

Abstract

Background

Since Belgium legalised euthanasia, the number of performed euthanasia cases for psychological suffering in psychiatric patients has significantly increased, as well as the number of media reports on controversial cases. This has prompted several healthcare organisations and committees to develop policies on the management of these requests.

Method

Five recent initiatives that offer guidance on euthanasia requests by psychiatric patients in Flanders were analysed: the protocol of Ghent University Hospital and advisory texts of the Flemish Federation of Psychiatry, the Brothers of Charity, the Belgian Advisory Committee on Bioethics, and Zorgnet-Icuro. These were examined via critical point-by-point reflection, focusing on all legal due care criteria in order to identify: 1) proposed measures to operationalise the evaluation of the legal criteria; 2) suggestions of additional safeguards going beyond these criteria; and 3) remaining fields of tension.

Results

The initiatives are well in keeping with the legal requirements but are often more stringent. Additional safeguards that are formulated include the need for at least two positive advices from at least two psychiatrists; an *a priori* evaluation system; and a two-track approach, focusing simultaneously on the assessment of the patient's euthanasia request and on that person's continuing treatment. Although the initiatives are similar in intent, some differences in approach were found, reflecting different ethical stances towards euthanasia and an emphasis on practical clinical assessment versus broad ethical reflection.

Conclusions

All initiatives offer useful guidance for the management of euthanasia requests by psychiatric patients. By providing information on, and proper operationalisations of, the legal due care criteria, these initiatives are important instruments to prevent potential abuses. Apart from the additional safeguards suggested, the importance of a decision-making policy that includes many actors (e.g. the patient's relatives and other care providers) and of good aftercare for

the bereaved are rightly stressed. Shortcomings of the initiatives relate to the aftercare of patients whose euthanasia request is rejected, and to uncertainty regarding the way in which attending physicians should manage negative or conflicting advices, or patients' suicide threats in case of refusal. Given the scarcity of data on how thoroughly and uniformly requests are handled in practice, it is unclear to what extent the recommendations made in these guidelines are currently being implemented.

Keywords: Medical assistance in dying, Psychiatry, Mental health, Belgium, Euthanasia, Guidelines

1. Introduction

In 2002, Belgium conditionally de-criminalised euthanasia performed by a physician, legally defined as 'intentionally terminating life by someone other than the person concerned, at the latter's request'. The Belgian Euthanasia Law, however, lays down several substantive and procedural due care criteria that need to be fulfilled in order for euthanasia to be legally permissible. On the basis of their freedom of conscience and their professional autonomy, physicians are at liberty to refuse involvement or to make their involvement dependent upon the fulfilment of additional requirements.¹⁸⁵

Euthanasia is only legally allowed in the BeNeLux countries (i.e., Belgium, the Netherlands, and Luxembourg), Canada, and Colombia. Laws on medical assistance in dying, excluding euthanasia, are implemented and effective in Switzerland and the following American States: Oregon, Washington, Montana, Vermont, California¹⁸⁶, Hawaii, Colorado, and Washington D.C.¹⁸⁷ Recently and strictly taken, the Australian State of Victoria has legalised medical assistance in dying, though also euthanasia in case of a patient being physically incapable of the self-administration of the lethal drug substance.¹⁸⁸

Under the Belgian Euthanasia Law, euthanasia is allowed not only for patients who are expected to die within the foreseeable future but also for patients who are not expected to die within the foreseeable future (in which case the Law requires the fulfilment of additional due care criteria). The latter is almost always the case for psychiatric patients. In line with a general increase of euthanasia cases, the number of cases of euthanasia for psychological suffering is steadily rising.^{189,190} Analysis of the biennial reports of the Belgian Federal Control and Evaluation Commission for Euthanasia (FCECE) indicate that, whereas euthanasia for psychological suffering in psychiatric patients was virtually nonexistent between 2002 and 2007, numbers increased to an average of eight per year between 2008 and 2010, then to approximately 30 per year between 2011 and 2013, and to approximately 60 per year in 2014 and 2015, before decreasing to approximately 40 per year in 2016 and 2017.^{112,114,116,117,191-194}

Euthanasia for psychological suffering in psychiatric patients gives rise to significant concerns regarding the assessment of several of the due care criteria

set out in the Law, including: 1) the patient's mental competence, as this might be affected by a psychiatric disorder; 2) the requirement for the psychiatric disorder to be incurable, as some (symptoms of) psychiatric disorders tend to change over time; 3) the requirement for the well-considered nature of the request, as a death wish may be a symptom of a psychiatric disorder; 4) the constant and unbearable nature of the psychological suffering, given that a clear definition and an effective assessment instrument are still lacking; and 5) the requirement of the non-alleviability of the psychological suffering.

As a result, the clinical assessment of these criteria is very difficult and extreme care should be required before a request from a psychiatric patient for euthanasia for psychological suffering is granted.¹⁶² To illustrate the contentiousness of this issue, case reviews in the Netherlands suggest that in some of the reported cases of euthanasia on patients suffering from a psychiatric disorder some of the due care criteria may have been evaluated suboptimally.^{132,133} Remarkably, however, no such research on Belgian cases has been conducted.

Prompted by the lack of clarity of some of the legal due care criteria, some hospitals have developed protocols to manage requests for euthanasia for psychological suffering⁸⁹. In addition, three end-of-life consultation centres (ULteam in 2011, LEIF Western-Flanders in 2013 and LEIF.Ghent in 2015) have been established by the association LEIF (Life End Information Forum), which was founded in 2003 with the aim to provide information about, and assistance in, end-of-life care.^{90,91} However, the considerable increase in cases of euthanasia for psychological suffering and media reports on controversial cases – of which one has been referred to the public prosecutor^{195,196} and another one has been referred to the Court of Assize¹⁹⁷ – raise concerns about a potentially overly permissive approach¹⁹⁸. As a consequence, some critics suggest the banning of euthanasia for psychological suffering, whereas some organisations and institutions have published guidelines that may enhance the quality of practices.

The aim of our study is to analyse the five Belgian guidelines that have recently been issued regarding the Belgian practice of psychiatric patients requesting euthanasia for psychological suffering (Box 1, at the end of this Chapter), in order to identify and discuss: 1) the measures proposed to operationalise the

legal requirements; 2) suggestions for additional safeguards going beyond the legal requirements; and 3) suggestions regarding the most important issues that are not addressed in the Belgian Euthanasia Law. These guidelines will be analysed using a critical point-by-point reflection, focusing on each of the substantive and procedural legal due care criteria. This allows us to formulate general recommendations for an ethically sound clinical practice in Belgium and will allow readers in other jurisdictions considering adopting euthanasia legislation to identify helpful lessons regarding medical assistance in dying concerning this specific patient group.

Note that the Belgian Act on Euthanasia became effective in the same year as the Dutch 'Termination of Life on Request and Assisted Suicide (Review Procedures) Act'. The Dutch Act contains similar substantive and procedural criteria that must be followed if a patient requests euthanasia. The Dutch Association for Psychiatry published its guidelines on how physicians should assess requests for euthanasia from patients with psychiatric disorders in 2009¹⁹⁹, the same year when Ghent University Hospital developed its step-by step protocol (I). The other guidelines that we discuss in this paper (II-IV) are heavily inspired by the recommendations and suggestions made in the first two editions of the Dutch guidelines (published in 2004 and 2009), but adapted to the Belgian legal context (e.g., the requirement that for euthanasia of a non-terminally ill patient two physicians should be consulted instead of one, as prescribed by the Dutch Act).

Switzerland has no legislation on medical assistance in dying but its criminal law provisions on assistance to suicide (Article 115 of the Criminal Code) do not criminalise assisted suicide for non-selfish motives. Some non-profit organisations (e.g., EXIT and Dignitas) provide assisted suicide to terminally and non-terminally ill psychiatric patients who request physician assistance in dying, subject to the fulfilment of the due care criteria set out in the organisations' own dedicated protocols.

As for Canada, following the adoption of the Law on Medical Assistance in Dying, many provinces have developed policies for medical assistance in dying for terminally ill patients, e.g. Ontario's Policy Statement on Medical Assistance in Dying²⁰⁰). A discussion to expand the Canadian Law to also include the non-terminally ill is still ongoing. The Council of Canadian Academies recently

published three 'final reports' of Expert Panels on Medical Assistance in Dying for Mature Minors, on Advance Requests, and concerning cases in which a Mental Disorder is the Sole Underlying Medical Condition.²⁰¹

This paper was constructed as follows. First, each of the substantive and procedural legal criteria was noted down in a structured bullet point list. Second, when reading the first guideline, every piece of information on the substantive and procedural legal criteria and on the possible additional due care criteria discussed in the guideline was systematically collected, noted down, and summarised under the relevant legal criterion on that list. This method was repeated for each of the subsequent guidelines. Subsequently, the similarities and differences between the guidelines were examined, with particular attention to the way in which they interpreted the legal criteria and to suggestions to include additional due care criteria.

The substantive criteria for eligibility for euthanasia in Belgium

1.1. CHARACTERISTICS OF THE PATIENT

The first substantive criteria concern two patient characteristics, namely the patient's age and mental competence.

1.1.1. The age of the patient

The Euthanasia Law stipulates that the patient who requests euthanasia must either be an adult (i.e. 18 years of age or older) or an emancipated minor (i.e. a minor who, as a result of marriage, or after the age of 15 and on the basis of an order by the juvenile court, is legally competent to autonomously make decisions that touch upon their person). In 2014, the Euthanasia Law was extended to all minors, regardless of age, who have the capacity for discernment, but only in relation to euthanasia for physical suffering and only if additional legal criteria are fulfilled.^{65,202}

1.1.2. Mental competence

To be eligible for euthanasia, the patient must have legal capacity (i.e. must not have been placed under guardianship). In addition, the Euthanasia Law requires patients to be able to make a well-considered request and so to have the

necessary mental competence. This means that they need to be able to demonstrate the ability to understand the real implications of a euthanasia request. Finally, patients also need to be conscious at the moment of making the request.

Some physicians, including psychiatrists, question mental competence in (some) psychiatric patients who are suffering. The five guidelines that are the topic of this paper acknowledge that mental competence can indeed be reduced due to a patient's psychopathology (e.g. temporary psychoses), but they emphasise that this is not automatically the case. In that respect, mental competence should be considered as being task dependent. In the context of a euthanasia request, most of the guidelines (II-V) identify reasons to assume that some psychiatric patients can make a reasoned, well-considered choice for termination of life, accompanied by suitable emotions, and to a certain degree also irrespective of psychopathology. For example, some patients suffering from recurrent depressive, manic or even psychotic episodes find themselves also in temporarily symptom-free waiting periods of remission, before the eventual likelihood of symptom recurrence and/or relapse. Like the psychopathology itself, a patient's mental competence can thus change over time.

However, physicians face great difficulties regarding the evaluation of mental competence in psychiatric patients. Representing the professional group of psychiatrists, one of the guidelines (IV) specifies the clinical assessment of mental competence on the basis of four criteria. First, the degree of the following four cognitive competencies should be assessed in patients: 1) the ability to make and communicate personal choices; 2) the ability to comprehend the information provided; 3) the ability to apply this information to one's own context and situation; and 4) the ability to reason and deliberate. Second, a properly considered euthanasia request must be present (i.e. a 'flash of the moment'-decision must be excluded), and must be accompanied by appropriate emotions. In this respect, ambivalence could also be interpreted as a logical consequence of fear of death, rather than as a symptom of reduced mental competence. Moreover, ambivalence could also be used as a lever to get the patient to focus (again) on exploring options of recovery or rehabilitation. Third, a euthanasia request that could be attributed directly to a symptom of the patient's disorder must be rejected. Fourth, the presence of a sufficient degree of

'practical rationality' must be present. More specifically, the patient should be able to place her euthanasia request in the context of values and goals that are meaningful to herself and that are not overly influenced by her psychopathology.

Regarding the evaluation of the patient's mental competence, four of the guidelines highly recommend taking sufficient time and making use of hetero anamnesis (II-V) and interdisciplinary consultation (I-V). Suicidality receives specific attention in three guidelines (III-V), as this is inherent to many psychiatric disorders. A distinction is made between acute and rational suicidal ideations and plans. It is proposed that the latter should be subject to therapeutic treatment processes that can run parallel with the euthanasia procedure (starting after a euthanasia request has been formally expressed). Involuntary admission to a psychiatric ward should only be considered in cases of acute suicidality, resulting from a serious psychiatric disorder, and only when the patient's safety cannot be ensured via voluntary treatment (IV).

1.2. CHARACTERISTICS OF THE EUTHANASIA REQUEST

The Euthanasia Law requires that the euthanasia request is "voluntary, well-considered and repeated, and not the result of external pressure".

1.2.1. Voluntary euthanasia request

Voluntariness implies that the patient's euthanasia request is not the result of mistaken beliefs or of coercion or undue influence. The exclusion of external pressure from the patient's social environment can be addressed by means of hetero anamnesis and observation of the patient's interaction with family and friends. However, some of the guidelines (II, IV,V) also recommend excluding irrational *internal* pressure originating from the patient's psychopathology in terms of a perceived sense of guilt or feeling of being a burden to others. In this regard, one of the guidelines (IV) indicates that the perception of being a burden can be grounded in the patient's awareness that this burden is a real and logical consequence of one's psychopathology. For instance, in cases of chronic behavioural disorders, the burden on families can be manifold: from emotionally

copied with a patient's distressing behaviour, over disruption of household routine, to restriction of social activities. It is argued that this type of rational internal pressure need not be a reason to reject the patient's euthanasia request in advance (IV).

1.2.2. Well-considered euthanasia request

This criterion, which is closely related to the issue of mental competence, is concretised as follows in the guidelines that elaborate on it (II,IV,V). The patient should express a clear and well-considered death wish, taking into account aspects of the patient's life that make it worth living, and based on sufficient self-knowledge and capacity to cognitively process all information on (the consequences of) the condition and the available treatment options. The legal condition of a well-considered euthanasia request presupposes that the patient has been well-informed by the physician concerning: 1) her (psycho)pathology; 2) possible ways to alleviate her suffering; 3) side effects of the available treatment options; and 4) the prognosis (with and without treatment).

In the context of euthanasia, physicians need to be alert to the patient's cognitive and emotional information processing and should inform the patient on: 1) the physician's own stance on euthanasia in general and the patient's euthanasia request in particular; and 2) available alternatives to euthanasia, including palliative care. When a physician decides to become involved in a patient's euthanasia procedure, clear information should also be given on the euthanasia procedure itself, including on the need for multiple consultations and the involvement of other physicians and, where relevant, important others.

One guideline (IV) also addresses the difficulties in case of a psychiatric patient's reduced awareness of illness. According to guideline V, that is precisely the reason why physicians need to act with the greatest caution. For a euthanasia request to be legally justifiable, the patient must be aware of the symptoms and the consequences of her disorder by way of her realising how it affects her behaviour and life situation. The following example has been given in guideline IV: "In case of depressive disorders, a patient can present and argue her euthanasia request from a pessimistic, nihilistic view of herself, her past, and

future life, while more objective facts that shed a more realistic light on her past, present, and future do not enter the assessment process. The patient's opinions are then distorted, while not realising the consequences of her mental state."^{203(p23)} In these clearly symptom-induced periods of psychopathology, the patient should not be considered eligible for euthanasia.

The guideline further defines a sufficient degree of self-knowledge and of awareness of illness as follows: "the patient's knowledge of her own personal qualities that have an essential influence on her quality of life, implying the realisation of how certain character traits influence her perception of her interaction with others".^{203(p23)} However, and especially in case of personality disorders, some guidelines (II and IV) acknowledge that the patient-physician-interaction can be strongly influenced by pathological personality characteristics of which the patient may be unaware. These characteristics do sometimes not only affect the patient's suffering, but also the tendency to undermine treatment compliance and other life support, which is challenging in the context of a euthanasia request from a medical and ethical perspective. According to these guidelines, both the patient and the psychiatrist must endeavour to achieve a degree of insight that is as substantial as reasonably can be expected on the basis of the patient's psychosocial and intellectual background. It is acknowledged that an optimal awareness of illness and an optimal self-knowledge may be essential for the success of a medical treatment or rehabilitation plan. Hence, an insufficient degree of self-knowledge and awareness of illness is, in their opinion, a reason to prolong the euthanasia procedure in order to provide sufficient time for patient information and psycho-education.

1.2.3. Repeated and durable euthanasia request

It should be the case that the patient repeatedly expresses a death wish towards the physicians involved. According to the guidelines, it is preferable that the patient has also expressed her death wish towards her close inner circle of family or friends (II-V). The patient's request must be spread out over a period of several months, in order to exclude a 'flash of the moment'-decision and to allow sufficient time to assess the origin and evolution of the death wish (I-V). In

addition, the patient's request should be durable. In case the abovementioned expressed ambivalence between the patient's fear of death would over time diminish or even disappear and if, as a result, the death wish would become more pronounced, this would be a sign that the patient had made up her mind (IV).

1.3. CHARACTERISTICS OF THE PATIENT'S CONDITION

According to the Euthanasia Law, euthanasia is only allowed if the patient who requests euthanasia is suffering from a serious and incurable condition, caused by illness or accident.

1.3.1. Serious character of the condition: the presence of a diagnosable condition

For a euthanasia request to be eligible, it needs to be based on a medical somatic and/or psychiatric disorder. Two of the guidelines (II,IV) introduce a further distinction between a euthanasia procedure involving a patient suffering from a psychiatric disorder and a procedure involving a patient suffering from a neuropsychiatric (e.g. dementia) disorder, declaring that the latter procedure requires a slightly different approach from the one discussed in their recommendations concerning the assessment of euthanasia requests from psychiatric patients. Regardless of the specific type of condition, the condition does not only need to be serious and incurable, but also medically diagnosable. Psychiatric disorders, even in the absence of somatic co-diagnoses, are recognised as diagnosable medical conditions.

1.3.2. Incurable nature of the condition

The evaluation of the legal requirement of incurability is left to the expert opinion of the physician involved as it should be based on the current state of the art of medicine. Different terminologies are used in practice to address this legal criterion. Some psychiatrists use the concept 'medical futility' in order to refer to treatment resistance, or to ineffective or inappropriate treatment. Some

guidelines (III, V) refer to persisting intense debates in the literature regarding the question as to whether, and if so when, a psychiatric condition can be considered incurable as these types of conditions frequently change over time.^{145,148,153,158,204,205}

In some of the guidelines, to address this problem, the concept of 'no reasonable treatment perspective' was introduced, which had earlier been proposed and explained in the former guideline of the Dutch Psychiatric Association.¹⁹⁹ According to the former (and recently revised) guideline as well as some of the Belgian guidelines (II-V) discussed in this paper, therapeutic options for a particular condition should be considered if they meet the following three requirements: 1) a real prospect of improvement; 2) the possibility to administer adequate treatment within a reasonable period of time; and 3) a reasonable balance between the expected treatment results and the burden of treatment for the patient.

In an attempt to operationalise these three requirements, the following criteria have been formulated (IV). First, it is advised to fully apply the current psychiatric State of the Art Treatment protocol in terms of; 1) all indicated regular biological interventions; 2) all indicated psychotherapeutic interventions; and 3) social interventions that could alleviate the patient's suffering. These interventions should be offered by qualified caregivers. Second, to assess what would count as a reasonable time period for these interventions, the following criteria should be taken into account: 1) the patient's medical history; 2) the duration of suggested pharmacological and psychotherapeutic treatments; and 3) the patient's age. Third, the benefits and disadvantages of interventions should be based on: 1) the plausibility, expected nature, and expected extent of improvement; 2) the plausibility, nature, and seriousness of side effects; and 3) the patient's coping capacity.

In some cases of euthanasia for psychological suffering, a recently discovered (and thus previously missed) psychiatric diagnosis was invoked as an additional reason to consider the patient to be in a medical condition without prospect of improvement. One guideline (IV) strongly disagrees with such a view and recommends that new diagnoses should be seen as a reason to explore the possibility of improvement.

The guidelines differ in their recommendations for cases when patients refuse reasonable treatment options. One guideline (III) indicates that no consensus was found on this issue, while other guidelines (II, IV) recommend that the euthanasia *must not* be carried out in such a case.

1.4. CHARACTERISTICS OF THE PATIENT'S SUFFERING

According to the Euthanasia Law, euthanasia is only allowed if the patient is in a condition of constant and unbearable physical or psychological suffering that cannot be alleviated. The guidelines formulate more objectifiable criteria in order to evaluate the various requirements for the patient's suffering: the suffering should be assessed in multiple consultations with the patient that are spread out over time, and the assessment should, more specifically, be made by means of thorough patient observation and examination of the patient's medical history and life context. With the consent of the patient, physicians can obtain access to the patient's medical record. Without this consent and thus without access to the patient's medical files, a euthanasia request cannot be legally admissible, as the law provides that all physicians involved need to have access to the medical record. An interdisciplinary evaluation of the patient's suffering is strongly recommended by all the guidelines.

1.4.1. Physical or psychological suffering

According to the Law, a patient's euthanasia request needs to be based on physical and/or psychological suffering that results from a serious and incurable condition. The consequences of the patient's condition will typically not be restricted to physical and/or psychological suffering alone, as they can also include social and existential aspects. The latter aspects cannot be fully evaluated from a medical perspective. Recent qualitative research has revealed that some socio-economic (e.g. social inequalities) and even financial issues (e.g. low income) are additional circumstances that can make patients consider requesting euthanasia.²⁰⁶ This observation necessitates a broad societal debate, as euthanasia should never be used as a way to resolve society's failings.²⁰⁶ In this respect, it should be noted that physicians may play an important role in reducing patients' social suffering by strengthening their social environment, for

instance by encouraging an open dialogue between the patient and her family and social network.^{207,208}

According to the Law, the euthanasia request should be based on physical and/or psychological suffering that is directly caused by the patient's medical condition. The biennial reports from the Federal Control and Evaluation Commission for Euthanasia (FCECE) indicate that most cases of euthanasia that are reported involve a combination of physical and psychological suffering, as, for example, cancer patients might suffer from a perceived loss of dignity, whereas patients with anorexia nervosa can suffer from physical problems.

Diverging views exist on the precise meaning of the requirement of causality in the Euthanasia Law (III).²⁰⁹ Taking into account the subjective nature of suffering, some experts are in favour of not strictly medicalising this criterion, out of fear that psychiatric patients, in whom tissue damage is not always apparent, might then be excluded from receiving euthanasia, whereas others argue that completely disconnecting the suffering and the medical condition (i.e. disregarding the causality requirement) would pave the way for physicians to grant euthanasia requests that have no medical basis and are therefore beyond their professional expertise. A key question in this regard is which physician should evaluate the causal relationship between the patient's medical condition and her suffering (III). If this prominent role is entrusted to the attending physician alone and not also to the two legally required consulted physicians, it can be problematic if the former is not a psychiatrist. This is one of the reasons why several of the guidelines (I,III-V) recommend that two of the consulted physicians should be psychiatrists – instead of one, as prescribed by the Euthanasia Law – and that in their assessment of the fulfilment of the due care criteria these psychiatrists need to pay specific attention to evaluating the causal relationship between the patient's medical condition and her suffering. Obviously, establishing this causal relationship is a complex task, even for experienced psychiatrists.

1.4.2. Constant suffering

The constant nature of the suffering can be operationalised when taking into account the origin, evolution, and continuity of the suffering. For psychiatric

disorders, even those with an episodic character, symptoms can be chronically and severely persistent, progressive, and/or continuously alternating.

1.4.3. Unbearable suffering

The unbearability of suffering cannot easily be operationalised, as it is inherently a subjective criterion and objective parameters are lacking. Due to their predominantly non observable complaints and frequent lack of neurobiological markers in patients with psychiatric disorders, their suffering experiences are way more difficult to assess. There is no consensus on how and by whom (the patient and/or the attending physician and/or others) the unbearable nature of the suffering should be assessed (III). Some claim that this assessment should be totally left to the patient. Others suggest that unbearability always needs to include a medical component and that the requirement to ascertain unbearability is closely related to the physician's task to detect, suggest, and apply potential therapeutic solutions to alleviate the patient's suffering. Despite these differences of opinion, a consensus can be observed in the guidelines in the emphasis on the physician's empathic understanding of the patient's perception and judgment of the unbearability of her suffering, in the light of the patient's current and past life context, the disabling consequences of her condition, her physical and mental strength, her coping capacity, and her personality (II-V).

1.4.4. Non-alleviability of the suffering

This criterion clearly encompasses a medical component and is closely related to the criterion that a prospect of improvement should be absent. It is left to the expert opinion of the physician(s) involved to judge whether there are therapeutic options left to alleviate the patients' suffering and to discuss these options with the patient. The Federal Control and Evaluation Commission for Euthanasia has repeatedly reported dissensus between its members regarding the question how to understand and evaluate the requirement of non-alleviability of unbearable (psychological) suffering.^{194(p31),210(p23)} Guideline III questions the Commission's assumption that the final judgment on the non-alleviability of the suffering should be left to the patient herself, when the Commission states that euthanasia can be performed if the patient's refusal of further treatment options

is based on 'severe treatment-related side effects or treatment applications *perceived* as unbearable'. According to this guideline, side effects can only emerge *after* a treatment option is applied. The Commission's view could then, for instance, pave the way for a severely depressed patient to refuse the state-of-the-art intervention of electroconvulsive therapy (ECT) on the ground of perceptions of it being unbearable. By contrast, guideline III explicitly prefers the approach as prescribed in the former (and adopted in the recently revised) Guideline of the Dutch Psychiatric Association, stating that it is part of the clinical and ethical duty of the psychiatric profession to follow all the state-of-the-art medical procedures before a request for euthanasia can be regarded as legally eligible.

2. The *a priori* procedure for decision-making regarding euthanasia

2.1. A TWO-TRACK APPROACH

As regards the decision-making process that precedes the granting or refusal of euthanasia requests, some of the guidelines clearly go beyond the legal requirements with their explicit recommendation of a two-track approach. This approach is characterized by focusing on *life* by way of continuing treatment of the patient, in parallel with a focus on *death* by way of assessing the patient's euthanasia request.

This view is based on two fundamental, although not absolute, ethical values: respect for the autonomy of the patient by respecting and taking seriously a patient's death wish, and the duty to protect human life by first exploring meaningful life perspectives for a patient who has expressed a death wish (II,IV,V). The rationale behind this two-track approach is that it should not be ruled out that the euthanasia request is a cry for help and the result of suffering that might be adequately addressed by other means. For that reason, whereas on the death track the reasons for, and the eligibility of, a patient's euthanasia request will be explored, a life track will be pursued simultaneously, in which the

alternatives to death will be explored from a medical and psychological as well as from a social and existential perspective.

First, the patient's current treatment must be evaluated, intensified, and/or otherwise adjusted, even if this means changing caregivers. Second, the potential of psychiatric rehabilitation options must be addressed in order to enhance the patient's autonomy, social participation (e.g., via social support groups or peer support groups) and, consequently, quality of life. In addition, attention should be paid to opportunities for so-called 'crustative care': a specialised, tailor-made 'palliative' psychiatric care for those patients for whom there are no therapeutic options left in terms of alleviation of suffering, although their quality of life, perception of dignity, and connectedness with others could still be restored and enhanced. According to several guidelines (II, IV,V), connectedness with others is a crucial condition for the exercise of autonomy as patients can only make well-considered choices when they are closely connected with important others. Third, guidance needs to be offered in the search for potential sources, goals, and projects to regain meaning in life.

The physicians involved in the euthanasia procedure can focus on, or be involved in, both tracks to a different extent (IV). The main idea is that each physician may combine these two tracks or may decide to just focus on one track, but that both tracks should always be simultaneously explored. Interestingly, one guideline (I) emphasises that, as a quintessential premise of their protocol, their hospital's psychiatrists can only be involved in the assessment of a patient's euthanasia request while the patient's own physician remains responsible for the treatment of the patient's psychopathology. As for the other physicians involved, the consulted physicians normally will focus only on the death track.

It should also be pointed out that there is an overlap between the life track and the death track and between their underlying values (i.e. respect for the autonomy of the patient vs. duty to protecting life), as the death track might protect patients by preventing brutal suicide attempts, whereas the life track might exceptionally lead to additional suffering and even suicide attempts. Contrary to what has occasionally been reported in practice, a patient's request for euthanasia should not be a sufficient reason for withholding treatment or

hospitalisation in a psychiatric ward.

2.2. NUMBER AND ROLE OF PHYSICIANS INVOLVED

If the patient is not expected to die within the foreseeable future, the Law requires that the euthanasia request be assessed by at least three physicians: the attending physician and two consulted physicians. At least one of these consulted physicians needs to be a psychiatrist or a specialist in the patient's medical condition. To each of the physicians involved, specific and limited roles are allocated by the Euthanasia Law. The physician(s) should be independent from the patient and from each other.

It is advised by guideline IV that the attending physician is the first to be consulted by the patient. In that specific role, the attending physician should take the lead in the euthanasia procedure and refer the patient to the physicians who will be acting as consulted physicians. According to this guideline, this sequence is not always applied in practice, as sometimes physicians are already consulted during the euthanasia procedure before one of them refers the patient to a physician who would be willing to perform the euthanasia and therefore takes on the role of attending physician at the end of the euthanasia procedure.

The latter illogical sequence is deemed ethically inappropriate in guideline IV, as it might cause the patient to be confused over the exact role of the physicians involved. Some guidelines (II, IV) recommend that both the attending and the consulted physicians have several conversations with the patient. This goes beyond the Law's requirements that, whereas the attending physician should have several conversations with the patient, the consulted physicians merely need to examine the patient and to review her medical record.

2.2.1 Specific role of the attending physician

The attending physician who approves a euthanasia request is not obliged to perform euthanasia herself. In the context of building a relationship of trust between the patient and the physician, the latter needs to conceive of herself as

being able and willing to perform euthanasia if and when all legal requirements are fulfilled. The patient's treating physician may also be the patient's attending physician as long as the two-track approach and referrals to independent consulted physicians are guaranteed (IV).

2.2.2 Specific role of the consulted physicians

Due to the complexity of euthanasia requests for psychological suffering, it is suggested (IV, V) or prescribed (I) that two, instead of one, of the consulted physicians should be psychiatrists and that they should assess all substantive due care criteria, instead of only the criteria that the Law requires them to assess (IV, V). In addition, it is proposed (II, IV, V) or made mandatory (I) to also involve the patient's treating physician in the procedure, although never as one of the consulted physicians, in view of the risk of a biased assessment.

The Euthanasia Law requires the consulted physicians to be independent but does not specify how this is to be understood. However, in its information brochure for physicians, the Federal Control and Evaluation Commission for Euthanasia states that the consulted physicians must not have a therapeutic relationship with the patient nor be a relative or a hierarchical subordinate or superior to the attending physician.⁷² Moreover, in the legal literature the view is advocated that the consulted physician should not be a member of the attending physician's doctor's office or hospital department, although the condition of independence does not require that consulted physicians should come from outside the hospital where the attending physician is treating the patient.^{211,212}

One guideline (I) has formulated specific rules on how to handle euthanasia requests from patients who are referred from outside the hospital's walls. The protocol stipulates that the attending psychiatrist should only manage the patient's euthanasia request (i.e., should not take over her treatment) and should have as many consultations with the patient as needed to decide whether the legal requirements are met. The results of the consultation and evaluation must be communicated to the patient's treating psychiatrist. When the attending physician has ascertained that the legal requirements have been fulfilled, the patient must be referred to a second psychiatrist (i.e., the first consulted

psychiatrist) within the hospital's department of psychiatry and, after that person has provided a positive opinion, also to an independent third psychiatrist (i.e., the second consulted psychiatrist) belonging to a department of psychiatry of another Flemish university hospital. The second and third psychiatrist should review the patient's medical file and have at least one consultation with the patient to independently determine whether all legal requirements are met. To ensure independent decision-making, the second consulted psychiatrist from outside the hospital is appointed by the multidisciplinary Hospital Ethics Committee. Only when the three psychiatrists involved have independently verified that all legal requirements are met, can euthanasia be performed.

According to guideline IV, all legal requirements should be assessed by each of the physicians involved, albeit not necessarily to the same extent. This guideline states that the first consulted psychiatrist, like the attending physician, needs to address the underlying reasons for the euthanasia request. This could lead to a strong relationship of trust that may include the risk of transference (i.e. the euthanasia request and procedure may provoke feelings in the patients) and countertransference (i.e. the patient's euthanasia request may provoke feelings in the physician), that may decrease the objectivity and independent judgment. Hence, the role of the second consulted psychiatrist should be strictly limited to evaluating the legal due care criteria, with specific attention to the non-alleviability of the suffering. This should reduce the risk of bias due to (counter)transference.

2.3. INVOLVEMENT OF RELATIVES OR IMPORTANT OTHERS

The Euthanasia Law does not require the attending physician to involve the patient's relatives in the euthanasia procedure. However, the attending physician is required to ascertain that the patient has had the opportunity to discuss the euthanasia request with the persons whom she wants to talk to. Some guidelines consider this a quintessential criterion (II, IV, V). One guideline is stricter than the legal requirement in that at least one other person in the patient's social circle has to be involved, even if the patient specifically refuses and asks that no relatives be involved (IV). The involvement of family members and/or important others does not mean that these persons need to approve the euthanasia

request. However, an interpretative dialogue with the patient's family members and/or important others gives all actors a deeper insight into the patient's social context and background, and it might reveal opportunities to strengthen meaningful relationships, communication, and commitment. This might influence the patient's perspectives on her suffering and her death wish. If the patient would eventually receive euthanasia, having been involved might limit the psychological impact, grief, and bereavement of the relatives. If the patient rejects their involvement, the physician should look for the underlying motives and try to clarify them. Some guidelines point out that if the patient's resistance is unwarranted, the consultation procedure might be halted (II, IV, V).

2.4. INVOLVEMENT OF OTHER CAREGIVERS

The Euthanasia Law stipulates that, if there is a nursing team that has regular contact with the patient, the attending physician needs to discuss the patient's euthanasia request with the nursing team or with members of that team. However, some guidelines also urge the involvement of all other important caregivers involved in the patient's treatment (II, IV, V). Besides the nursing team, guidelines II, IV and V recommend the inclusion of other current or even former caregivers in an interdisciplinary team in order to further explore and compare the patient's background and current life context with a view to detecting any unnoticed meanings of the patient's euthanasia request. As contacting relevant caregivers is deemed quintessential by these guidelines, the attending and consulted physicians might even need to refrain from the assessment procedure if the patient does not give permission to contact any of her caregivers.

Guideline II strongly advises not only the involvement of an interdisciplinary team but also the provision of extensive additional support. Going beyond the legal requirements, this additional support is recommended to involve: 1) a central, interdisciplinary End-of-Life Support Group (covering all the psychiatric centres of this network and open to external experts), established in order to gain objective and independent advice; 2) a local End-of-Life Support Group (covering one or more psychiatric centres in a specific region), established in order to gain objective, independent advice or practical support; and, optionally

and especially in cases where the consultation procedure is in an advanced stage, 3) trained physicians of the Life End Information Forum (LEIF)⁹⁰ for support and advice regarding the performance of euthanasia.

2.5. OTHER PROCEDURAL DECISION-MAKING ASPECTS

2.5.1. Decision-making procedures

The Euthanasia Law requires that, if the attending physician believes that the patient is not expected to die within the foreseeable future, a waiting period of at least one month should be respected between the patient's written request and the performance of euthanasia. In addition, as indicated above, the attending physician will need to consult two physicians instead of one. The advices issued by the consulted physicians are merely advisory.^{59,68,212}

The guidelines, however, plead for more stringent decision-making procedures. One guideline (IV) advocates detailed written reports of the physician's face-to-face discussions, accessible to all physicians and caregivers involved, so as to enable an open, transparent round-table discussion, preferably even before formal advices are obtained, in order to achieve a broader evaluation horizon and enhance the level of due care.

A built-in safeguard is provided in guideline I in terms of an additional meeting with the Hospital Ethics Committee in order to *a priori* discuss and determine whether or not a euthanasia request can be declared admissible for further management and evaluation. Guideline II takes a more restrictive stance and establishes an *a priori* and interdisciplinary evaluation committee consisting of the following 3 groups: 1) staff members from the facility in question: the attending physician, the chief physician of the department, and two other staff members of whom at least one is a non-physician; 2) at least two staff members of the network, with expertise in euthanasia in the context of psychiatry, though not employed in the facility in question; and 3) at least two members from outside its walls and hence not employed in the facility, but with expertise in the euthanasia topic. The chief physician coordinates the evaluation committee. If

consensus has been reached, an appropriate timing and place of death will be planned. In case of disagreement, the evaluation committee will advise the attending physician against performing euthanasia. Nonetheless, this cannot be enforced due to the physician's therapeutic freedom to act in conformity with her own moral and professional values.

In guideline III, some recommend the establishment of an authoritative *a priori* evaluation by an *ad hoc* committee. This committee would be complementary to the existing Federal Control and Evaluation Commission on Euthanasia's *a posteriori* review. Specifically in the context of euthanasia cases for psychological suffering, this type of *a priori* evaluation is recommended in view of the complexity of decision-making related to the patient's disorder (e.g., unpredictable prognosis of a non-terminal illness), the multifactorial reasons underlying the patient's death wish and the irreversibility of euthanasia. However, others involved in the drafting of this guideline oppose this proposal, arguing that an *a priori* review is against the 'spirit of the Law' and would lead to euthanasia procedures resembling 'tribunal hearings'.

As for the number of consultations and the duration of the euthanasia procedure, the guidelines recommend that the consultations be spread over a longer period than the legally required one-month waiting period. Some guidelines do not specify the required duration (I, IV), whereas others advocate a waiting period spanning at least 6 months (II) or 1 year (V) taking into account the involvement of all important actors. In guideline III, some Committee members are in favour of maintaining the minimum of one month to avoid suicide attempts 'out of despair', also in respect of many patients' long medical history. They also fear the phenomenon of patients 'shopping' for more permissive psychiatrists if the attending physician is inclined to take his or her time. Other members prefer a waiting period of at least one year (as the psychiatric state-of-the-art protocol includes one year to give therapeutic alternatives a fair chance of success and because the euthanasia procedure creates a new patient-physician dynamic that needs to be fully explored). As observed in practice, the euthanasia procedure might offer sufficient peace of mind, which could be a signal to explore opportunities for extended aid, rehabilitation, etc.¹²⁶ Most of the guidelines (I, IV, V) are more restrictive than the Law as they argue that performing euthanasia is only justifiable after obtaining at least two uniformly positive advices from at

least two consulted psychiatrists. In case of negative advices, these should also be taken into account. However, none of these guidelines describes to what extent possible negative advices should affect the euthanasia procedure and/or the final decision.

2.5.2. (After)care for the relatives and friends

As mentioned above, the involvement of the patient's relatives and important others is quintessential according to several of the guidelines (II, IV, V). During the assessment of the euthanasia request, these actors need to be informed regarding: 1) the euthanasia procedure; 2) the patient's life perspectives; and 3) the physician's final decision regarding granting or refusing the euthanasia request. This can take place in close collaboration with the treating physician.

If the patient's relatives and important others are already involved in the euthanasia procedure, the attending physician should inform and invite them for information on the final outcome of the euthanasia procedure. In addition, the involvement of the treating physician (responsible for the life-track), other caregivers, or a religious official who has a close connection to the patient's relatives and important others, can be sought. After the euthanasia has been performed, appropriate aftercare is important to deal with the grief and to soften the mourning. However, this aspect receives little attention in the guidelines.

2.5.3. Conscientious objection and other value-related factors

In order to balance the respect for the autonomy of the patient who requests euthanasia and the physicians' freedom of conscience and professional autonomy, the Euthanasia Law stipulates that no physician may be forced to perform euthanasia and that, similarly, no other person may be obliged to assist in performing euthanasia. This provision is grounded in the right to conscientious objection, a general principle which is itself founded on the freedom of thought, conscience, and religion.

Some of the guidelines (II, IV, V) emphasise the need for physicians to explore their own values and emotions towards euthanasia in general and their role in the decision-making process and outcomes. However, the right to conscientious objection should not be seen as a mechanism to pave the way for 'absolute value-driven medicine', as other ethical principles, such as respect for patient autonomy and compassion with suffering, should also be held in the highest regard. On the other hand, concerns are expressed regarding some physicians' exclusive focus on the patient's self-determination, which might render them blind to relational and social aspects that may underlie the euthanasia request and to mechanisms such as projection, transference, and countertransference.

As stated in the Law and in an attempt to reconcile respect for patient autonomy and the physician's right to conscientious objection, an attending physician who refuses to perform euthanasia must inform the patient clearly and in a timely fashion on (the reasons for) this refusal in order not to create false expectations. If the refusal is based on medical considerations, these should be noted in the patient's medical record. Furthermore, a physician who refuses to perform euthanasia must share the patient's medical record with another physician designated by the patient, if the patient so requests.

When confronted with conscientious objection within the context of performance of euthanasia, the guidelines agree with the advice of the Belgian Order of Physicians ²¹³ that the patient – after being adequately and timely informed – should be referred to a medical institution concerning the further assessment of the euthanasia request. However, the physician does not need to ensure this medical institution's stance and conceivability towards euthanasia performance. Hence, in case of a physician's conscientious objection, the patient requesting euthanasia should thus be referred to a colleague physician inside or outside the physician's affiliated health care facility.

Considering that exploring the underlying reasons for a euthanasia request might open the door for transference and countertransference, decision making may be seriously affected by such occurrences. Physicians themselves may be confronted with their own mortality or loneliness, but also with feelings of helplessness resulting from the inability to sufficiently alleviate suffering, irrational rescue phantasies, or even complete intolerance towards the patient. Intervention, supervision or even referral to another, more neutral physician might be needed.

One guideline (I) mentions some procedural guidelines to proactively protect the integrity and the well-being of the physicians involved.

3. Medically careful performance of euthanasia

According to the Belgian Law on Euthanasia, the act of euthanasia can only be performed by the attending physician administering a lethal dose of a suitable drug to the patient. If none of patient's treating physicians conceives of performing euthanasia herself, the attending physician can appeal to the competence and expertise of Life End Information Forum (LEIF)-physicians and/or -nurses to support or even assist the performing physician if and when needed. One guideline (II) refers to the particularly challenging situation of euthanasia in an institutional context as this could act as a potential pull factor for other patients. The utmost caution needs to be exercised to prevent potentially traumatic effects on other patients. Therefore, it is necessary that the caregivers involved look for a course of action that maximally prevents and limits a traumatic impact on fellow patients, both in the processes of the preparation and performance of euthanasia and at the stage of aftercare. Another guideline (I) stipulates that euthanasia must not be performed in the psychiatric ward, but in a single-bed room on a somatic ward, in the presence of the patient's treating and attending psychiatrist, and with an anaesthesiologist on stand-by. The required lethal dose must be prescribed by the staff member of the psychiatry department. Guideline IV refers to the LEIF-brochure in which is stated that the performing physician should not be identified at the end of the euthanasia procedure, in order to create a trust-based relationship with the patient and to ensure that all legal requirements are met. This guideline also refers to the LEIF-brochure for a correct clinical performance of euthanasia.

4. *A posteriori* control : Reporting to the Federal Control and Evaluation Commission for Euthanasia

In accordance with the Law, the Federal Control and Evaluation Commission for Euthanasia is composed of 16 members, appointed on the basis of their knowledge of, and experience with, issues surrounding euthanasia. Eight of its members are physicians, of whom at least four are Professors at a Belgian university. In addition, four of its members are Professors of Law at a Belgian university or practising lawyers, and the remaining four members are persons who deal with incurably ill patients on a regular or day-to-day basis. One guideline (V) recommends that at least one Commission member needs to be a psychiatrist.

The Law stipulates that the attending physician must submit a report within four days after the euthanasia has been performed. This report consists of an anonymous part and a part with the identifying data of the persons involved. The anonymous part includes information on: 1) the nature of the condition from which the patient suffered; 2) the nature of the patient's suffering; 3) the reasons why this suffering could not be alleviated; 4) the elements that assured the physician of the voluntary, well-considered, and repeated nature of the patient's euthanasia request; 5) whether the patient was expected to die within the foreseeable future; and 6) the capacity of all persons consulted and, with regard to the advising physician(s), their qualifications and findings.

If there is doubt as to whether the legal criteria were met, the Commission can by a majority decision decide to open the part which contains the names and addresses of the patient, the attending physician, the consulted physicians, and the other consulted persons. This allows the Commission to request the attending physician to provide any information from the medical record that relates to the euthanasia. If upon this examination the Commission decides with a two-thirds majority that the legal criteria have not been met, it is required to refer the case to the Public Prosecutor.

According to one guideline (I), the patient's death certificate and the other documents that should be submitted to the Commission for *a posteriori* review should be filled out by the attending psychiatrist and not by any of the other physicians or healthcare professionals involved. In addition to the document drafted by the Commission that has to be submitted to it as an official report for each of the cases of euthanasia performed, the Flemish Association of Psychiatrists has developed an additional reporting form that could offer

guidance for decision-making and final reporting concerning the euthanasia procedure. This document, attached as an appendix to guideline IV, contains questions to be answered regarding the integration of the information collected from the consulted physicians and other persons, the assessment of all legal due care criteria, and the outcome of the patient's euthanasia procedure. The document can help physicians to obtain from colleague-physicians essential information concerning the patient and her euthanasia wish. It could also help the attending physician to fill in the report that needs to be sent to the Federal Control and Evaluation Commission for Euthanasia within four days after the euthanasia performance.

Guideline III recommends following the Dutch model, where it is not left to the attending physician to indicate the nature and the content of the advices obtained from the consulted physicians, but the latter are themselves required to submit a report to the Commission. This recommendation was prompted by evidence that in Belgium euthanasia cases are sometimes performed in complete disregard of two negative advices of the consulted physicians or in the absence of sufficient advices.^{174,214} Moreover, this guideline calls upon the FCECE to follow the Dutch example and thus to increase transparency by means of: 1) reporting on its website anonymised data regarding 10 percent of the reported cases of euthanasia (in proportion to the types of disorder); and 2) including already in the first part of the report the identifying data of the physicians involved, which would allow the members of the FCECE to have this information without first having to agree on the opening of the second part of the report.

For an overview of the operationalisations of the substantive and procedural legal criteria, and of the additions to the procedural legal criteria recommended by the guidelines, see Table 1 (at the end of this Chapter).

5. Discussion

In the 16 years since the adoption of the Belgian Euthanasia Law, the number of cases of euthanasia for psychological suffering involving psychiatric patients has significantly increased, as has the number of healthcare organisations (e.g.

hospitals and nursing homes) that have developed and implemented written clinical-ethical policies on the management of such requests.^{86,215-217}

One guideline (I) that we have analysed is an example of such a protocol, in that it is describing a transparent procedure to be followed for requests of euthanasia for psychological suffering. The other guidelines discussed in this paper are published by organisations at the intermediate level between specific, local mental health institutions such as hospitals and nursing homes, and overarching bodies such as the National Order of Belgian Physicians. They contain detailed practical advice for interpreting and assessing the requirements of the Euthanasia Law, and for dealing with various challenges in euthanasia practice (see Table 1, at the end of this Chapter).

In many respects the guidelines are more stringent than the Law, for instance by stipulating that at least two positive advices should be obtained from at least two psychiatrists, by requiring physicians to follow a two-track approach, and by proposing a more stringent *a priori* evaluation system. Although these guidelines contain recommendations that resemble the ones put forward in the former Guideline of the Dutch Psychiatric Association, there are minor differences, for instance regarding the eligibility of a euthanasia request if a psychiatric patient rejects reasonable treatment options, or regarding the involvement of important others.

Some guidelines put more emphasis on the practical aspects of the clinical assessment (I, II and IV), while others focus more on a broad ethical reflection (III and V). Some of the differences between the guidelines reflect different ethical stances towards euthanasia, while others reflect differences in views regarding the practical implementation of the legal due care criteria, e.g. the involvement of a Hospital Ethics Committee (I) versus the establishment of local and central support groups (II) for preliminary reflection, and different stances on whether or not (III), and if so to what extent, the waiting period from the euthanasia request to the performance should be extended (II,IV,V).

Notwithstanding the major added value of these guidelines, some shortcomings remain, as listed in Box 2 (at the end of this Chapter). Although all the guidelines stress the importance of a decision-making policy that includes many actors (e.g., the patient's relatives and other care providers) and although they

emphasise the importance of good aftercare for the bereaved, not much attention has been paid to the aftercare of patients whose euthanasia request is rejected. One guideline (I) refers the patient back to his or her treating physician. By contrast, the other guidelines only mention the (not legally required!) referral procedure in case of conscientious objection by the physician. This is remarkable, as evidence from the Netherlands shows that requests for euthanasia from psychiatric patients (as well as from patients suffering from severe dementia and patients being tired of living) are much less likely to be granted as compared to requests for euthanasia from patients suffering from physical disorders, and that only a minority of physicians are willing to perform euthanasia for psychological suffering (although the number is increasing over time).^{88,218} Well-founded responses are thus needed concerning the aftercare for patients whose euthanasia request is not granted. Recent qualitative research shows that a death wish might diminish, but rarely disappears, in patients whose euthanasia request has been refused, yet very few treating physicians further discuss or evaluate the patient's death ideation or situation after the refusal.²¹⁹ Moreover, none of the guidelines explicitly addresses how, and to what extent, treating and/or attending physicians should handle negative or conflicting advices, or suicidal threats by the patient in case of refusal.

Furthermore, in the context of conscientious objections attention should be paid to avoiding a potential 'revolving door' scenario in which a treating physician who is opposed to euthanasia would refer the patient to potential attending or consulted physicians, assuming that they will refuse or advise negatively. This scenario might increase feelings of despair and suicidal ideation in the patient and may prompt patients to shop around for physicians who are willing to get involved in the euthanasia procedure.

Another aspect that could contribute to the risk of the revolving door and of shopping around by patients, is that different guidelines (some more restrictive than others) may put at risk the uniformity of the physician's own approach regarding practice of euthanasia for psychological suffering involving psychiatric patients and of the patients' right of equality in mental health care and that they might also lead to patients directly contacting the end-of-life centres (which take

a more permissive approach) at their own initiative, without discussing it first with their treating physician.

Despite the guidelines' commendable efforts that may enhance clinical euthanasia practice, a significant knowledge gap remains about how thoroughly and uniformly euthanasia requests are handled in Belgium. Moreover, it is unclear how these guidelines are affecting euthanasia practice, and more specifically euthanasia for psychological suffering. Unfortunately, empirical research regarding euthanasia practice remains scarce and is complicated by the lack of an obligation to register (i.e. only the registration of performed euthanasia requests is legally required).¹¹⁷ Moreover, except from one study on 100 psychiatric patients in one mental healthcare practice¹²⁶, very little is known about the number of euthanasia requests being granted, refused, denied, ongoing or withdrawn.⁹¹

This lack of transparency is surprising, especially taking into account the heated debate. Although cases of euthanasia for psychological suffering are still rare, the number is increasing. In Belgium, as one of the pioneering countries on euthanasia, the clinical and scientific scrutiny must be rigorous in order to improve transparency and to ensure the quality of euthanasia practice.

Therefore, the guidelines discussed in this paper should be welcomed given their strong commitment to mitigate against potential abuses.

It is noteworthy that most of these guidelines were only published approximately 15 years after the adoption of the Euthanasia Law. This might be due to increased speculations regarding a slippery slope concerning euthanasia based on psychological suffering, potentially related to the increase of these euthanasia cases since 2008. This increase in turn might be related to the increasing number of hospital-based ethics policies and to the foundation of several end-of-life consultation centres since 2011, after which the number of performed euthanasia cases for psychological suffering quadrupled.

Moreover, the euthanasia case that has been referred to the Belgian public prosecutor in 2015, as well as strong disagreement between some of the end-of-life consultation centres regarding different approaches in the management of euthanasia requests⁹², have contributed to the need for more ethical reflection

and transparency on the clinical practice regarding euthanasia based on psychological suffering.²²⁰

In these respects, the guidelines can be considered as potentially important instruments to prevent potential abuses by means of providing information on, and proper operationalisations of, the legal criteria, recommending more stringent procedural criteria and/or practical step-by-step decision-making and reporting forms in order to improve the quality and transparency of Belgian euthanasia practice. However, the question remains whether and to what extent it might influence the practice of euthanasia for psychological suffering involving psychiatric patients and whether, paradoxically, the development and implementation of several different guidelines may fail to achieve the goal of protecting patients' right to an equal consideration of their interests in this specific domain of end-of-life care. In this respect, it should be noted that equality does not require uniformity of treatment for all patients, but rather receiving a treatment that conforms to the regulatory framework and is tailored to the specific situation of the patient. Every patient is entitled to an equal consideration of her (medical) interests.

One end-of-life centre is already collaborating with academic researchers for the prospective longitudinal registration of requests for euthanasia for psychological suffering (including euthanasia requests being carried out, refused, denied, ongoing or withdrawn). We would warmly recommend other end-of-life centres to follow this example. Moreover, guideline III calls upon the Federal Control and Evaluation Commission for Euthanasia to increase transparency. However, the Commission is not legally obliged to do so and is in fact installing more barriers to research. In contrast to the situation in the Netherlands, in Belgium developments in the interpretation and operationalisation of the substantive and procedural legal requirements, and the potential problems and complexities of the review system are not the subject of systematic scientific research.

In addition, remaining bottlenecks beyond the medical profession should also be addressed on the political and societal agenda in order to reduce the socio-economic inequalities that may contribute to unbearable suffering and may make patients consider euthanasia. The medical profession is not meant to resolve society's failings by means of euthanasia. On the contrary, it can facilitate and

improve rehabilitation and aftercare (e.g., peer-oriented support groups for patients with rejected versus withdrawn euthanasia requests or custative care).

Another highly important recommendation for the Belgian practice would be for medical professional organisations (e.g., the Belgian Order of Physicians) to issue guidelines in an attempt to avoid bottlenecks and close loopholes, rather than relying on bottom-up approaches (e.g. initiatives of hospitals and nursing homes) that might impede the uniformity, transparency, and quality of the euthanasia practice.

As for the latter, these guidelines are established to assess the euthanasia request, and to manage the euthanasia procedure, of patients who primarily suffer from severe mental disorders. It is noteworthy that mental disorders can vary greatly, especially since the current DSM-5 indicates that an insufficient scientific basis exists to make distinctions in the type of mental disorders via the multi-axial system.

As a consequence, the former distinction between Axis I (all clinical psychiatric disorders except personality disorders and mental retardation) and Axis 2 (personality disorders and mental retardation) was abandoned. Mental disorders can also vary greatly from patient to patient, even among those who are diagnosed with the same disorders. Moreover, due to the variety in severity of the mental disorders, the patient's treatment may take place in a variety of settings (ambulant versus residential in- or outpatient psychiatric treatment) in the absence of a one-size-fits-all approach. As a consequence, the guidelines concern the assessment of all psychiatric patients, irrespective of the nature of their psychiatric disorder (no explicit distinction between former Axis I and II disorders) or treatment setting, but excluding neuropsychiatric disorders (e.g. dementia) and without considering the particular situation of mental retardation and involuntarily committed persons.

As mentioned in some of the guidelines (II and IV), a distinction needs to be made between the euthanasia request and procedure involving patients suffering from psychiatric disorders and those suffering from neuropsychiatric disorders (e.g., dementia). We believe that another distinction needs to be made, and thus an additional guideline is needed, with regard to psychiatric patients who are involuntarily committed (e.g., in prison). As prisoners do have the same rights to

medical care as any other Belgian citizen, this implies that they can also request, and die by means of, euthanasia. Moreover, euthanasias have already been performed in the medical facilities of Belgian prisons, based on terminal cancer. However, during the last decade, 20 requests were registered from mentally ill offenders that were primarily based on psychological suffering.^{221,222} Such requests raise additional ethical and legal dilemmas that should be further discussed and adequately addressed in additional guidelines.

As regards the value of these guidelines in an international context, one cannot readily transpose existing guidelines from one jurisdiction to another. This is not only due to the slightly different legal requirements (e.g., eligibility criteria, procedural safeguards, and reporting requirements) regarding this specific context of end-of-life care. Interpreting these guidelines for Canada and other countries which might be considering euthanasia or other means of medically assisted-dying should also take into account the characteristics of the healthcare system and the regulatory framework, as well as the differences in culture, geographies, and demographics.

Nevertheless, there are lessons that can be learned from the Belgian situation, other than the top-down approach to address the great need for guidelines to elaborate and operationalise the legal criteria. For example, more built-in safeguards are needed to improve the patient's well-being after refusal and to protect the physicians involved from a potential passing-the-buck and revolving door scenario.

BOX 1: Five organisations and their proposed guidelines and procedures regarding requests for euthanasia for psychological suffering

I) Ghent University Hospital

Ghent University Hospital is situated in the Northern Dutch-speaking part of Belgium. The hospital is visited by 3,000 patients a day. The psychiatric unit contains six centres of excellence where, e.g., seven psychiatrists and ten psychiatrists in training provide care to adult psychiatric patients. In January 2010, Ghent University Hospital developed and implemented a practical step-by-step protocol entitled 'Procedure concerning euthanasia and psychological suffering'.

II) The Belgian Brothers of Charity

The congregation of the Brothers of Charity was founded in 1807 as the starting point for the development of a comprehensive mental health care network. Nowadays, the Belgian branch of the Brothers of Charity provides mental health care in 13 psychiatric centres, 13 sheltered housing initiatives, and one centre for drug prevention and treatment. In March 2017, the Belgian branch of the Brothers of Charity published its 'Vision on euthanasia for psychological suffering in non-terminally ill patients' to be applied in its centres.

III) The Belgian Advisory Committee on Bioethics

The Belgian Advisory Committee on Bioethics was established by the Federal Government in 1993. It has 70 members from different disciplinary backgrounds, including a range of other characteristics reflecting the Belgian population's diversity. In September 2017, its 'Opinion no. 73 – Euthanasia in cases of non-terminally ill patients, psychological suffering and psychiatric disorders' was published.

IV) The Flemish Association of Psychiatrists

The Flemish Association of Psychiatrists was founded in 2004, with the aim to unite and represent all psychiatrists working in Flanders, to foster the quality of psychiatry as a mental health care specialism, and to inform the societal and political debate regarding psychiatric mental health issues. Close to 700 psychiatrists are associated members of the Flemish Association of Psychiatrists. In December 2017, the Association published its advisory text on 'How to handle a euthanasia request in psychiatry in accordance with the legal due care criteria?'

V) Zorgnet-Icuro

Zorgnet-Icuro was founded in 2016, with the aim to unite and represent all privately and publicly funded social profit health care organisations in Flanders. More than 775 health care organisations are associated members of Zorgnet-Icuro. In January 2018, its ethical advice on 'End-of-life care for non-terminally ill patients with serious psychiatric disorders' was made public.

Table 1: Operationalisations of and Additions to the Legal Requirements

Operationalisations of the Legal Requirements		
Mental competence (4 criteria)	4 cognitive competencies	<ol style="list-style-type: none"> 1. Ability to make and communicate personal choices 2. Ability to comprehend the information provided 3. Ability to apply this information to one's own context and situation 4. Ability to reason and deliberate
	Euthanasia request is not a manifestation of a symptom of the patient's disorder	
Well-considered euthanasia request	The patient needs to be <i>well-informed</i> by the physician concerning: <ol style="list-style-type: none"> 1) her psychopathology; 2) possible ways to alleviate her suffering; 3) side effects of available treatment options; 4) prognosis (with and without treatment); and 5) the euthanasia procedure. 	
	Properly considered euthanasia request (no 'flash of the moment'-decision), accompanied by appropriate emotions.	
Voluntary euthanasia request	Exclusion of external pressure from the patient's social environment.	
	Exclusion of internal pressure (perceived sense of guilt or feeling of being a burden to others).	
Repeated euthanasia request	Expressed toward all actors involved (e.g., physicians, close inner circle of family or friends).	
	Patient's request repeated over a period of several months.	
Medical condition	Somatic and/or psychiatric disorder.	
	Medical diagnosis (ICD-10).	
Incurable nature of condition	No real prospect of improvement with current State of the Art Treatments	<ol style="list-style-type: none"> 1) regular biological interventions 2) psychotherapeutic interventions 3) social interventions

	No possibility to administer adequate treatment within a reasonable period of time	<ol style="list-style-type: none"> 1) the patient's medical history 2) the duration of suggested treatments 3) the patient's age
	No reasonable balance between the expected treatment results and the burden of treatment for the patient	<ol style="list-style-type: none"> 1) plausibility, expectation, and extent of improvement 2) the plausibility, nature and seriousness of side effects 3) the patient's coping capacity
Suffering	Physical or psychological suffering	Requirement of causality between medical condition and suffering.
		Cannot be fully evaluated from a medical perspective as it also includes social and existential aspects.
	Constant suffering	<ol style="list-style-type: none"> 1) Taking into account the origin, evolution, and continuity of patients' suffering. 2) Symptoms can be chronic, progressive, and/or alternating.
	Unbearable suffering	<p>Physician's empathic understanding of the patient's</p> <ol style="list-style-type: none"> 1) perception and judgment of unbearability; 2) current and past life context; 3) disabling consequences of her condition; 4) physical and mental strength; 5) coping capacity; and 6) personality.
	Non-alleviability of the suffering	Can only be evaluated after all the state-of-the-art interventions are applied.
Independence of the advising physicians	No therapeutic relationship or blood ties with the patient.	
	No relative, no hierarchical relation with the attending physician.	

Additions to the Legal Requirements		
1	One-track approach	Two-track approach
	The death track: Assessment of the euthanasia request	Death track parallel to life track 1) Evaluation, intensification, and/or other adjustments of current treatment. 2) Addressing the potential of psychiatric rehabilitation options (e.g. social support groups and custative care). 3) Offering guidance in the search to (re-)discover meaning and quality of life.
2	Involvement of physicians to assess the legal requirements	
	<p>Attending physician.</p> <p>Distinguishing terminally from non-terminally ill patients.</p> <p>One advising physician (terminally ill patient) OR two advising physicians (non-terminally ill patient), including one specialist in the disorder/psychiatrist</p>	<p>Attending physician required at the start or early stadium of the euthanasia procedure.</p> <p>No distinction between terminally and non-terminally ill patients.</p> <p>At least two advising psychiatrists.</p>
3	Involvement of other caregivers	
	If applicable: nursing team.	All current and even former caregivers.
4	Involvement of important others	
	Not required.	<p>Essential requirement:</p> <p>1) Need to inform important others regarding:</p> <ul style="list-style-type: none"> - the euthanasia procedure; - the patient's life perspectives; and - the physician's final decision regarding the euthanasia request to be granted or refused.

		2) At least one other person in the patient's social circle has to be involved.
5	Required advices	
	Two advices as guidance, not binding.	At least two positive advices. Negative advices also to be taken into account.
6	A priori evaluation committee	
	Not required.	Interdisciplinary <i>a priori</i> evaluation committee.
7	Duration of the euthanasia procedure	
	One-month waiting period between request and performance.	Extension of waiting period to six or 12 months.
8	Medical performance	
		Prevention of potentially traumatic effects on other in-house patients by performing euthanasia outside the psychiatric ward.
9	A posteriori review	
	1) Attending physician reports to the FCECE 2) Biennial (anonymised) reports.	1) Reports of advising physicians to be added to report to the FCECE. 2) Biennial (anonymised) reports. 3) Reporting data from 1/10 anonymised cases (in proportion to disorders) on the Commission's website. 4) Lifting of physicians' anonymity to the Committee, though treated with discretion and confidentiality.
10	(After)care for relatives and friends	
	Not required.	1) Essential condition. 2) In close collaboration with the treating physician. 3) In addition to the treating physician, other caregivers or a religious official can be involved.

BOX 2. Issues that have not been (adequately) addressed

Aftercare for patients whose euthanasia requests have been rejected.
Aftercare for the bereaved after euthanasia of their loved one.
Handling negative or conflicting advices.
Handling suicidal threats after rejecting a patient's euthanasia request.
Conscientious objection and the mechanism of passing the buck.

CHAPTER 3 :

GHENT UNIVERSITY HOSPITAL'S PROTOCOL REGARDING THE PROCEDURE CONCERNING EUTHANASIA AND PSYCHOLOGICAL SUFFERING

Verhofstadt M, Audenaert K, Van Assche K, Sterckx S, Chambaere K.
Ghent University Hospital's protocol regarding the procedure concerning euthanasia and psychological suffering. *BMC Medical Ethics*. 2019;20(1):1-7.
doi:10.1186/s12910-019-0400-z

"Twixt devil and deep sea, man hacks his caves;
Birth, death; one, many; what is true, and seems;
Earth's vast hot iron, cold space's empty waves."

William Empson (Arachne)

Abstract

Notwithstanding fears of overly permissive approaches and related pleas to refuse euthanasia for psychological suffering, some Belgian hospitals have declared that such requests could be admissible. However, some of these hospitals have decided that such requests must be managed and carried out outside their walls.

Ghent University Hospital has developed a written policy regarding requests for euthanasia for psychological suffering coming from patients from outside the hospital. The protocol stipulates several due care criteria that go beyond the requirements of the Belgian Euthanasia Law. For instance, the legally required first and second consulted physicians should all be psychiatrists and be affiliated with a psychiatry department of a Flemish university hospital. Moreover, euthanasia for psychological suffering can only be performed if the advices of these consulted physicians are positive. Importantly, preliminary reflection by the multidisciplinary Hospital Ethics Committee was introduced to discuss every request for euthanasia for psychological suffering coming from outside the hospital.

In this way, the protocol supports psychiatrists faced with the complexities of assessing such requests, improves the quality of euthanasia practice by ensuring transparency and uniformity, and offers patients specialised support and guidance during their euthanasia procedure. Nevertheless, some concerns remain (e.g., relating to possible unrealistic patient expectations and to the absence of aftercare for the bereaved or for patients whose requests have been refused).

Keywords: Medical assistance in dying, Euthanasia, End-of-life care, Psychiatry, Mental health, Ethics, Hospital Guidelines

Background

In Belgium, euthanasia (defined as intentionally terminating life by someone other than the person concerned, at the latter's request) is decriminalised since 2002.¹⁸⁵ Euthanasia requests can be carried out on the condition that, inter alia, the patient who is requesting euthanasia is in a medical condition of constant and unbearable physical or psychological suffering that cannot be alleviated and that results from a serious and incurable condition caused by illness or accident, without prospect of improvement.¹⁸⁵ The number of patients euthanased for psychological suffering has steadily increased over the years.¹¹⁷ In the years 2016-2017, respectively 37 and 40 cases of euthanasia of patients suffering from 'mental and behavioural disorders' were reported to the Belgian Federal Control and Evaluation Commission for Euthanasia, amounting to 1.75% of all reported euthanasia cases.¹¹²

As with all other euthanasia requests from patients who are manifestly not expected to die within the foreseeable future, requests based on 'mental and behavioural disorders' are subject to two additional procedural requirements as compared to requests from terminally ill patients (i.e. a one-month waiting period between the written euthanasia request and the performance; and the consultation of at least two physicians, including one psychiatrist).¹⁸⁵ Despite these stricter procedural criteria, heated discussions are taking place, with pleas ranging from prohibiting euthanasia for the mentally ill, over introducing more strict procedural criteria, to extending the scope of the Law (e.g. to patients with advanced dementia or tired of life).^{93,94,223,224} In the midst of these debates, several organisations involved in psychiatric care, such as the Belgian branch of the congregation of the Brothers of Charity²²⁵ and the Flemish Association of Psychiatrists²⁰³, have recently published advisory texts on how to more adequately deal with requests for euthanasia for psychological suffering. Interestingly, much earlier, in 2009, an institutional protocol for addressing such requests had already been developed at Ghent University Hospital.

This protocol, entitled 'Procedure Concerning Euthanasia and Psychological Suffering', is specifically designed to address requests from patients who are referred from outside the hospital. Ghent University Hospital is situated in the

Dutch-speaking Northern part of Belgium and has a catchment area of 3.000 patients a day. Its psychiatric unit contains 8 problem-based centres.²²⁶

Discussion of the protocol

Soon after the Belgian Euthanasia Law came into effect, members of the Hospital Ethics Committee (HEC) informally got in touch with the hospital's psychiatry department to reflect on the need to introduce a specific procedure for the assessment of requests for euthanasia for psychological suffering. This initiative was prompted by concerns regarding the complexity of assessing the fulfilment of the legal due care criteria, including: (1) the patient's mental competence, as this might be affected by a psychiatric disorder; (2) the requirement of the incurability of the psychiatric disorder, as some (symptoms of) psychiatric disorders tend to change over time; (3) the requirement of the well-considered nature of the request, as a death wish may be a symptom of a psychiatric disorder; (4) the constant and unbearable nature of the psychological suffering, given that a clear definition and effective assessment instrument are still lacking; and (5) the requirement of the non-alleviability of the psychological suffering. Acknowledging that some patients can make a well-considered euthanasia request on the basis of constant and unbearable psychological suffering that cannot be alleviated by means of therapeutic interventions, it was decided that performing such cases of euthanasia within the hospital's walls should not be ruled out but needed to be subjected to criteria that are more strict than those prescribed by the Law.

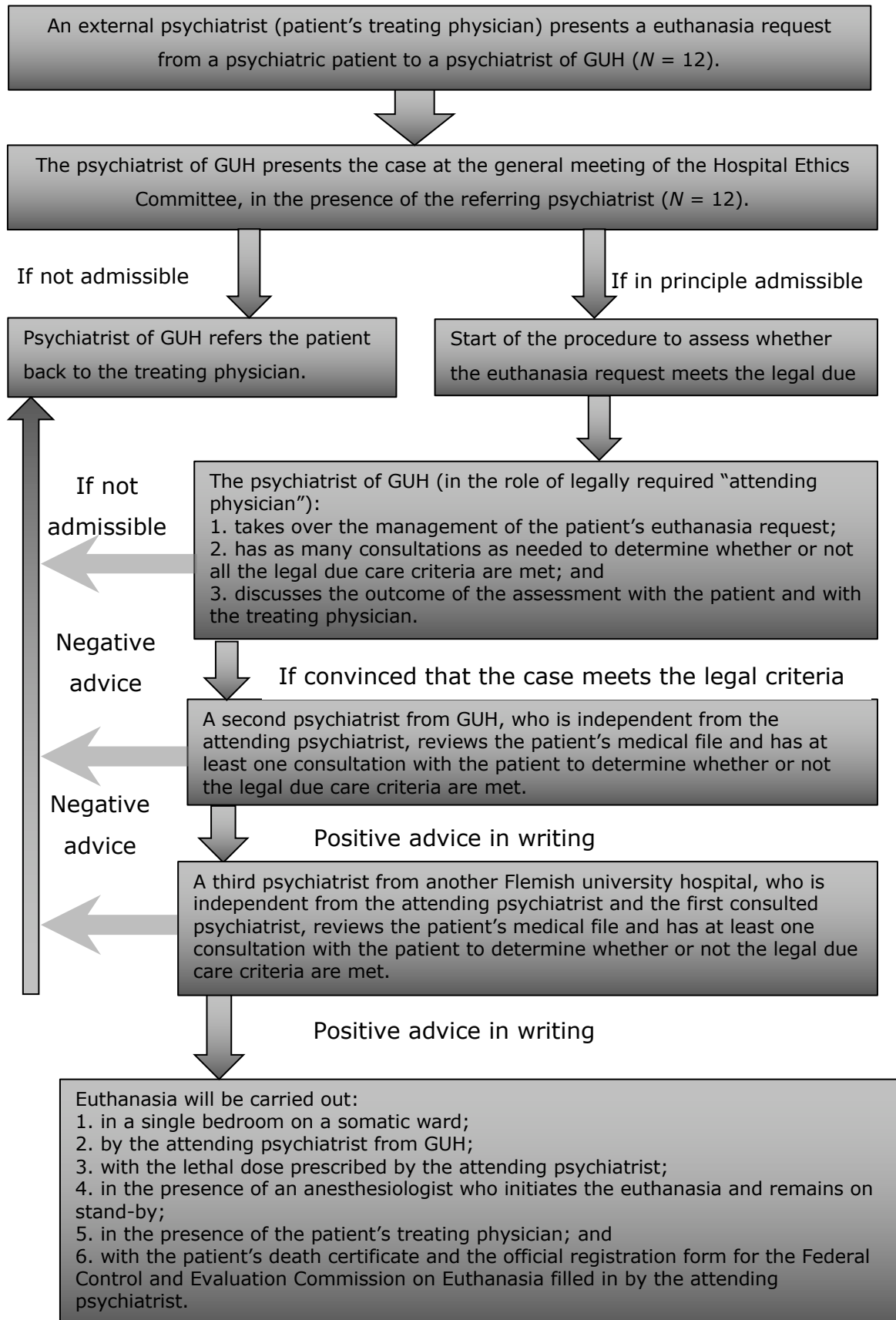
In 2008, a neighbouring psychiatric hospital decided that requests for euthanasia for psychological suffering would need to be managed and carried out outside its walls. When the department of psychiatry of Ghent University Hospital was tentatively sounded out about its preparedness to assess such requests, the HEC agreed on the need to develop a written policy for the management of requests for euthanasia for psychological suffering coming from patients referred by an outside institution or external physician. To develop this policy, the HEC established an ad hoc working group, consisting of some of the permanent HEC members and invited clinical experts. In April 2009, two months after a draft had

been debated at a plenary HEC meeting, the final proposal was unanimously approved by the Board of Governors. The step-by-step procedure of this protocol is listed in Figure 1.

The procedure starts when an external psychiatrist presents a euthanasia request from a psychiatric patient to a psychiatrist of Ghent University Hospital. If the latter is of the opinion that the euthanasia request may be legally admissible, he or she presents the case at a plenary HEC meeting, where the referring psychiatrist also has to be present. Involving the HEC serves to introduce a higher level of scrutiny in the preliminary screening of the eligibility of the euthanasia request. This procedure of shared reflection is an additional safeguard to assist the psychiatrist of Ghent University Hospital in navigating the complexities of the euthanasia request. Moreover, adding this filter protects the hospital's psychiatry department from being flooded by euthanasia requests from patients coming from outside the hospital who might be attracted by the false prospect of having a straightforward access to euthanasia, once it becomes known that Ghent University Hospital has adopted a policy that is open to such requests. Although the outcome of the prior discussion is only advisory, in practice it leads to a consensus agreement between all parties. If the HEC declares the case admissible, the assessment of the fulfilment of the legal due care requirements is initiated. If not, the patient is informed about this decision and the case is referred back to the psychiatrist from outside the hospital.

In order to protect the hospital's psychiatry department from a possible 'oversupply' of difficult-to-treat patients (e.g., patients suffering from borderline disorder), discharged by their treating psychiatrists, it is a quintessential premise that the psychiatrist of Ghent University Hospital is involved only in the management of the patient's euthanasia request, while the patient's referring psychiatrist remains responsible for the treatment of the patient's mental disorder(s).

Figure 1



If the case is declared admissible by the HEC, the psychiatrist of Ghent University Hospital assesses the patient's euthanasia request. At this stage, that psychiatrist takes on the role of the legally required 'attending physician'.¹⁸⁵ More specifically, in accordance with the due care criteria provided by the Euthanasia Law, the psychiatrist first has to ascertain: (1) the patient's competence; (2) that the euthanasia request is voluntary, well-considered, repeated, and not the result of any external pressure; (3) the patient's constant and unbearable psychological suffering; and (4) that there is no reasonable alternative solution available for the patient's situation. To that aim, the psychiatrist must have several conversations with the patient spread out over a reasonable period of time, taking into account the progress of the patient's condition. The patient and her treating psychiatrist are informed about the results of this assessment.

If the psychiatrist of Ghent University Hospital is of the opinion that the euthanasia request meets all the legal due care criteria, a second psychiatrist (i.e. the legally required 'first consulted physician') of the hospital's psychiatry department independently reviews the patient's medical record and has at least one consultation with the patient in order to evaluate whether or not the legal due care criteria are met. If both psychiatrists give a positive advice, the attending psychiatrist refers the patient for an additional consultation to a psychiatrist (named by the HEC) of a psychiatry department of another Flemish university hospital. In the capacity of legally required 'second consulted physician', this third psychiatrist also independently reviews the patient's medical record and has at least one consultation in order to evaluate whether or not the legal due care criteria are met. Only if all psychiatrists declare the euthanasia request to be in conformity with the legal requirements, euthanasia can be performed at Ghent University Hospital. This procedural requirement goes beyond the legal requirements, as the Euthanasia Law stipulates that the advice of the two consulted physicians is not binding.¹⁸⁵

Figure 1 shows the entire euthanasia procedure with numbers of the requests made ($N = 12$), granted and performed ($n = 7$), or rejected ($n = 5$) at a certain stage of the procedure. Up to the present day, the first psychiatrist always functioned as a gatekeeper who decided which patients were eligible to start the procedure in the Ghent University Hospital protocol.

However, it is important to keep in mind that the protocol stipulates that both the second and the third psychiatrist involved should decide autonomously (e.g. independently from the patient, from the attending psychiatrists and from each other) whether or not to grant the patient's euthanasia request.

In theory, it could occur that some patients who are found eligible by the first psychiatrist are filtered out in the next stages of the procedure. As the first and second psychiatrist are affiliated to the Ghent University Hospital, it is logical that their opinions are crucial in the decision whether or not the psychiatric patient can be euthanased in the hospital. Hypothetically, although this situation has not yet occurred, the opinion of a fourth psychiatrist can be sought when the opinion from the external psychiatrist is negative, if both the first and the second psychiatrist are still of the opinion that the psychiatric patient is eligible for euthanasia. All the opinions of the psychiatrists involved are thoroughly discussed by the HEC at each stage of the procedure, although, in accordance with Belgian law, the advice from the HEC should be considered as providing guidance rather than being legally binding.

According to the protocol of Ghent University Hospital, euthanasia should be performed in a single bedroom in the department of neurology. This is dictated by concern for a negative impact on other patients and staff if euthanasia were to take place in the psychiatry department, possibly giving rise to suicide attempts and ideation or even unleashing a wave of euthanasia requests. It should be noted that, in accordance with the Euthanasia Law, the nurses from the department of neurology have the right to refuse any involvement. In order to protect the patient's right to privacy, the hospital room where the euthanasia will be performed is booked by a member of the HEC.

The hospital policy prescribes that euthanasia must be performed in the presence of both the patient's treating and the patient's attending psychiatrist. Because of the lack of technical expertise on the part of psychiatrists, the euthanasia is initiated by an anaesthesiologist, although the attending psychiatrist is assigned to complete the official registration form and to deliver this document to the Federal Control and Evaluation Commission for Euthanasia.

Conclusion

During the first 15 years of Belgian euthanasia practice, a few similar hospital-based protocols were developed regarding the assessment of requests for euthanasia for psychological suffering (viz. University Hospital Brussels without and University Hospital Louvain with additional procedural criteria as compared to the Euthanasia Law, e.g. repeated multidisciplinary consultations during the euthanasia procedure).⁸⁹ In its protocol Ghent University Hospital has included criteria that are stricter than legally required: (1) a procedure of preliminary reflection by the HEC; (2) the advices of the legally required first and second consulted physicians should be positive; (3) the consulted physicians should all be experienced psychiatrists affiliated with a psychiatry department of a Flemish university hospital; and (4) the patient's treating physician should be involved throughout the procedure and be present when the euthanasia is performed. Informal communications received by the authors confirm the positive effects of these additional criteria, especially where it concerns the procedure of preliminary reflection by the HEC. More specifically, discussions with experts from different areas (e.g., other medical specialties, ethics and law) seem to considerably broaden the perspective of the attending psychiatrist, including by making that person more aware of the risk of being (too) susceptible regarding a patient who threatens to commit suicide if the euthanasia request would be refused.

The protocol of Ghent University Hospital has made a valuable contribution to clinical end-of-life practice as: (1) it protects the hospital's own psychiatrists from an influx of difficult-to-treat patients; (2) it supports its psychiatrists faced with the complexities of assessing a request for euthanasia for psychological suffering; (3) it improves the quality of euthanasia practice by ensuring transparency and uniformity; (4) it offers a way out for psychiatrists working in settings where requests for euthanasia for psychological suffering cannot be met; (5) it offers patients specialised support and guidance during their euthanasia procedure; and, as a consequence, (6) it offers these patients a guarantee that they will not be deprived of therapeutic care. To emphasise the importance of the latter aspect, anecdotal evidence has revealed that some patients felt threatened with involuntary commitment after they expressed a euthanasia request or after

mentioning that a euthanasia procedure was initiated, and that some were even excluded from psychiatric stays.

Moreover, the protocol guarantees that the burden of the euthanasia procedure does not fall squarely upon the psychiatrist of Ghent University Hospital who was initially approached. This is achieved via: (1) an a priori reflection by the HEC; (2) the involvement of the patient's treating psychiatrist; (3) the referral to at least one other independent psychiatrist from the hospital and; (4) to at least one independent psychiatrist from another Flemish university hospital; and (5) the involvement of an anaesthesiologist to administer the lethal dose.

Nevertheless, the protocol also has some shortcomings. For instance, if the euthanasia request is denied, the protocol does not envisage follow-up appointments with the patient and her relatives, but instead just lets the hospital's physician refer the patient back to her treating physician, who might remain oblivious to the patient's and her relatives' needs after refusal in terms of aftercare.²¹⁹ Note that this concern also applies for all of the other rejected cases.¹⁸⁵

Even if the euthanasia request is granted, the protocol does not explicitly mention that aftercare should be provided to the bereaved. Moreover, the fact that the psychiatrist who assesses the euthanasia request is not involved in the patient's treatment could have as an unintended effect that alternatives, such as peer-support recovery-oriented groups, remain underexplored. Furthermore, the protocol may focus too much on assisting and protecting psychiatrists confronted with a request for euthanasia. By contrast, nothing is written on the impact of the euthanasia procedure on the patients. More specifically, the protocol does not include any information on how to anticipate, clarify and address unrealistic patient expectations that the euthanasia request will be granted quasi automatically. For example, if the advices of the first and second psychiatrists are positive, the patient may get the false impression that the consultation of the third psychiatrist is a mere formality.

At a brainstorm meeting with some members of the HEC who were involved in drafting the protocol, it was mentioned that the protocol should be considered as a work in progress that might need to be amended in the light of future challenges. For example, the protocol was written with a specific type of patient

in mind, namely that of a severely depressed patient who has become treatment resistant after having been treated in a variety of ambulant and psychiatric in-patient settings for many years, including having been subjected to electroconvulsive therapy without satisfactory results.

In this respect, it should be noted that the protocol does not exclude any psychiatric conditions. However, the protocol was developed at a time when there was a lack of information about which patients would be encountered. In the early years after the adoption of the Euthanasia Law, euthanasia on psychiatric patients was virtually non-existent, as on average only 1 psychiatric patient per year was euthanased. This number increased considerably from 2008 onwards. More detailed information on these cases was published in the biennial report of the Federal Control and Evaluation Committee on Euthanasia in 2010, which is precisely the year in which the protocol was agreed and implemented. Five years after the adoption of the Ghent University Hospital protocol, one quantitative descriptive study¹²⁶ and a recent trend analysis¹¹⁷ revealed more details on the characteristics of psychiatric patients in terms of biological sex, age, nature of their psychopathology, and characteristics of the euthanasia procedure and outcome.

Since the Ghent University Hospital developed this protocol before the publication of these studies, it had no information to build on except for their own psychiatrists' general expertise in psychiatry and personal experience with some cases of euthanasia on psychiatric patients. It turned out that their experiences were congruent with the main findings of these studies. However, these studies describe the most common profiles of patients encountered in practice, whereas other profiles (i.e., in terms of disorder and life context) do occur and can increase the complexity.

In practice, Ghent University Hospital has already been confronted with euthanasia requests made by a variety of patients, including young patients suffering from anorexia nervosa and patients suffering from autism spectrum disorder. Although the characteristics of these cases had not been anticipated, they did not necessitate adjustments to the protocol, as the protocol did not exclude any patient group. The protocol made it clear that psychiatric patients might fulfil all the legal requirements for euthanasia, irrespective of age or nature of the disorder. However, due to their expertise in psychiatry (including in

end-of-life care for psychiatric patients), the psychiatrists involved in the development and implementation of the protocol were considered to be the most suitable to adequately manage and discuss these requests and to inform the HEC if there would be a need to make adjustments to the protocol, e.g. to insert additional safeguards.

The HEC also remains alert for the potential situation where future psychiatrists of Ghent University Hospital might have a more permissive stance towards requests for euthanasia for psychological suffering or might want to take a decision without following the procedure outlined in the protocol.

To date, seven cases of euthanasia for psychological suffering have been performed at Ghent University Hospital. The characteristics of these cases cannot be disclosed out of respect for these patients' and their relatives' privacy. According to anecdotal evidence provided by members of the HEC, this number is similar to that of other Flemish university hospitals. It is low as compared to the increasing number of cases that are being reported in Belgium, which might suggest that more institutions are prepared to allow euthanasia within their institution. To illustrate this suggestion, the Brothers of Charity recently changed their euthanasia policy so as to allow outside physicians to perform euthanasia on their in-house psychiatric patients.²²⁵ Alternatively, the relatively low number could be due to physicians referring their patients preferably to end-of-life consultation centres that have specialised in complex euthanasia cases and might take a more permissive approach.¹²⁶ It should, however, be noted that it is unclear for what reasons some of the external requests might have been refused, since this type of information is not systematically collected.

Moreover, little is known about the number of requests coming from in-house patients, since an institutional protocol that explicitly addresses this issue is still lacking. However, informal communications suggest that such a request has recently been formulated by an in-house psychiatric patient and was discussed by the HEC, which stressed the need to establish a protocol to address this type of requests.

It should be noted that, during a roundtable meeting with the HEC, the HEC emphasised that financial costs or gains should in no way influence access to euthanasia, which should only be based on medical expertise, sound decision-

making, interdisciplinary reflection, and transparent communication and responsibility. Therefore, during the assessment procedure no additional costs are charged to the patient except for the normal costs of the consultation of the psychiatrists. If the patient is euthanased, the invoice of that intervention is split into three parts: one part will be borne by the patient's basic health insurance, the second part will be borne by the patient's hospitalisation insurance (if applicable), and the third part will need to be borne by the patient. If the patient has no relatives and has not paid in advance, the invoice will only be met after a few years (e.g., from the patient's estate or, failing that, the patient's debt might eventually even be paid off by Ghent University Hospital).

In sum, the benefits of holding a preliminary reflection meeting with a multidisciplinary HEC, formulating a clear stance on euthanasia for psychological suffering and providing clear guidance on addressing its challenges in a way that guarantees the correct application of the legal due care criteria and the hospital's additional criteria, would be important to be taken into account by other jurisdictions that consider medical assistance in dying for psychiatric patients.

PART TWO:

PATIENT PERSPECTIVES

Chapters are based on the following publications or submissions:

Chapter 4

Verhofstadt M, Thienpont L, Peters G-JY. When unbearable suffering incites psychiatric patients to request euthanasia: qualitative study. *British Journal of Psychiatry*. 2017;211(4):238-245.

doi:10.1192/bjp.bp.117.199331

Chapter 5

Verhofstadt M, Chambaere K, Leontjevas R, Peters G-JY. Towards an assessment instrument for suffering in patients with psychiatric conditions: assessing cognitive validity. *British Journal of Psychiatry Open*. 2019;5(3):e35.

doi:10.1192/bjo.2019.25

Chapter 6

Verhofstadt M, Pardon K, Audenaert K, Deliëns L, Mortier F, Liégeois A, Chambaere K. Why adults with psychiatric conditions request euthanasia: A qualitative interview study of life experiences, motives and preventive factors. *Journal of Psychiatric Research*. 2021;144:158-167.

doi:10.1016/j.jpsychires.2021.09.032

Chapter 7

Verhofstadt M, Chambaere K, Pardon K, Mortier F, Liégeois A, Deliëns L, Audenaert K. The Impact of the Euthanasia Assessment Procedure: A Qualitative Interview Study among Adults with Psychiatric Conditions. *BMC Psychiatry*. 2021 (in revision)

CHAPTER 4 :

WHEN UNBEARABLE SUFFERING INCITES PSYCHIATRIC PATIENTS TO REQUEST EUTHANASIA : A QUALITATIVE STUDY

Verhofstadt M†, Thienpont L†, Peters G-JY. When unbearable suffering incites psychiatric patients to request euthanasia: qualitative study. *British Journal of Psychiatry*. 2017;211(4):238-245. doi:10.1192/bjp.bp.117.199331

† shared first authorship

More detailed information is available online in the Open Science Framework repository (OSF), via this link: <http://osf.io/pe25n>

“What really raises one's indignation against suffering
is not suffering intrinsically,
but the senselessness of suffering”
Friedrich Nietzsche (The Antichrist)

Abstract

Background

The concept 'unbearable suffering' is central to legislation governing whether euthanasia requests may be granted, but remains insufficiently understood, especially regarding psychiatric patients. This study aims to provide insights into the suffering experiences of psychiatric patients with death requests.

Method

26 testimonials from psychiatric patients with a death request were analysed via QualiCoder.

Results

Five domains of suffering could be distinguished: medical, intrapersonal, interpersonal, societal, and existential. Hopelessness as important contributor was confirmed. The lengthy euthanasia procedure itself was experienced as a cause of suffering and added to experienced hopelessness, while encountering physicians who took a death request seriously offered new life perspectives.

Conclusions

With this report, 2 lists with aspects and descriptors of patients' unbearable suffering are published, which can be developed into measurement instruments to assess the nature and extent of suffering as experienced by psychiatric patients, aiding both patients and physicians to navigate the complicated and sensitive procedure of euthanasia requests adequately and humanely. Some correlates of suffering (e.g., low income) indicate the need for a broad medical, societal, and politic debate on how to reduce the burden of financial, socio-economic difficulties and inequalities in order to reduce patients' desire and request for euthanasia. Euthanasia may never be seen as a way to resolve society's failure.

Keywords: Euthanasia, mental disorders, end-of-life decisions, assisted suicide

Introduction

As of February 2016, euthanasia (i.e. deliberately ending a patient's life by administering life-ending drugs at the patient's explicit request)¹⁸⁹ and/or physician assisted suicide (i.e. deliberately assisting a patient's suicide attempt or providing the patient with the means to commit suicide)¹⁸⁹ can be legally practised in five of the United States (Washington, Oregon, Montana, Vermont and California), four European countries (The Netherlands, Belgium, Luxembourg and Switzerland) and Colombia.^{189,227-229} Euthanasia legislation is mostly geared towards unbearable suffering of the terminally ill. Only in Belgium, Luxembourg and the Netherlands, can requests for euthanasia from both terminally ill and non-terminally ill patients be legally granted on grounds of untreatable and unbearable suffering.²²⁹ Belgium and Luxembourg are the only countries in the world where the law explicitly specifies the nature and origin of suffering as 'physical and/or psychological suffering that cannot be alleviated and results from a serious and incurable disease, caused by accident or illness' as a valid ground for requesting euthanasia.^{58,69,162,185,230}

However, although patients' unbearable suffering is clearly a crucial factor in legally granting a patient's euthanasia request, both a generally accepted definition of unbearable suffering - and a detailed description of the specific characteristics of patients' experiences that determine whether they are perceived as unbearable - still remain to be developed.¹⁷⁷ Due to the vagueness of the term, the Belgian Federal Control and Evaluation Commission on Euthanasia (FCECE) - established to review if all legal requirements relating to the case have been fulfilled in order to decide whether or not the case should be referred to the Belgian public prosecutor - has mentioned (in former reports) dissension concerning the question of how to comprehend and evaluate unbearable (mental) suffering.^{193,210} The current paper describes and interprets relevant qualitative data in an effort to set the research agenda to develop this definition and explore which factors render psychiatric patients' suffering unbearable. This is necessary to improve the capacity to understand and accurately evaluate patients' unbearable suffering, and - from a preventive and curative perspective - to improve physicians' abilities to prevent, detect, understand, treat and evaluate (potentially) unbearable suffering. This would

also ensure better legal protection in relation to both patients and physicians involved in these euthanasia-related decision processes.

According to the latest officially registered prevalence rate, the 3950 patients who died in the years 2014 and 2015 as a result of euthanasia constitute 1.8% of all deaths in Belgium.¹¹⁴ In one out of every seven of these cases (15%), the patient suffered from a non-terminal illness, and almost one in five of those (19%, 3% of the total) was diagnosed with at least one mental or behavioural disorder.¹¹⁴ Belgian Law on euthanasia allows euthanasia requests from psychiatric patients to be granted, and this already has been practised on a small subgroup of patients with a euthanasia request. However, specific Belgian guidelines for the management of euthanasia requests from individuals with a psychiatric disorder are still lacking.¹⁶² However, the specific guidelines of the Dutch Psychiatric Association (NVvP)¹⁹⁹ and an as yet unpublished '4-track-approach' are available as guidance alongside the Belgian Law.¹²⁶ According to the Belgian Law, a physician has to come to 'a level of mutual understanding' with the patient about the extent of his or her unbearable suffering.²³¹ The extent to which the suffering is unbearable is patient-related, which means that it can only be determined from the perspective of the patient him- or herself, and may depend on his or her physical and mental strength and personality.⁵⁹ With regard to non-terminally ill patients, it is a specific legal requirement of due care that two additional physicians, one of whom must be a psychiatrist or specialist in the disorder, are required to make a careful evaluation of the patient's mental capacity and the suffering experienced in the context of the patient's (psycho)pathology.^{185,230}

Although a clear understanding of the concept of unbearable suffering could improve this careful evaluation, and as such offer both better legal protection and protection of human rights for all patients and practitioners involved, research contributing to such an understanding is scarce.¹⁷⁶ Early research often failed to acknowledge the complexity of the suffering experience, and did not explore which aspects of an individual's suffering led him or her to consider his or her suffering unbearable.^{175,232} Presently, on the basis of a literature review from 2010, unbearable suffering in the specific context of a euthanasia request is provisionally defined as 'a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a

significant duration and a central place in the person's mind.¹⁷⁷ Being provisional, this definition has a generic nature that might not clearly distinguish between the suffering experiences of patients with somatic and/or mental disorders.

However, the scant evidence currently available suggests that this distinction may be important. One qualitative study found that unbearable suffering was generally the result of an intensive process that often found its origin in the medical symptoms of patients' disorders.¹⁸³ In addition, it was found that psychological, socio-environmental, existential and biographical factors affected the suffering experience, hopelessness in particular. This research implies that fundamental differences may exist between the unbearable suffering experiences of patients with physical illnesses and those with mental disorders. Moreover, the results showed that only patients with a psychiatric diagnosis or with both a psychiatric and physical diagnosis were more likely to characterise their suffering as taking place 'all the time'.¹⁸³ These findings underline the importance of developing an evidence base regarding the nature and extent of the experience of unbearable suffering in patients with somatic and/or mental disorders. Such an evidence base would then allow the provisional definition by Dees et al.¹⁷⁷ to be further refined, making distinctions in instances where the experiences of patient groups differ enough to necessitate acknowledging those differences. Yet, the existing evidence base is insufficient to enable the decisions that are necessary to take the definition further towards a point where it can serve in practice.

One of the reasons for the scarcity of research into the experience of unbearable suffering may be the complicated research context. As mentioned above, only a minority of euthanasia cases involve patients suffering mainly from psychiatric disorders. Moreover, these individuals are already considerably burdened, so asking them to spend their scarce energy participating in research studies is not straightforward from a social or ethical perspective. The principle that no *new* data should be gathered unless absolutely necessary seems very applicable here. One possible way of gaining more insight into the euthanasia requests from this minority group, is to analyse existing data. The current paper describes the qualitative analysis of a rich dataset of self-written or -recorded 'testimonials' (about the underlying reasons for wanting to die and experiences of unbearable

suffering) from 26 psychiatric patients with a euthanasia request. These cases were all consulted by LT. The goal of these analyses is to contribute to an evidence base that will eventually enable the further development of a definition of unbearable suffering. In the short term, it is hoped that the data described in this paper will help to increase the transparency in terms of the application procedure for euthanasia and make therapeutic guidance (early detection and prevention of suffering experiences becoming unbearable) more efficient. In these analyses, we strive to do justice to the complexity of the whole patient population who request euthanasia.

Methods

Patients

We analysed a dataset consisting of self-written or recorded 'testimonials' from 26 psychiatric patients (Table 1). These testimonials provided a means for the patients to express both the reasons for their euthanasia request and their experiences of unbearable suffering. General descriptive information regarding a group of 100 patients - of which these 26 patients were a member - is available elsewhere.¹²⁶ All patients were consulted by author and psychiatrist (LT) at an outpatient psychiatric clinical setting in the Dutch-speaking region of Belgium, with intake beginning at the end of 2007 and ending in December 2011 (when LT joined a newly founded central institute in Belgium to manage end-of-life cases, therefore ceasing case management at her private practice).

Table 1: Patients' Socio-Demographic Characteristics, Diagnoses and Death Request Outcomes

Gender	Residency Status	Socio-economic Status	Diagnoses at intake	Death request Outcomes
Female	living alone	disabled	Personality disorder Anxiety Depression	Euthanasia performed
Female	living with partner	disabled	Psychosomatic disorder Somatic co-disorders	Death request on hold

Female	living alone	retired	Depression, Personality disorder Complicated grief	Euthanasia performed
Male	living alone	disabled	Personality disorder Substance abuse	Death request on hold
Female	multigenerational living	disabled/ student	Bipolar disorder Borderline	Death request on hold
Female	living with partner	disabled	Depression, Obsessive compulsions Chronic fatigue	Death by suicide
Male	living alone	disabled	Substance abuse Anxiety Depression, Somatic co-disorders	Euthanasia performed
Female	living with children	disabled	Personality disorder Depression Post-traumatic stress disorder	Death request on hold
Female	living alone	employed	Psychosomatic disorder	Unknown
Female	living alone	disabled	Personality disorder Depression Somatic co-disorder	Unknown
Female	living alone	disabled	Dissociative disorder	Euthanasia performed
Female	living alone	retired	Depression, Complicated grief	Euthanasia performed
Female	living with partner	disabled	Psychotic disorder Depression	Death by suicide
Female	living with partner	disabled	Depression Personality Disorder Anxiety	Death request on hold
Male	living alone	disabled	Personality disorder	Death request on hold
Female	psychiatric ward	disabled	Personality disorder, Schizophrenia Depression	Euthanasia performed
female	living with partner	disabled	Eating disorder	Death by palliative sedation
female	living with partner	disabled	Substance abuse Psychosomatic disorder Somatic co-disorders	Death request on hold
female	living alone	disabled	Depression, Somatic disorder	Euthanasia performed
male	living alone	retired	Somatic disorder Complicated grief	Euthanasia performed
female	living with partner	disabled	Somatic disorder Personality disorder	Death request on hold
female	living alone	disabled	Borderline, Dissociative disorder Depression Autism spectrum disorder	Death request on hold

male	living with partner	disabled	Autism spectrum disorder Depression	Death request on hold
male	living alone	disabled	Personality disorder Anxiety Depression	Euthanasia performed
female	living alone	disabled/ student	Attention deficit hyperactivity disorder Post-traumatic stress disorder	Death request on hold
female	living alone	employed but on sick leave	Anxiety somatic disorder	Death request on hold

The sample consisted of 20 women and six men, ranging in age from 22 to 80 years ($M = 50.46$, $SD = 14.93$). At intake, 24 patients were professionally inactive, including three patients in retirement and two disabled students. The two other patients were professionally active, with one patient on sick leave. Fifteen patients lived alone, eight patients lived with their partners, one patient with her children (part-time), one in a multigenerational household, and one stayed in a psychiatric ward. Twenty-two patients presented with more than one psychiatric diagnosis, and occasionally with an additional physical diagnosis.

The outcomes from each patient's euthanasia request were examined by reviewing all medical files and contacting the physicians who treated the patients. Twelve patients were still alive (i.e. had cancelled or put their euthanasia on hold) and 12 patients had died: nine as a result of euthanasia, two had committed suicide and one had died after receiving palliative sedation. The outcomes of two patients were unknown. Note that permission had not been requested from the Institutional Review Board to personally contact (the relatives of) our sample group, nor was that deemed appropriate (as we were using existing data from a minimum of five years ago, and we wished to avoid the chance of doing harm when bringing back painful memories). The sample is also described in Table 2 at [OSF](#).

Procedure

Between October 2007 and December 2011, 100 psychiatric patients presented themselves with a request for euthanasia at an outpatient psychiatric clinical setting in East Flanders. During or after their consultation (e.g. clarification of their euthanasia request), 26 of these patients spontaneously handed in a self-

written or –recorded testimonial to LT, in which they expressed the reasons for their euthanasia request and their experience of unbearable suffering. Six testimonials were sent by mail, nineteen were written on paper, and one was video recorded. These testimonials were kept in the patients' medical files. In 2013, LT decided to use these testimonials for scientific use. It is in recognition of this procedure that the term 'patients' is used instead of 'participants'. The testimonials were anonymised, imported into QualiCoder software²³³ and given a unique identifier. Attributes were then added to facilitate identification of patterns related to demography.

LT and MV simultaneously coded one brief proof testimonial from a different medical record, received at a later date, in order to compare coding principles, and to discuss and resolve any discrepancies. The 26 testimonials were then independently coded by LT and MV. During this period, neither coder conducted literature searches or (re-)read literature in order to minimise any potential bias towards existing empirical and theoretical evidence. To further prevent bias, when the coding was completed, GJP (who has no research history in the area of euthanasia) was given access to the data in QualiCoder and inspected both the coding structure and coded fragments.

The coding procedure consisted of four phases. First, the testimonials (all in Dutch) were carefully examined by LT and MV, and all suffering-related fragments were given specific codes (in English). Second, the results of this coding procedure were compared and discussed. Where synonyms were found, the most distinct synonym was chosen as code. Third, GJP was asked to read all data and check all coded fragments. Fourth, all fragments were re-read by LT and MV and their codes were sorted into more abstract subcategories (in English), and then generally classified in overarching main categories (in English), as suggested by MV and discussed with LT and GJP. The hierarchical coding structure is available in Figure 1 at [OSF](#). Finally, at the end of September 2015, the physicians who had treated the patients were contacted to establish whether their patients were still alive, and, if not, how they had died.

In order to illustrate both the coding structure outlined above, as well as the dimensions of unbearable suffering identified, some raw data fragments are provided (translated from Dutch).

As this study can be seen as an extension of a non-interventional medical record analysis study¹² that has already been approved, an amendment for the continuation of this study was submitted at the Ethics Committee of the Antwerp Hospital Network. Ethical approval (EC Approval No. 4183) was obtained on 22/12/2015 (also available at [OSF](#)).

Findings

Five broad categories of codes emerged, each representing a dimension of unbearable suffering in psychiatric patients requesting euthanasia: medically related suffering, intrapersonal suffering, suffering related to interpersonal interaction, suffering related to one's place and interaction in society, and existential suffering. In addition, a number of different descriptions of the extent of patients' suffering emerged. First, we will outline the different aspects of suffering (i.e. the nature of suffering), as well as provide descriptions of the extent of suffering (from a patient perspective). We will then present a compilation of these outcomes in a format designed to facilitate future research.

Medically related suffering

Patients presented themselves with a wide range of psychological symptoms typically related to the disorder. For example, disruptions of identity in relation to a dissociative disorder, or a struggle with food intake in relation to an eating disorder. Alongside these specific psychological symptoms, more general symptoms were mentioned, such as stress, despair, and shame. A wide range of specific physical symptoms were also mentioned. These ranged from gastro-intestinal damage or complaints (or even organ dysfunction) to visual and auditory impairments, as well as more general physical symptoms such as pain (throughout various body parts and muscles), nerve damage, general malaise, headaches, and fatigue. The psychosomatic complaints included fibromyalgia, chronic fatigue, nausea, attacks of fever, but also lack of sexual desire and physical symptoms which resulted in both mental and aesthetic distress (eczema,

oedema, alopecia or complete/partial edentulism etc.). Among the cognitive symptoms, severe problems with memory or perception were reported.

These symptoms often co-occurred, and often started at an early age. Although different kinds of suffering were mentioned, mental suffering was experienced as more disruptive than physical suffering, sometimes explicitly so:

“Mental suffering is much worse than physical suffering, as it can’t be seen by anyone.”

(man, 22 years old)

The symptoms of the disorders mentioned were often chronic and progressive, sometimes continuously alternating between several different ‘attacks’ of pain or dysfunctions.

The burden of medical suffering was also described as being beyond patients’ capacity to cope with, due to a number of treatment-related reasons. Firstly, some patients reported suffering greatly from the deleterious or ineffective effects of medication, treatment, or surgery procedures (for example, iatrogenic trauma can result from a physician administering unnecessarily radical surgery procedures). Even during stays in psychiatric wards, sometimes the symptoms being treated got worse rather than better. Similarly, sometimes former (in)voluntary residential stays in psychiatric wards resulted in an accumulation of feelings of despair, decline and loss of control, particularly when patients felt like ‘guinea pigs’ when taking part in (several) clinical trials for medication, or when they had been abused (sexually, physically and/or mentally) during their stay(s). The opposite scenario - exclusion from any residential treatment option (due to the severity and continuity of their disorder(s)), or from any prescription for medication (due to earlier suicidal acts) - was also mentioned as contributing to patients’ suffering. Second, long term suffering experiences were mentioned in relation to (different) wrong, unspecified, or even missed diagnoses, and the resulting erroneous treatment experiences. Third, difficulties in the communication patterns between patients and their physicians were mentioned, such as lack of comprehension of patients’ suffering experiences. Some physicians were considered ignorant, professionally incompetent, unsound and/or incapable of talking things through with their patients. Internal miscommunication between co-physicians was also reported. Fourth, and often

as a consequence of the previous reasons, patients reported no longer hoping for any recovery - or even for any improvement - when medication turned out to be ineffective, when patients were no longer eligible for further medical treatment(s) and/or when physicians declared a patient's disorder(s) to be incurable:

"I'm through with therapy. According to me, if you're in therapy, you have to work towards something, but that isn't the case anymore, and hasn't been for maybe a few years. After 25 years of therapy, there's nothing left to work on: the therapy just keeps the engine running. But life is more than an engine kept running. I've taken a lot of antidepressants. I lost faith in them, as there are no pills that can cure me. They barely help me."
(woman, 42 years old)

The data suggests that applying for the euthanasia procedure might contribute to additional suffering. First, patients reported an unwillingness on the part of the physician to discuss a euthanasia request. Second, patients experienced a lack of transparency in the euthanasia application procedure. Sometimes they were left ignorant about the legal requirements (e.g. how many physicians should be consulted, how much time the procedure could take, and whether alternative options would still be available if the euthanasia request would be refused, etc.). This lack of transparency also occurred when, for example, a patient's (former) physician remained 'impervious' (resistant) to a patient's wish to die, avoided taking an explicit position regarding euthanasia (requests), or 'deceived' (mislead) the patient by saying that psychiatric patients are not allowed to ask for euthanasia. Third, patients reported difficulty in finding physicians willing to accept, advise about, or perform euthanasia. Fourth, and as a consequence of this, the euthanasia procedure could be experienced as drawn-out:

"If I understand it correctly, I need to find three physicians and convince them that euthanasia is the only solution for me. And I suppose I need to be very lucky to find even one physician willing to perform euthanasia. So, if I'm able to find - at least three times - that needle in a haystack, a process that could take months or years, then I might die at last. Wouldn't it be better to just ask a completely paralyzed person to run a marathon

without the use of a wheelchair or other tool? Do you know some physicians who might be willing to give such a recommendation? Or should I just take the Yellow Pages and prepare a stack of letters to explain my issues to every physician?"

(woman, 47 years old)

While on the one hand, the testimonials illustrate that a lack of transparency or unwillingness to discuss a euthanasia request may have further aggravated the suffering experiences of patients, on the other hand, encountering physicians who took a death request seriously or were aware of the options to proceed with euthanasia may have led to new treatment perspectives being (re-) considered:

"It surely is a long agonising wait before a physician allows euthanasia, because there is always something left to try to make your suffering more bearable. Recommendations from two other physicians are also needed, and, in the meantime, time goes by and you're still suffering. Moreover, the people around you cannot believe that you want to die, because you're looking so good, so no one would allow you to die. So when I finally got the permission to die, that was a huge relief. (...) I have to admit that since my request to die was considered to be acceptable, I'm experiencing better moments and I'm also in doubt now. I'm still in therapy and there we discuss other available options."

(woman, 52 years old)

Intrapersonal suffering

Suffering experiences resulted from a variety of intrapersonal experiences, such as a patient's traumatic background history. This trauma could be, for example, psychological (suicide of important others, troubled childhood) or sexual (different kinds of sexual abuse within or outside of the family context). Furthermore, trauma experiences could (re)occur in later life (suicide of important others, troubled marital status, sexual abuse, etc.).

Patients also reported suffering from (several) self-destructive thoughts and acts in the past and/or present, ranging from substance abuse or addiction and self-

injury (e.g. burning, cutting) to suicidal thoughts and attempts. As end-of-life decisions do not happen overnight, they are also coupled with self-destructive considerations such as a patient's fear of the act and the possible consequences of self-destruction in the future. The consequences of previous failed suicide attempts (e.g. shame) and the fear of surviving another attempt were taken into account by patients when a request was made for euthanasia. Suicide in general was considered as painful, horrific, and humiliating, but still evaluated as a possibility by patients whose euthanasia requests could not be granted. However, dying in a caring environment, eventually surrounded by loved-ones, was very much the preferred option. In addition to suicide, palliative sedation as a result of suspended *physical* treatment options was also considered as an alternative in cases where a pending euthanasia request would not be granted.

Alongside considerations related to themselves, patients also considered the feelings of others when choosing euthanasia over suicide attempts. Despite the urgency of their wish to die and perceived psych-asthenia (psychogenic weakness), a reluctance to harm important others was also reported. This led, in some instances, to conflicting feelings, such as an urgent wish to a hastened death on the one hand, and on the other hand, a certain willingness to reduce the burden of this on loved ones. This willingness was reflected in the advance preparation of all kinds of financial and practical arrangements, from the preparation of a warm and serene atmosphere in which the act of euthanasia would take place at home, to making sure that the act of euthanasia would not take place near or during holiday seasons (e.g. Christmas).

Suffering related to interpersonal interaction

First, the testimonials mentioned serious conflicts or disruptions with important others (parents, partners, and/or children) both in the past and the present. Second, irreparable losses were mentioned, such as the death of beloved family members, friends or pets. Third, in relation to social contacts, a lack or loss of social support or understanding from important others concerning patients' troubles in life was reported. For example, friends, family and/or physicians neglecting or underestimating these struggles and suffering experiences in the

patient's life, or 'sweeping aside' (ignore) the patient's request for euthanasia.

"Saying that someone is working, studying and experiencing a good home situation - and therefore asking what the problem is - is a commonplace platitude that undermines my readiness to open up, as you've noticed earlier. It's a question that I can expect from non-therapists and which detracts from the fact that I suffer unbearably. Would that also mean that a cancer patient, who works and experiences a good home situation, can't suffer unbearably? Work or study isn't sufficient, as feeling at home in this world means so much more."

(woman, 30 years old, after consultation)

Fourth, patients reported suffering as a consequence of withholding information from important others. These problems included difficulties confessing an extremely painful or shameful issue, such as rape, or discussing a taboo subject, such as failed suicide attempts. The reasons to withhold information included fear of not being believed, fear of being misunderstood, or stigmatized ('craziness'), and fear of others believing but dismissing patients' beliefs, feelings or experiences.

The testimonies suggested that a variety of personal social shortcomings could initiate and/or exacerbate suffering experiences related to interpersonal interaction. For example, a mental shortcoming that manifested as a cycle of attraction to and rejection of other people, or a general dislike and avoidance of human company and interactions. Patients sometimes reported having unconsciously reduced social contacts due to feelings of inferiority, problems with small talk, or an inability to deal with perceived high expectations of others. Another personal social shortcoming was the perceived burdensomeness of one's presence. For example, the impact of patients' suffering experiences on family members was described as so omnipresent or exigent that it led to disruption within the family. The impact of (the consequences of) a patient's mental disorder(s) could also lead to a patient wanting to relieve his or her loved ones and believing that his or her loved-ones would be better off without her.

"The pain has become so overpowering. This is very confusing and depressing, not at least for XX (husband), who no longer knows how to react to it. While this endures, I'm dragging him into a depression. He gets totally exhausted."

(woman, 51 years old)

Suffering related to one's place and interaction in society

Three socio-economic problems were reported: the pressure to make a living when there was no financial support from others, additional (financial) insurance problems due to insufficient medical care following an accident, and/or a low income necessitating careful consideration to determine whether alternative admissions and treatments (i.e. non-psychiatric) were feasible.

Some work-related issues contributed to the overall suffering experience – for example, difficulties in finding a suitable job or unsuitable working conditions that indirectly led to work loss when additional support at the workplace was unavailable. Physical or mental health problems could also directly lead to (permanent) disability and, as a consequence, resignation:

"I miss my job as a caregiver for the elderly. I've tried to start again as a volunteer and succeeded, via trial and error, for seven months. But at the end it couldn't be helped. Back then I realised I didn't have any problems with my work as a caregiver, I just couldn't manage to keep my head above water in the interactions with my co-workers. This hurts. I've been avoiding every article, any news, television programmes, ... about care for the elderly and dementia ever since. The fact that I can't go to work anymore saddens me enormously." (woman, 42 years old)

In addition, three types of environmental factors could be identified. First, some behavioural adjustment problems were described. For example, society was sometimes seen as an overwhelming rat race in which a 'highly sensitive' person could not function properly. In order to deal with this, individuals reported that they felt they had to wear a 'mask', or fake their way through social life, but that there came a point in one's life where these defensive strategies no longer

worked:

“I’m not myself anymore. I’m scared of myself, scared of hurting or harming others. Until now, I’ve managed to direct the torturing obsessions solely at myself, but I’m really scared. I’m full of aggression; I just don’t know what to do with myself. I’m not myself anymore. I don’t recognise myself anymore, I’m not an aggressive person. But it has become difficult to put on a mask whenever I go outside, whenever I close the door behind me. It’s just not normal what I’m feeling - what is happening to me?”

(woman, 43 years old)

Second, some patients not only felt that they were a burden to society, but also blamed society for spending a substantial amount of money on keeping patients with a wish to die alive, when they felt that this money could be better spent if society would instead concentrate on helping those people who want to live. In fact, some felt that this amounted to preventing lives being saved – of those who wished to live – as those who wished to die would be willing to donate their organs to save the lives of others. Third, additional aspects of suffering, for example, the experience of solitude or loneliness due to a lack of social support from ‘society in general’, was reported. This kind of social isolation ‘by choice’ sometimes resulted from the (perceived) experience of being socially or emotionally isolated from others or removed from society. Some patients spent excessive time alone at home, not allowing visits from others and avoiding any kind of meaningful contact with relatives, friends or acquaintances. Instead, these patients severely restricted such contact to limited, superficial, or accidental meetings with neighbours. This can be distinguished from *unwanted* social isolation, where, for example, patients regretfully described not having relatives or friends anymore due to the (symptoms of their) illness, or due to the fact that their relatives were living abroad.

Existential suffering

Three kinds of existential suffering experiences emerged. First, feelings of being overwhelmed by an existential ‘fear of life’, in which no quality of life could be found.

"I'm scared to wake up, scared to get myself through the day, and scared to go to sleep."

(woman, 31 years old)

Second, feelings associated with a lack or loss of control concerning (the symptoms of) their disorder occurred. Some patients experienced a devaluation of their personal integrity; merely feeling a puppet to the medical findings and recommendations of physicians (when patients' themselves had already assigned these findings and recommendations concerning certain symptoms as subordinate to their own overall existential suffering experiences). Third, a (symbolic) death of patients' 'self' or self-representation or even a complete transcendence or loss of the self was described. Some patients felt mentally detached from their body, or felt themselves to be a person detached from the real world in which they're living, but not really or fully participating in. When these experiences of suffering progressed, perspectives on life itself could get damaged or even eliminated. This occurred when a patient perceived his or her condition to be medically futile, for example when none of the proposed treatments could be seen as realistically improving the patient's medical and/or existential condition.

Some patients also found themselves in a futile condition (meaning that the overall suffering itself is unbearable and untreatable, and there is no prospect of any improvement), unrelated to a medical condition. This was, for example, due to gradually losing their function as a partner, parent or employee. Particularly in cases when such misfortunes accumulated, patients experienced their lives as meaningless. This experience of engaging in a daily battle to deal with multiple causes of suffering, combined with the feeling that this battle could never be won, led to some patients reporting that they were tired with life.

Extent of suffering: descriptors used by patients

Participants consistently used a number of descriptors to express the extent of their suffering, which could be clustered into three broad categories. Firstly, the intensity of suffering experiences could be classified as: (A) extremely severe, causing extreme levels of distress and discomfort or (B) so unbearable that it

was beyond the patient's capacity to cope. Secondly, several temporal variables contributed to the extent of suffering reported (e.g. chronicity, duration, and early onset suffering). Patients reported (C) chronic, non-stop suffering resulting from the symptoms of the disorders and additional problems in daily life: sometimes alternating from one symptom or problem to another, sometimes continuously suffering from a more repetitive pattern of symptoms or problems, (D) long-term suffering whereby suffering experiences persisted over an extended period of time, and (E) an early onset of the suffering history, with problems starting at early age and therefore contributing to the experience of long-term suffering. Thirdly, a pessimistic view of the future was outlined: (F) a progressive and deteriorating evolution of patients' health condition was experienced, as symptoms and problems worsened over time, and (G) feelings of hopelessness and (H) incurability appeared as patients felt or were told by their physicians that their suffering could not be alleviated or that there was little - if any - hope for recovery or even improvement.

Guiding future research: a systematic description of the results

One of the aims of this study is to guide future research investigating the suffering experiences of psychiatric patients. To facilitate future researchers, as well as acknowledging the need to Fully Disclose research outcomes²⁰, the results of this study have been made publicly available at [OSF](#). In addition to other resources from this study - such as the final Coding Structure and the letter of ethical approval - we compiled two lists (See the codes listed in BOX 1 and BOX 2). The first contains the different aspects of patients' suffering. The second contains the eight (A-H) descriptors patients used to describe the extent of their suffering.

BOX 1: Hierarchical Coding Structure: Aspects of Suffering

Categories	Subcategories	Codes
Medically induced suffering	Medical symptoms	Psychological symptoms Psychosomatic symptoms Physical symptoms
	Adverse effects of medication/treatment	Negative effects of medication Negative effects, ineffectiveness or refusal of treatment (procedures) Difficulties in communication patterns (between patient and treating physician)
	Added suffering by euthanasia procedure	Prolonged euthanasia procedure Lack of transparency Incomprehension of death wish Search for doctors accepting/performing euthanasia (request)
Intrapersonally induced suffering	Traumatic events/background	Sexual trauma Physical trauma Psychological trauma
	Self-destruction	Fear of self-destructive thoughts Fear of self-destructive acts Committed self-destructive acts
	Internal shortcomings	Perceived burdensomeness on others Reluctance to harm (important) others with death wish/problems in life Feeling torn (self-interest versus other's interest)
Interpersonally induced suffering	Issues in social life	Conflicts/ruptures with important others Loss of important others Lack of social support/comprehension
	Personal social deficiencies	Behavioural adjustment problem Communication problem Perceived burdensomeness Social interaction problems
Societally induced suffering	Environmental factors	Socio-economical problems Lack of social support/comprehension Social isolation
	Work-related issues	Work finding difficulties Unsuitable work conditions Loss of work (ability)
Existential suffering	Through with life	Affected/ Worsening/No life perspective Futile condition Accumulation of misfortunes Tired of life
	Existential difficulties	Fear of Life Lack/loss of control Loss of one's self

BOX 2: Extent of Suffering: Descriptors used by Patients

Categories	Descriptors
Degree of suffering	Extremely severe symptoms Unbearable suffering
Chronicity	Continuous suffering
Duration	Worsening condition Long-term suffering Early onset
Suffering outcomes	Incurability Hopelessness

Discussion

The aim of this qualitative study was to take the first steps to better understand the unbearable suffering experience(s) of psychiatric patients with a euthanasia request. We hope that a better understanding of these issues will help practitioners, patients, and policymakers in Belgium, as well as in other countries where euthanasia is legal or debated. The results show that the unbearable suffering experienced by psychiatric patients originates from a wider variety of sources than the psychological symptoms of a patient's disorders alone. Psychiatric patients do not only suffer from psychological symptoms, but also from general and specific physical and/or psychosomatic symptoms. These outcomes corroborate the findings of the FCECE data of the 3.950 patients who died as a result of euthanasia in the years 2014 and 2015.¹¹⁴ These data show that, despite the fact that most patients were terminally ill patients and only a minority suffered from a non-terminal mental disorder, in 3.752 cases (60.6%) unbearable physical suffering and in 2.437 cases (39.4%) unbearable psychological suffering was reported as the reason to make a euthanasia request.¹¹⁴ This also suggests an interaction between mental and physical health processes in both patient groups. These results also confirm the earlier finding that psychiatric patients may suffer 'continuously'¹⁸³, as illustrated by their descriptions of continuously suffering from their disorder or continuously alternating between several, different 'attacks' of pain or dysfunction.

Earlier research has suggested that while unbearable suffering experiences often find their origin in the medical symptoms of patients' disorders, they are also

highly affected by psychological, socio-environmental, existential and biographical factors, with hopelessness being a critical element.¹⁸³ The data presented here support these findings, and extend them, by suggesting that, in psychiatric patients, these symptoms may start at early age and may further progress due to insufficient and/or poor patient-physician communication and inefficient treatment practices. Moreover, financial issues are also relevant - for example, low income necessitating careful consideration to determine whether alternative stays and treatments are feasible. Such findings may have implications for (and direct criticism towards) some current health policies, particularly financial aspects of these policies. However, it is worth noting here that financial issues can never be a reason for granting euthanasia requests. Note that extreme care in euthanasia decision-making processes should be applied as a euthanasia request can be a symptom of a patient's mental disorder.¹⁶² For example, feelings of hopelessness that are experienced by a patient can be a symptom of clinical depression (unusual preoccupation with death or dying) or a more rational response to the absence of a prospect of improvement, as seen in in psychiatrically and medically ill patients (e.g. cancer patients). As Grassi et al. (2010) stated, this kind of hopelessness 'seems not exclusively to correspond to depression, but is related to various other psychosocial factors, such as maladaptive coping, as well'.^{234(p201)} This precarious ambiguity warrants in-depth exploration in future research.

According to the law, euthanasia can only be granted if both physician and patient have to come to the conclusion that there is no reasonable alternative left that will relieve the patient's suffering. In practice, the guidelines provided by the Dutch Psychiatric Association (NVvP) are then followed in order to qualify untreatable suffering (e.g. any therapeutic option for a particular condition must meet the following three requirements. There must be: (i) a real prospect of improvement, (ii) the possibility to administer adequate treatment within a reasonable period of time, and (iii) a reasonable balance between the expected treatment results and the burden of treatment consequences for the patient must be reached).¹⁹⁹ Our data suggest that a wider political and societal debate may be needed to find ways to reduce the medical costs and/or improve the financial situation of certain individuals in order to reduce the desire to request euthanasia.

In addition to these medical factors, it is clear that a variety of intrapersonal, interpersonal, societal, and existential elements contribute to the suffering experience, ultimately rendering it unbearable. In relation to intrapersonal suffering experiences, our data showed that a traumatic background could initiate a patient's medical and other suffering experiences. Further traumatic experiences, self-destructive thoughts/acts, and the perceived burdensomeness of one's situation and outlook could then lead to additional suffering, which could, in turn, undermine a patient's motivation to continue living. This situation, in combination with a reluctance to harm important others, can result in a well-considered wish to die, but one that prevents patients from undertaking another suicide attempt. In cases where euthanasia is performed in a serene atmosphere, the mourning process of relatives and friends can be alleviated, as compared to the additional suffering resulting from suicide attempts.

As for dimensions of suffering related to interpersonal interaction, a perceived lack of comprehension or social support, conflicts, and discord with important others, and mourning over the death of important others can all contribute to a patient's suffering. Different personal social shortcomings (such as behavioural adjustment, communication, and social interaction problems) also emerged as potential causes for sustained social difficulties, an inability to connect, and the resulting isolation and loneliness.

On the level of societal suffering, our results highlight a distinction between external social difficulties (socio-economic problems, environmental factors such as social isolation) and difficulties related to work (patients being declared unfit for work or not being able to find a suitable work environment). Note that these societal factors are beyond the control of both patients and physicians, as they are the topic of a broader public and political debate on how to reduce the impact and consequences of financial and societal inequality. These problems cannot be a direct reason for granting requests for euthanasia, but nevertheless might affect (as additional suffering determinants) a patient's capacity for resilience and coping.

As these suffering experiences progressed, they could become more existential in nature. In such cases, patients perceived their situations as futile, devoid of any hope of improvement. Due to the accumulation of a variety of suffering

experiences, misfortunes, and traumas, patients can feel that they are through with life itself. Keeping the higher suicide risk of psychiatric patients in mind, as well as the further increases in these risks posed by comorbidity of axis I and II, this underlines the importance of the early and adequate detection and treatment of symptoms related to suffering, in order to prevent this suffering from becoming unbearable.²³⁵

It is noteworthy to mention the added suffering experiences resulting from end-of-life decision-making difficulties. Patients struggled with negative feelings associated with self-destructive acts (that had already occurred), and in some cases the consequences of previous suicide attempts. Importantly, the findings of the present study also highlighted, for the first time, that the process of applying for euthanasia may further contribute to suffering that is already perceived to be unbearable. This was illustrated in patient reports of a lack of understanding surrounding patients' euthanasia requests, a lack of transparency in the euthanasia application procedure, and a lengthy search for physicians who would be willing to grant the euthanasia request and perform the procedure. Further research could examine the barriers and enablers of effective communication skills between patients and physicians dealing with a euthanasia request.

It is also noteworthy that at the beginning of October 2015, 12 of the 26 psychiatric patients who had submitted a request for euthanasia were still alive. According to Dutch guidelines, a request for euthanasia should, initially, be considered as a cry for extended life aid with assisted suicide and euthanasia being seen as a final resort. From this perspective, physicians need to respond with a formal '*No, unless...*'¹⁹⁹ to a patient's request for euthanasia, which in cases of emergency can be transformed into a '*Yes, unless...*'. It seems worthwhile to study the impact of physicians' communication approaches (a reticent versus an admissible approach) towards euthanasia requests. For example, it would be useful to know whether paradoxically an admissible approach may be so relieving to patients that it results in less rather than more completed cases of euthanasia.

The current findings may suggest that changing the first formal reply a '*Yes, unless...*' might be a more effective way both of reassuring patients' whose

euthanasia request represented a cry for extended life aid and minimising the suffering of those whose requests reflected a fundamental desire to end their lives. The relief patients feel when a physician takes their wish to die seriously, in combination with the knowledge that they have the option to proceed with euthanasia if they wish to do so, may provide (for example) a new perspective on further treatment. As for those patients determined to see their request through to the end, the procedure would cause less suffering and feelings of hopelessness.

On the basis of a literature review, unbearable suffering in the specific context of a request for euthanasia was provisionally defined as *'a profoundly personal experience of an actual or perceived impending threat to the integrity or life of the person, which has a significant duration and a central place in the person's mind.'*¹⁷⁷ The unbearable suffering described by the 26 psychiatric patients in this database confirms the individually perceived profound experiences of permanent distress, hardship, despair and/or shame that threaten the quality and/or integrity of a patient's life. The suffering experiences of this patient group were often rooted in the nature and consequences of their particular disorder. The experience of suffering often started at an early age, particularly if the onset was linked to a traumatic personal background or accident, and then gradually worsened due to an accumulation of traumatic misfortunes, intrapersonal, interpersonal, societal and/or bad (or sub-optimal) medical practice. In the long term, it appears that persistent suffering experiences became existential when there was no prospect of improvement, and the extent and nature of the suffering became beyond a patient's capacity to cope. As a consequence of these unbearable suffering experiences, patients developed suicidal thoughts, committed suicide attempts, and made euthanasia requests.

An important limitation of this study to bear in mind is that as the testimonials were written spontaneously; they are profoundly and solely dependent on the written communication skills of each patient. The subtleties and complexities of this topic might not have been picked up in as much detail using this method as compared to (open-ended and funnel) questions provided in in-depth interviewing (confounder bias). Furthermore, as the patients were depending on the approval of physicians, including author (LT), in order to get their euthanasia request granted, they may have felt a need to convince the author about the

underlying meanings for their euthanasia request being beyond their capacity to cope, while hiding some other information (information bias).

However, this method did provide a unique insight into the experiences of this hard-to-study target population, and, importantly, the data could be analysed without incurring any participant burden for this target population that is defined by unbearable suffering. None of these spontaneously written or recorded and presented testimonials were censured or left out of the analyses in order to minimize the risk of selection bias. The content of some testimonials was written so clearly that it indicated the nature and extent of the patient's suffering in detail, whereas other testimonials were written rather covertly or in a more poetic form. However, as it concerns testimonials from patients consulting author LT in her group practice, sampling and thus also selection bias may have occurred. The fact that patients were not given direction on how to write their testimonials by the authors, and rather had total freedom to express and share their thoughts and experiences, may also have prevented bias, and in addition, resulted in very rich data.

Another strength of the procedure we followed was that, in order to minimise bias in the coding process due to LT's (as a clinical professional) and MV's (as a researcher) familiarity with the topic of euthanasia, available scientific studies were not reread, nor was an extra literature search conducted that could have influenced the coding processes in the direction of specific theories or evidence from the literature. Bias was further minimised by the third author (GJP), who was unfamiliar with the topic of euthanasia, scrutinising the process.

The goal of this study was to provide direction for future research into the unbearable suffering experiences of psychiatric patients. In addition to the present report of our findings, we have compiled two lists that accompany this paper at OSF. The first list contains the different dimensions of patients' suffering experiences. These could be used to develop a measurement instrument to explore the nature of patients' suffering experiences. The second list contains the descriptors that patients used to describe the extent of their suffering. These could be used to develop a measurement instrument to assess the extent of suffering as experienced by psychiatric patients.

In addition to the quantitative research needed to develop such measurement

instruments, additional qualitative research using interviews could further clarify these lists and contribute towards improving a definition of unbearable suffering as experienced by psychiatric patients in the euthanasia context.

These interviews should be conducted by an independent interviewer (not involved in the clarification of the euthanasia request) and not focus solely on what makes patients' suffering unbearable, but also on what could make the suffering experiences bearable. With patients mentioning physicians' poor communication and comprehension skills, further research could examine the barriers and enablers of effective communication between physicians and patients with a euthanasia request who are experiencing unbearable suffering. Therefore, it is also important to investigate communication and comprehension skills (between physician and patient) from the perspective of the physician. In this respect, the qualitative study by Dees et al., in which five relevant themes to optimise this decision-making process emerged, seems to be a good initial step.¹⁷⁰ As the authors also stated, the communication skills that professionals require to address complex decision-making need to be investigated.

As mentioned previously, 12 of the 26 patients who requested euthanasia have put their request on hold and are still alive. Comparing suffering experiences between psychiatric patients in which euthanasia was performed to those of patients who decided to continue their life, and between psychiatric patients with/without a request for euthanasia and the general population, can help us to understand the nature and extent of the suffering experience, and when exactly it becomes truly unbearable. Such insights could help to identify alternative treatment options and adjust the euthanasia procedure for psychiatric patients, tailoring it to provide hope and a new perspective on life to those whose suffering can be alleviated, and to minimise the additional suffering and hopelessness it causes in those whose suffering is indeed unbearable and cannot be alleviated.

CHAPTER 5 : TOWARDS AN ASSESSMENT INSTRUMENT FOR SUFFERING IN PSYCHIATRIC PATIENTS: ASSESSING COGNITIVE VALIDITY

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More detailed information is posted in the Open Science Framework repository accompanying this paper: <https://osf.io/bhde3/>

“This tremendous world I have inside of me.
How to free myself, and this world, without tearing myself to pieces.
And rather tear myself to a thousand pieces
than be buried with this world within me.”
Franz Kafka (Diaries, 1910-1923)

Abstract

Background

Unbearable suffering is a key criterion in legally granting patients' euthanasia requests in Belgium, yet, a generally accepted definition of unbearable suffering remains elusive. The ability to understand and assess unbearable suffering is essential, particularly in psychiatric patients, in which underlying causes are not always apparent. To enable research into when and why suffering experiences incite psychiatric patients to request euthanasia, and to help explore preventive and curative perspectives, the development of an assessment instrument is needed. This study aimed to improve the cognitive validity of a large initial item pool used to assess the nature and extent of suffering in psychiatric patients.

Method

Cognitive validity was established via two rounds of cognitive interviews with psychiatric patients both with ($N = 9$) and without ($N = 5$) euthanasia requests.

Results

During the first round of cognitive interviews, a variety of issues in content, form and language were reported and missing aspects identified. During the second round, the adjusted items were perceived as sufficiently understandable, sensitive to delicate nuances, comprehensive, and easy to answer accurately. Neither research topic nor method were perceived as emotionally strenuous, but instead as positive, relevant, comforting and valuable.

Conclusions: This research resulted in an item pool that covers the concept of suffering more adequately and comprehensively. Further research should examine potential differences in the suffering experiences over time and between psychiatric patients with and without a euthanasia request. The appreciation patients demonstrated regarding their ability to speak extensively and openly about their suffering and death wishes further supports the need to allow the patient to speak freely and honestly during consultations.

Keywords: euthanasia, mental disorders, assisted suicide, cognitive validity, psychiatry

Introduction

The suffering experiences that prompt psychiatric patients to consider ending their life by means of suicide or medical assistance in dying (MAID) has been understudied and remains insufficiently understood.^{177,236,237} MAID has been legally justifiable in some states in the U.S. and in several countries for the terminally ill.^{227,228} However, in the Netherlands, Belgium and Luxembourg, euthanasia requests can be legally granted for non-terminally ill patients, including those with psychiatric conditions. In Belgium, the ability to grant euthanasia requests requires that patients experience constant and unbearable suffering stemming from one or more somatic or mental disorders, without any (reasonable) prospect of improvement.²³⁸ The number of psychiatric patients who died by means of euthanasia has increased annually, particularly from 2008 onwards: from five patients in the years 2002 to 2007, to 72 between 2008 and 2012, and to 181 from 2013 to 2017.^{112,117}

Whether or not psychiatric euthanasia requests are justifiable remains controversial, with particular emphasis on the challenges involved in comprehending, assessing, and evaluating unbearable mental suffering in these patients.^{93,94,210,239} Several instruments have been devised and are used to assess suffering-related constructs such as bodily pain,^{240,241} mental pain^{236,242}, and the association between them.²⁴³ However, suffering cannot be reduced to one single aspect (e.g. pain²⁴⁴), as it involves many other social, societal and existential aspects of life.^{183,206,245-247} Therefore, instruments have been developed to assess suffering using instruments for broader concepts like quality of life and well-being, based on the assumption that low scores on these indices may represent a high level of suffering.¹⁷⁸ However, there is clinical evidence suggesting that this may be invalid: among patients who display unaffected or stable levels in their quality of life over time, some patients requested euthanasia, while others did not.¹⁷⁹

While an intrinsic aim of the healthcare practice is to alleviate patients' suffering, suffering is seldom addressed comprehensively, regularly overlooking patients' perspectives in clinical and scientific settings.^{170,175,179,244,248} Over the last several

decades, a growing interest in the concept of suffering has led to the development of suffering scales, assessing psychosocial, social and existential aspects of suffering. However, as focus on the topic has been primarily from a clinician's perspective, only a few of the tools designed to assess suffering have been developed in the end-of-life context, with a target population consisting advanced or terminally ill patients, primarily suffering from somatic disorders.^{179,249} Hence, while it is crucial that the items of an instrument accurately and comprehensively represent the specific topic of interest and assessment goals, and thus reflect the specific target population and context, insufficient research has been undertaken in this field.

Ruijs and colleagues¹⁷⁹⁻¹⁸¹ were the first to develop and test the State of Suffering-V (SOS-V), an assessment tool that directly addresses unbearable suffering in the end-of-life context. However, being developed for terminally ill cancer patients, it may not be a valid tool within a psychiatric patient population that may present with less apparent biomedical conditions, while still experiencing a high level of suffering, a construct which may be apparent to the patient, yet less salient to physicians.

Unfortunately, there is no generally accepted theoretical model of suffering nor definition of unbearable suffering in the end-of-life context.¹⁷⁷ Moreover, the existing definition does not include psychiatric patients' perspectives on unbearable suffering. To date, only two studies, both qualitative, have addressed psychiatric patients' perspectives on unbearable suffering^{206,250} of which one exclusively dealt with suffering experiences of psychiatric patients with a euthanasia request.²⁰⁶ This study yielded 44 terms that participants used to describe the nature and extent of their suffering,²⁰⁶ a useful starting point in the development a new assessment instrument.

Given that unbearable suffering is an important condition for legally granting euthanasia requests, yet suffering and death requests remain uncomfortable topics of discussion during physician-patient consultation¹⁷⁰, support is sorely needed. In order to serve in practice, an assessment instrument (similar to the SOS-V, but tailored for psychiatric patients) that can help professionals and patients discuss the intensity and duration of patients' suffering experiences needs to be carefully developed and standardized. Given the inherent subjective nature of suffering experiences, it is paramount that the items comprising such

an instrument have high cognitive validity (achieved when all items are interpreted by the target population as intended by its developers and end-users, and free from bias introduced by, for example, social desirability²⁵¹⁻²⁵⁵). Studies assessing cognitive validity for new and validated measurement instruments typically find those measurement instruments lacking in both respect.²⁵⁶⁻²⁶⁰

This study aimed to optimize the cognitive validity of an initial item pool that was derived from a qualitative study.²⁰⁶ The resulting item pool can then serve as a starting point for further study as well as the development of an instrument that can assist professionals and patients in discussing the patients' suffering experiences.

Methods

Research design

We applied Rattray and Jones' eight stages in developing an assessment instrument²⁶¹ and Willis' cognitive interviewing protocol²⁶² to design the procedure used when conducting the face-to-face cognitive interviews with psychiatric patients, with or without euthanasia request.

The questionnaire was developed in eight consecutive steps, which were undertaken in a series of three phases: Phase one (three steps) involved the generation and scale construction based on relevant literature; phase two (subsequent three steps) concerned the evaluation of item answers, including the relevance of the answers produced, including stylistic and formal criteria, all followed by basic statistical analyses; phase three (final two steps) focused on the development of a final version of the instrument, to be tested with regard to additional psychometric qualities in case of unidimensional constructs (variables).” The full procedure utilized in this study, including the first three steps of Rattray and Jones' eight-step plan, that were followed in order to define both the need for as well as the structure of a new questionnaire, are listed and described in detail in the supplemental document on [OSF](#).

Original item pool

The working title of the initial item pool on suffering was the 'Nature and Extent Of Suffering indices' (NEOSi). It contained 71 items that were based on the domains and descriptors of suffering, as identified in the qualitative study that produced the item pool.²⁰⁶ Two separate, but related, item pools map the nature (NOSi) and extent (EOSi) of suffering experiences.

Nature of Suffering index (NOSi): this first item pool contained 62 items examining the frequency and intensity of different aspects of unbearable suffering. Out of consideration for the target population's vulnerability, these items were then sorted into eight clusters, which were then ranked from 'concrete' and 'emotionally safe' to 'abstract' and 'potentially emotional'. Specifically, these clusters were: 1) medical complaints (e.g. "Clearly demonstrable physical complaints, such as gastrointestinal infections, cardiac arrhythmias but also hearing loss."), 2) problems with former or current therapies and diagnostics (e.g. "Negative experiences with diagnostics (diagnosed falsely or too late)"), 3) physician-patient communication problems (e.g. "The feeling that physicians do not completely understand you and your experience with suffering"), 4) the euthanasia procedure (e.g. "The fact that the euthanasia procedure takes quite some time and energy"), 5) financial and work-related problems, (e.g. "Financial worries (low income or debt)"), 6) social problems (e.g. "Conflicts with important others (partner, kids, family, friends)"), 7) traumas (e.g. "The experience of a sexual trauma during childhood"), and 8) feelings and fears (e.g. "The feeling that your suffering experiences have deprived you of your dignity as a human being").

Each cluster was titled and its questions prefaced. Responses to each item were registered using two side-by-side Likert scales. The first scale measured frequency and consisted of five answer options using the labels 'never', 'yearly or less', 'monthly', 'weekly', and 'daily'. The second scale measured intensity and consisted of four answer options using the labels 'non-existent', 'slightly disturbing', 'deeply disturbing', and 'overwhelming'. Each cluster was followed by an invitation to answer an open-ended question regarding whether the participant experienced additional contributors related to a given experience associated with suffering.

Extent of Suffering index (EOSi): This item pool contained nine questions combined with Visual Analogue Scales (VAS) to assess the extent of patients' overall evaluation of their suffering experiences with respect to *intensity* (e.g.: "How would you describe your suffering in general?" anchored by "bearable" versus "unbearable"), *duration* (e.g.: "How long have you been you suffering?", with anchors "at short term" versus "at long term"), *chronicity* (e.g.: "How often do you suffer from the symptoms of your disorder(s)?", with anchors "sporadically" versus "continuously"), and *perspective* (e.g.: "How do you feel concerning your situation?", with anchors "hopeless" versus "hopeful"). Each VAS used a slider with minimum value of 0 and maximum value of 100. Higher scores indicated more intense and salient suffering. The full lists of original, adjusted and final items are available at the OSF repository.

Procedure

Sampling and recruitment strategy

In order to be eligible to participate in this study, participants had to be legally competent and Dutch speaking adults. Individuals presenting with acute grief, signs of acute substance abuse, psychosis, and dementia were excluded.

Potential participants were recruited via two approaches. First, MV contacted patients with psychiatric diagnoses through her extended social circle; second, an independent psychiatrist recruited potential participants with at least one psychiatric diagnosis and a currently active or withdrawn euthanasia request.

Procedure cognitive interviews

The first round of cognitive interviews took place from August through September of 2016. Before the start of the cognitive interview, four initial questions were asked: age, gender, diagnosis and whether the participant had requested euthanasia.

MV conducted all interviews with study participants. A psychiatrist was always on call (but not present), to offer medical and emotional support if needed.

Two cognitive interviewing methods were combined. The basic paradigm was the 'think aloud' method, in which each participant was asked to read out loud, comment on and discuss the items, and, subsequently, had the option to pick a (non-) numeric score which represented her answer to the item. The theoretical evidence is based on Ericsson & Simon's work²⁶³ in which a distinction is made between the cognitive processes of 1) the working memory for concurrent reasoning and 2) long-term memory for retrospective reasoning.

The goal of think-aloud research is to get a deeper insight into the processes of working memory. However, as not all information reaches our working memory, because of its limited capacity to store information, and as working memory has the tendency to be overruled by new information, only verbally expressed information that follows very rapidly after a thought process can be perceived as the most accurate reflection of participants' thoughts. However, with regard to this methodology, Ericsson and Simon warned that the repeated practice of a task might lead to automaticity before thought processes could be reported.²⁶³

Therefore, the think aloud technique was combined with 'probing', where the researcher asked supplemental questions regarding how items and answer categories were understood, interpreted, and evaluated, whether the questions and answer options were precise and easy-to-answer, and whether there were omissions or ambiguities.²⁵⁵ The following issues were probed when no information was spontaneously provided: 1) relevance, 2) interpretation, 3) clarity, 4) linguistic correctness, 5) sequence of clusters, questions and answer options and layout in general, and 6) social desirability answering risk. As is generally the case, iterative rounds of interviews needed to be scheduled before data saturation and cognitive validity had been reached (i.e. no new information gained after at least three successive interviews).^{251,264,265} Finally, each participant was asked to provide their general opinion on the items, research topic and method, and willingness to participate in follow-up research. Each remark from the participants was noted in order to enable adjustments to the research procedures in future studies. When suggestions or opinions of participants differed, the opinion of the majority was considered when implementing changes. However, all remarks were noted for closer investigation in a second round of cognitive interviews, which took place from October through

December 2016, in which slight changes to the interviewing procedure were implemented (see Results and [OSF](#)).

To ensure participants' privacy, cognitive interviews were not recorded, but instead written down as carefully and literally as possible. During transcription of these notes, attention was paid to participants' anonymity. Transcripts were then saved in a folder on a secure server and coded in QualiCoder (qualitative data coding software).²³³ All participants were offered the opportunity to review the manuscript and – if applicable – to correct their quotes.

Analyses and criteria

Cognitive interviews were systematically analysed according to the criteria of Willis²⁶⁶ and are schematically represented in the [OSF](#) repository. The following overarching themes were used as guidelines: 1) item interpretation (with item interpretation issues as subthemes), 2) item formulation (with vagueness and nuances as subthemes), 3) language (with typing error, word choice and grammar as subthemes), 4) sequence (with cluster sequence and item sequence as subthemes), 5) answer categories (with frequency and intensity as subthemes), 6) introduction, 7) lay out, and 8) opinion (with NEOSi, research topic and research method as subthemes). The theme coding model with codes representing the key findings were first labelled as brief keyword-type subthemes and then covered in overarching themes.

Ethics

This research project received provisional ethical approval from the Ethics Review Board (ERB) on Research (cETO) of the Open University with reference U2016/03311/FRO (pending approval by a Belgian ERB) and definite approval of the Medical Ethics Committee of the Vrije Universiteit Brussel (VUB) with reference B.U.N. 143201628847.

Results

Participants of the first round of Cognitive Interviews

The sample consisted of nine adults between 35 and 76 years of age. All participants with a euthanasia request were female, as well as one out of four without. Depression ($N = 6$) and autism spectrum disorders ($N = 3$) were the most common diagnoses. The interviews lasted between 60 and 210 minutes (Table 1).

NOSi: Feedback on Items

Of the 62 NOSi-items, (potential) problems were identified in 54 items (87%), mostly with regard to precision of interpretation, inadequate formulation of item and answer options, imprecision in language or the need for more accessible language, formal and structural aspects, and omission of 20 relevant suffering aspects.

Participants suggested the following adjustments: 1) reformulate items in order to make them univocal; 2) split items when certain elements represented various components of suffering; 3) include fewer, other or no examples when items were clear by themselves, to avoid invoking a specific mindset; 4) include relevant examples to broaden participants' mindset or to clarify the item subject; and 5) add new items that relevantly contribute to suffering experiences.

Finally, participants provided feedback concerning language and formal aspects, including word choice, grammar, and typographical errors. Furthermore, participants commented on the need for overt, rather than vague, statements or questions. For example, 'personal experiences' was used to cautiously describe 'traumas', though the majority of participants found this caution inappropriate because it insufficiently acknowledged crucial components of their suffering.

Regarding the options given to subjects when conveying the frequency of suffering, participants expressed a need for more precision and nuance: the gap between 'daily' and 'weekly' and, especially, the gap between 'monthly' and 'yearly' was considered too large. Moreover, the answer option 'never' was susceptible to double interpretation. For example, on the item 'Negative

experiences in psycho-diagnostics (wrong diagnoses or diagnosed too late), endorsing 'never' could either mean never having experienced this, or never having been diagnosed at all. Participants suggested including 'not applicable/never'. As for intensity, participants also expressed a need for more precision and nuance, based on the gap between 'deeply disturbing' and 'overwhelming'. (See the [OSF](#) repository for a full overview of all problems and adjustments).

NOSi: additional feedback

Participants' feedback on the introduction and structural aspects of the NOSi implied the need for indicating the number of items per cluster and changing cluster and item sequence. Participants suggested putting key themes (e.g. 'traumas' and 'social problems') at the beginning of the questionnaire and dividing the cluster 'social problems' into 'social problems with (important) others' and 'societal problems' because these imply different consequences. The participants suggested merging both clusters 'physician-patient communication problems' and 'treatment and diagnostics' because of their perceived interrelatedness. The last cluster 'feelings and fears', contrary to other clusters, was not perceived as a stand-alone suffering category.

EOSi: feedback on questions and anchors

Participants provided suggestions on how to improve eight of the nine questions and/or their anchors, given that item formulation was perceived as too vague (e.g. 'all sorts of problems') or subjective (e.g., when asked for the duration of suffering with the anchors 'short versus long' some participants expressed the need to correct for age while others did not). Suggestions were made to reformulate questions and include other anchors.

Issues with lay out and word choice in the introductory text were also identified by the participants. The use of 'future life perspectives' was perceived as inappropriate in euthanasia requests and it was suggested to change this term into the more neutral wording of 'future expectations'. Finally, one participant

refused to use the slider, instead using a grade from 0 to 10 to answer the negatively formulated anchor option. Afterwards, this participant suggested implementing this scoring system in the NOSi as well (see the [OSF](#) repository for an overview in Dutch, including illustrative quotations, leading to an adjusted NEOSi).

Opinions concerning NEOSi in general

All participants, except one, perceived all items as relevant and – when not applicable to themselves – applicable to others. Some participants spontaneously described their most genuine suffering experiences with terms such as ‘hopelessness’, ‘being tired of life’, ‘being through with life’, ‘loss of dignity’, and ‘suicide or self-destruction’. All participants appreciated the opportunity to clarify their suffering experiences with open-ended questions. Two participants indicated their opposition to filling out the NEOSi online, strongly preferring verbally conducted interviews (e.g. due to dyslexia). One participant advised including an additional open question at the end of the questionnaire to ensure no suffering aspects had been overlooked. Furthermore, the general question “Have you requested euthanasia?” also gave rise to differences in interpretation. Although the supervising physicians only referred participants with a current euthanasia request, some participants stated that they did not request euthanasia, as they perceived their euthanasia request as something preliminary if they had not yet officially put their request in writing, not yet discussed it with important others, or if it had been withdrawn or not (yet) been declared eligible. We, therefore, decided to include the following extra answer options for this question: “Yes/No, still considering”, “Yes, but it has not (yet) been declared admissible”, “Yes, the euthanasia procedure is ongoing”, “Yes, in the past, but it has been declined”, “Yes, in the past, but I withdrew it” and “No”, to be cognitively tested during the second round of interviews.

Opinions on research topic and method

All participants vocalized an appreciation for both the topic of study and the methodology utilized. Specifically, participants expressed appreciation for the

length, explaining that other, shorter questionnaires were often perceived as insufficiently addressing the core of the matter. In addition, the broad scope of the NEOSi was appreciated, as well as the fact that patients were involved as 'essential experiential experts' in this early stage of research. Participants also expressed their hope that the NEOSi could eliminate the taboo of unbearable mental suffering. Moreover, participants with a euthanasia request also declared that the NEOSi gave them the feeling that they were being taken seriously and their suffering acknowledged. Two participants revealed they had shared issues with the interviewer that have not (yet) been discussed in detail with the physicians involved in their euthanasia request. Finally, participants explained the cognitive interviews were not perceived as emotionally strenuous, but rather as comforting because they offered the possibility to talk openly, and without reservations, about their suffering experiences and –when applicable– their euthanasia request. Because these results were inconsistent with both our and the consulted ethical committees' prior expectations, we contacted the supervising physician, responsible for participant recruitment before, and well-being after, the study, who confirmed this finding. All participants were willing to participate in the follow-up study for further item pool improvements.

Second round of cognitive interviews: changes in methods

A second round of cognitive interviews was deemed essential to further optimise the cognitive validity of the highly adjusted NEOSi in order to detect whether the problems were resolved adequately, whether new problems surfaced, and to explore broad-based acceptance of form and content. The recruitment process was focused on recruiting more male participants with a euthanasia request, as the former population consisted only of females. The sample consisted of ten adults (six men and four women), five of whom had participated in the first round of cognitive interviews. The participants of the former study that could not participate were willing to participate at a later time but declined the invitation due to acute health or familial problems or need for a mindset completely focused on rehabilitation. Of the participants with a euthanasia request ($N = 6$), one had only recently requested euthanasia ($N = 1$), while others still had a euthanasia procedure that was ongoing ($N = 2$) or recently granted ($N = 1$), or had indefinitely withdrawn their euthanasia request ($N = 2$). For more

information on the sample, see Table 1. For more information on the recruitment procedure, see the [OSF](#) repository.

The feedback from the first round had been used to develop a total of six versions of the NOSi. Each contained 92 items, 20 of which were new and had been added based on participants’ feedback in the first round. In one version, the items were alphabetically ranked; in another version, items were clustered according to the five domains that were identified in the qualitative study on unbearable suffering of psychiatric patients with euthanasia request (medical problems, personal problems, interpersonal problems, societal problems, and existential problems).²⁰⁶ These two item orderings were combined with three response registration formats: Likert scales, visual analogue scales, or text entry fields to enter a number from 0 to 10. The EOSi still contained nine questions assessing the extent of suffering experiences with respect to intensity, duration, chronicity and perspectives, but with two response registration formats: one with a 5-point Likert scale and one with a visual analogue scale. Hence, six NOSi versions and two EOSi versions were reviewed. For detailed information on when which NOSi and EOSi version was presented and discussed, see our [OSF](#) repository.

Table 1: Participant’s Characteristics and Duration of the 1st round of Cognitive Interviews

Gender	Age	Diagnos(i)(e)s	Euthanasia Request	Duration interview (min)	
				1 st	2 nd round
Male	39	Burnout	X	90	60
Male	38	Depression	X	135	180*
Female	43	Autism Spectrum Disorder	Yes	120	180
Female	43	Eating Disorder Post Traumatic Stress Disorder Depression Autism Spectrum Disorder	Yes	60	X
Female	42	Burnout Depression Borderline Autism Spectrum Disorder Substance Abuse	Yes	150	X
Female	57	Eating Disorder Depression	Yes	150	X
Male	76	Depression	X	75	X
Female	51	Depression Dyslexia	X	210 ^a	150 ^a

Female	35	Post-Traumatic Stress Disorder Eating Disorder Bipolar Disorder	Yes	120	105
Female	29	Autism Spectrum Disorder Post Traumatic Stress Disorder	Yes	X	150 ¹
Male	55	Substance Abuse	X	X	135
Male	48	Autism Spectrum Disorder with psychotic features	Yes	X	150 ¹
Male	44	Autism Spectrum Disorder	Yes	X	180 ¹
Male	61	Post Traumatic Stress Disorder Depression	Yes	X	90

¹ Including smoke and/or coffee/thee breaks, in which memories of suffering experiences were shared with the executive researcher.

Table 2: Participant’s Characteristics and Duration of the 2nd round Cognitive Interviews

Gender	Age	Diagnos(i)(e)s	Actual/Former Interview	Duration Interview (min)
Male	39	Burnout	No	60
Male	38	Depression	No	180 ¹
Female	43	Autism Spectrum Disorder	Yes	180
Female	29	Autism Spectrum Disorder, Post Traumatic Stress Disorder	Yes	150 ¹
Male	55	Substance Abuse	No	135
Male	48	Autism Spectrum Disorder with psychotic features	Yes	150 ¹
Male	44	Autism Spectrum Disorder	Yes	180 ¹
Female	51	Depression, Dyslexia	No	150 ¹
Female	35	Post Traumatic Stress Disorder, Bipolar Disorder, and Eating Disorder	Yes	105
Male	61	Post Traumatic Stress Disorder, Depression	Yes	90

¹ Including smoke and/or coffee/thee breaks, in which memories of suffering experiences were shared with the executive researcher.

During the cognitive interviews, the same cognitive interviewing techniques and criteria were employed as in the first cognitive interview round.²⁶⁷ Additionally, to test social desirability, the participants were asked if their answers would be similar if asked in a different context, such as online or with a different interviewer. As opposed to the first round of cognitive interviews, when a participant made a suggestion or remark, this was probed further in later interviews with all subsequent participants, right before the following item, in order to gauge data saturation and hence, ultimately higher cognitive validity. At the end of the cognitive interview, whether and why there was a need to include an open question was asked by MV. As opposed to the first round of cognitive interviews, a broad support base on item relevance, content and sequence, as well as preference and convenience concerning layout out and sequence was sought: we set the criteria that the NEOSi was to be adjusted in case of $N = 8$ for feedback about layout and sequence and in case of $N = 4$ for content-related

feedback. In the case that these criteria for adjustment were not met, alterations to the NEOSi were to be made according to the majority's preferences and a third round of cognitive interviews would have to be organized.

Second round of cognitive interviews: results

NOSi: feedback on items

In general, participants perceived the items of the adjusted NOSi as sufficiently comprehensible, sensitive to delicate nuances, and complete. All participants recognized the suffering aspects in themselves and/or in others. However, suggestions for possible improvements were made in 35 of 92 (38%) NOSi-items on grounds of potential issues with interpretation, formulation, language, and missing relevant aspects of suffering.

As for interpretation, feedback was given on items that were perceived as possibly insensitive to nuances, although it did not lead to misunderstanding between participants. For example, item 48, 'thoughts about suicide or other self-destructive behaviours (e.g. cutting, burning or other self-injuries)' was commented on as follows:

"I know what you mean and to me it's clear, but please pay attention don't miss anything with people that are taking alcohol or drugs. (...) Besides, self-harm can also include poor, bad or not eating, don't forget that. You can also neglect taking care of yourself. Always working overtime could be seen as self-harm behaviour as well. You can also be self-destructive by means of self-isolation, as the more people are actively involved in your social network, the more chance you have of being protected when things might go the wrong way. Now your item examples only contain active behaviours, but that doesn't cover self-destructive behaviour, as a lack of actions can be self-destructive as well. Maybe you can include additional examples as 'poor diet or malnutrition', 'too many drugs', etc."
(participant with euthanasia request)

Participants suggested to make the following adjustments: 1) to reformulate items more accurately and precisely; 2) to include other examples to broaden participants' mindset; and 3) to add new items that relevantly contribute to the NOSi. Five items were added during probing ($N = 2$) or at the end of the NOSi questionnaire ($N = 3$). Although these new items were not perceived as key criteria for patients' own unbearable suffering, they were added to the adjusted NEOSi. The most commonly reported problem with the NEOSi was that the items specifically related to the euthanasia procedure were perceived as potentially inappropriate due to: 1) answer options dependent on the specific phase of the euthanasia procedure; 2) applicability also outside the euthanasia context; 3) possibility of provoking a euthanasia request, or 4) potentially too shocking (for one participant without euthanasia request). Suggestions were made and approved by the next participants to further improve the NOSi via: 1) item reformulation, 2) merging items, 3) splitting items, or 4) removing items.

In general, all participants agreed with the content of both answer categories, although the gap between 'one or more per month' and 'at most, once or more per year' for frequency was found to be too large and poorly formulated. As for intensity, there was broad support ($N = 9$) for the NOSi version using a grade from 0 to 10 because it was 1) more sensitive to nuance and 2) the value behind the answer options was clearer and more insightful.

Additional problems and adjustments NOSi, and preferences

Participants gave feedback on the introduction and structural aspects of the NOSi that implied: 1) a more precise time indication in the introduction, 2) a more logical item sequence, 3) layout, and 4) removal of small inaccuracies (e.g. too much whitespace).

Broad support ($N = 8$) for the clustered version was substantiated as a way to avoid: 1) the tendency to look back and detect possible double items, 2) difficulties in answering the items precisely because the sensitivity in nuances could only be detected when looking back to similar items, and 3) suddenly and abruptly changing from items on general suffering aspects, e.g. going back and

forth between questions concerning general irritations versus deep, personal emotions and experiences was perceived as too exhaustive or confusing.

“Sometimes you can only see the nuances between items if they are clustered together. Now I often wonder: Haven’t I already answered it?(...) It is confusing to me. I would stick with the items on physicians and other aid workers, then the items on people in the social inner circle, then items on society and finally the microcosm-like items. Now it’s a jumble and that’s why I find it difficult to answer.” (participant without euthanasia request)

EOSi: feedback on questions and anchors

Participants suggested reformulation of four out of ten anchors, especially concerning the duration of suffering experiences. Feedback was given on notions of problems and difficulties in life preceding the awareness that these notions could be designated as suffering. Other anchors were still perceived as too vague (‘short versus long’) or not befitting a suffering-related questionnaire (‘promising perspectives’). Participants’ suggestions to reformulate anchors were approved by the next participants. As for word choice and layout, no comments were made.

Four participants strongly preferred a Likert scale over a visual analogue scale (VAS), explaining that it: 1) allowed more precise answers, 2) avoided the risk of respondents just drawing a line without thinking and 3) was easy to answer, based on some of the participants’ observation that they would need to have used a ruler in order to give a correct answer. Four others slightly preferred the VAS as it was perceived a less ‘categorical’ than a 5-point Likert scale due to the sensitivity of nuance if and only if the adjusted EOSi would get a small vertical line to indicate the middle. Two other participants indicated no preference, as they stated that both scales were easy to comprehend and utilize to convey their responses. The participant who refused to use a VAS and insisted on giving a report mark in the former study was now more in favour of the Likert Scale method. See the [OSF](#) repository for a concise or complete overview of all

problems and suggestions (in Dutch).

Additional feedback on NEOSI

Participants of the first round commented that the adjusted NEOSi contained 1) fewer items that were subject to misinterpretations, 2) clear, accurate, concise and nuanced items, 3) answer categories that were easier to answer and more accurate, nuanced and complete. Most participants declared both a few times during, as well as after the interview, that the sensitivity for nuances was the most positive improvement, e.g. the difference between 'hopeless' versus 'without prospect'.

"It's good that you pull these apart, because they are slightly though really different in their essence. Hopeless is more like a feeling: it could refer to something depressing or another screwed up feeling. But 'without prospect' refers more to a context, a situation and as such contains something more rational, calculated or so. Something that you can evaluate over time, on a thoughtful way, well-considered or so, while hopelessness is more a feeling that suddenly you can be overwhelmed with."

(participant without euthanasia request)

Participants declared that nuances within the (phrasing/scoring) allowed greater variability within their responses to particular items and thus, their suffering experiences could be more accurately addressed (e.g. not only gauging a disorder, but also deeper, underlying, existential feelings). For example, one participant with a mood disorder stated that the item 'feeling/conviction that you are a burden to others' can be interpreted through a spectrum of intensities, with a general distaste for burdening others on one end and a true symptom of depression on the other, where an individual may feel, "*not being worthy to breathe and take oxygen out of the air, as others seem to have more right to it,*" (participant without euthanasia request). In addition, three participants recommended the executive researcher during or after the cognitive interview to use the NEOSi to assess the evolution of suffering by means of identifying the

possible influence of a more temporary episode inherent to a fluctuating disorder (multiple measurements). Moreover, participants suggested that the NEOSi should be used to assess differences in the nature and extent of suffering in patients with and without psychiatric diagnosis, as well as in psychiatric patients with and without euthanasia request. For instance, a possible distinction had been reported in items 35 (not or no longer having a role, function or meaning in life) and 39 (being tired of or done with life) as well as items related to negative experiences in personal background, mental aid and social contact.

The fact that the adjusted NEOSi contained 30% more items than the initial version was positively perceived as exhaustively addressing various forms of experiences with suffering. Nevertheless, every participant preferred to include an open question at the end, even participants who had no further information to include. There were two underlying rationales: to guarantee that no aspects of suffering or additional feedback were missed, and that emotional steam could be let off when needed. During and even after the cognitive interview, each participant with a euthanasia request spontaneously pointed out altogether up to 44 NOSi items as crucial aspects of unbearable suffering, and as a potential consequence, of a euthanasia request. Finally, participants also declared they would give the same honest answers regardless of whether the NEOSi was administered verbally, in writing or online.

Feedback on research topic and method

All former and new participants appreciated being involved in the research topic and method in the same terms as expressed in the initial study. During, as well as after, the cognitive interview, one patient with a euthanasia request said the NEOSi gave insight into many aspects of life that were still positive, providing the individual with extra motivation to pursue alternative treatment strategies.

“Gradually I realised how lucky I am. I do have great physicians with whom I can talk openly. I do have friends and from an economic point of view, I don’t have financial difficulties. It’s like I told you on the phone, yesterday. The first time I came here, I saw other people in the corridor

that were, how should I explain it... living more on the margin. Don't get me wrong, no offense, but you could see poverty by means of having lost everything. You can see it in people, sometimes, that they have lost everything. I'm not like them. And now by commenting this questionnaire I realize again what I still have, that despite everything, how well off I actually am."

(participant with euthanasia request)

Discussion

During the first round of cognitive interviews, participants suggested to make changes in 62 of 71 initial NEOSi items due to problems related to content, form and language. By thoroughly adjusting and presenting different NEOSi versions for feedback and transferring this feedback to the next participant during a second round of cognitive interviews, there was broad support for the adjustments to and commonly shared preferences on clustered items, item sequence and logical structure. This allowed enhancing the cognitive validity of the final item pool.

In addition, when participants compared the length of the NEOSi with other, often shorter questionnaires, the shorter versions were often perceived as not addressing the core of the matter sufficiently, which may suggest that these surveys were lacking in content validity. In general, the results of the first and second round of cognitive interviews are in line with other cognitive validation endeavours showing that items and answer options (in both new and validated instruments) are often interpreted differently between the developers and the target population, and as such may interfere with proper measurements.^{256,258–260}

This also underpins the need for cognitive validation studies to detect and eliminate these obstacles. This endeavour could be an aim, and a necessary component, of subsequent quantitative (validation) study.^{256,257} Cognitive interviews can also detect end-users' preferences and facilitates developing an end-user-friendly questionnaire. For example, initially, a short VAS-scale had been chosen to assess the extent of suffering, as this tool has often been used to research pain, perceived quality of life, and changes in medical treatment effects.

It also generates high face validity when directly examining patients' experiences.²⁶⁸ Although participants declared both versions were proper and easy to answer, some strongly preferred the Likert Scale and it was, therefore, chosen by the research team for the final adjusted EOSi version.

The methodology of cognitive interviewing resulted in rich, anecdotal evidence, encouraging participants to give extensive feedback on aspects such as item interpretation and sequence, layout, and missing items until data saturation had been achieved.²⁶⁵ Long and comprehensive face-to-face interviews, taking place in a serene atmosphere, allowed the interviewer to bond with the respondents while also keeping an eye on their body language, leading to many opportunities to delve further into their experiences, opinions and feelings.

Due to the scarcity of studies among the psychiatric patient population with euthanasia requests, there was a lack of knowledge on how participants would cognitively and emotionally react during this research project. Results showed that participants acknowledged the study's value and relevance in reducing the negative stigma associated with psychiatric euthanasia requests. They highly appreciated being involved in the early phase of instrument development, which was reflected in the fact that participants were willing to participate in a follow-up study. Participants with euthanasia requests declared that the nature and duration of the cognitive interview offered them a degree of consolation as they could talk openly, while being taken seriously, about their experience with suffering unbearably. This reaction to our study is in accordance with the results of an interview study on respondents' satisfaction, summarised in terms of being heard and making meaningful, relevant contributions via trustful, respectful communication.²⁶⁹ These findings are remarkable as both the research team and Ethics Committees had concerns about possible negative consequences for this highly vulnerable patient group.

Moreover, the fact that these patients did not conceal certain aspects of their suffering but clearly discussed even the most sensitive issues, emphasizes the value and necessity of involving this particular target population in further research endeavours. This result aligns with previous studies which showed not only a lack of adverse long-term effects in participants involved in psychiatric research (only a minority showed more distress immediately afterwards), but positive, rather than negative, reactions to the study itself.²⁷⁰ Although their

results were based on small sample sizes, a recent meta-analysis showed that exposure to suicide-related content paradoxically even reduced suicidal ideation and attempts. Especially interview-based studies had a positive impact on respondents (e.g. decrease in distress).²⁷¹

The validity of this tool in a variety of psychiatric patient populations should also be considered. Some authors consider a patient's euthanasia request as a symptom of suicidality, necessarily rooted in a patient's (underlying) depression.^{272,273} However, systematic review on suicide revealed that while high levels of mental pain indeed contribute to a higher risk for suicidal tendency, it does so independently from depression.²³⁷ Moreover, empirical evidence shows that in most terminally ill patients with a euthanasia request, no depressive disorder was found.²⁷³⁻²⁷⁵ The available evidence, albeit scarce, consistently shows that not every psychiatric patient with a euthanasia request suffered from mood disorders.¹²⁶ Moreover, some of these patients, even after having their euthanasia requests granted, withdrew their request, whereas others still committed suicide.¹²⁶ These data are in line with this study, in which four patients with a euthanasia request did not suffer from a mood disorder whereas three patients presented with such a disorder, but had not requested euthanasia.

It should be noted that because a convenience sample of psychiatric patients was used (i.e. either selected from the broad inner circle of the executive researcher or recruited by a supervising psychiatrist), it is possible that the item pool's apparent cognitive validity does not hold in the wider target population. It remains also vital to attend to participants' well-being before, during and after future data collection efforts. This problem can be addressed by administering the NEOSi face-to-face. In addition, as sampling was relatively limited, additional items as well as additional enhancements in item formulations, may emerge in future research.

Future research will be able to explore the validity of these statements by exploring how answers to surveys online, in person or via other media may differ. It should be considered, however, that even in the case of consistent, reliable answers being given across surveys presented in various medias forms, if each (or any) respondent is perfectly able to introspectively assess a given question with complete accuracy. If the NEOSi were used in clinical practice, this could lead to certain responses being given and perhaps a social desirability bias

depending on the patient's situation. As for patients asking a physician for euthanasia, they might feel the urge to portray their suffering in a more extended, frequent and intense way.

Although the study protocol had set a duration of approximately one hour according to the guidelines²⁶⁶, some interviews lasted more than two hours due to many personal memories, feelings and thoughts shared with the interviewer. Future research should take this into account when research concerns a sensitive topic that is regularly considered taboo, as participants may use this opportunity to discuss the topic in an open, non-judgmental setting. The interviews were not recorded to ensure participant's privacy and candid conversation, which also may have affected participants' openness as well as accurate conversation reproduction (note that any quotes used in this text were verified by the respective participants).

With regards to content, the results are consistent with the observation that suffering is not limited to the psychological or physical symptoms of the disorder.^{206,250,276} It is noteworthy that participants stressed the importance of a good patient-physician relationship, characterized by open, empathic and transparent communication, with respect for patients' perspectives and opinions on suffering and, if applicable, a death wish. Many of these patient needs have been raised in former research studies in the euthanasia context.^{170,277} The result that one participant with an ongoing euthanasia procedure declared that the NEOSi gave insights in the many positive aspects of life, leading them to reconsider further treatment options, anecdotally and paradoxically suggests that a comprehensive discussion of the nature and extent of suffering may have preventive effects. This may imply that in the clinical context, shying away from the suffering experiences and eventual death wish during consultation with the patient may have the unintended effect of contributing to their suffering and eventual death wish.

The item pool resulting from this study (available in its entirety at [OSF](#)) can help to understand the multi-dimensional construct of unbearable suffering and can aid professional-patient interactions in clinical practice. A comprehensive discussion on the nature and extent of suffering during physician-patient consultation may have preventive and curative effects. However, as suffering is a multidimensional and complex construct, a purely medical approach might be

insufficient, especially in psychiatric patients. Some correlates of suffering (e.g. social, socio-economic and financial difficulties) indicate the need for a broad medical, societal and politic debate. The cognitively valid item pool we presented can facilitate these discussions and help achieve a deeper understanding of the entire experience and meaning of unbearable suffering, extending the medical perspective.

As suffering does not seem to be a unidimensional psychological construct and thus difficult to 'measure', a fully-fledged psychometric quantitative follow-up study to further optimise psychometric qualities (e.g. the COSMIN checklist²⁷⁸) or to determine cut-off scores is ethically and scientifically not appropriate. As the concept of suffering has not been sufficiently examined and is, thus, poorly understood, more qualitative research is required in order to obtain deeper and clearer insight in the construct of suffering and its (underlying) properties. For example, in depth-interviews with patients who persisted in and patients who withdraw their euthanasia request, and interviews with patients, their relatives and physicians on suffering can reveal important insights into the overall concept of suffering.

Once a clear insight into the concept of suffering, specifically within the domain of end-of-life care, has been obtained, further quantitative research might reveal other aspects of suffering that were previously missing. Moreover, as our patient sample might not be representative of the whole spectrum of suffering in psychiatric patients, in terms of determinants such as marital status, SES and the influence of cultural/religious differences, further research may shed light on the clinical, personal and social backgrounds of psychiatric patients requesting euthanasia and the (differences in the) nature and extent of their experienced unbearable suffering. Finally, our patient sample might also not be representative, as the voices of APC non-proficient in Dutch or not willing or capable to participate via face-to-face communication for reasons of privacy and anonymity, or being more skilled in written communication, might be missing. Future research can make use of in real life and digital, as well as verbal and or written communication modes. It can also be more culture-sensitive by e.g., engaging an interpreter proficient in the participant's language during interview studies.

Lastly, a longitudinal research design will help us to further explore changes in suffering experiences over time and differences in patterns of suffering between and within groups. Specifically, studying the experience of suffering between patients with and without a euthanasia request, as well as between patients having their euthanasia requests denied, rejected, still under review or granted, may help us learn more about the relationship between the suffering and the potential outcomes of a euthanasia request.

CHAPTER 6 :

WHY ADULTS WITH PSYCHIATRIC CONDITIONS REQUEST EUTHANASIA: A QUALITATIVE INTERVIEW STUDY OF LIFE EXPERIENCES, MOTIVES AND PREVENTIVE FACTORS

Verhofstadt M, Pardon K, Audenaert K, Deliëns L, Mortier F, Liégeois A, Chambaere K. Why adults with psychiatric conditions request euthanasia: A qualitative interview study of life experiences, motives and preventive factors. *Journal of Psychiatric Research*. 2021;144:158-167.
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More detailed information is posted in the Open Science Framework repository accompanying this paper: <https://osf.io/j9fvz/>

“A thing there was that mattered; a thing, wreathed about with chatter, defaced, obscured in her own life, let drop every day in corruption, lies, chatter. This he had preserved. Death was defiance. Death was an attempt to communicate; people feeling the impossibility of reaching the centre which, mystically, evaded them; closeness drew apart; rapture faded, one was alone. There was an embrace in death.”
Virginia Woolf (Mrs. Dalloway)

Abstract

Objective

As the empirical picture of adults with psychiatric conditions (further referred to as 'patients') requesting euthanasia is still incomplete, this study aims to deepen our understanding of why these patients request euthanasia, how this relates to the option of suicide, and what could have prevented these-patients from considering death and requesting euthanasia.

Methods

A qualitative study using in-depth, face-to-face interviews was conducted with 16 patients who had their euthanasia request under assessment in the period 2016-2020. Thematic coding was used.

Findings

Most patients were in a state of feeling emotionally worn-out as a result of the many accumulated misfortunes and setbacks, leading to the all-pervasive sense that life is no longer worth living. Whereas some patients reported lifelong adversity, others struggled predominantly in later life. Whereas some patients longed for death strongly, others expressed ambivalence towards death ideation, and some even requested euthanasia to hear of their ineligibility for it, to restore hope and to (re)find meaning in life. Patients valued euthanasia over suicide as being more dignified and acceptable, both for themselves and for their inner circle. With regard to preventive factors, patients posited the need for improved accessibility and quality of mental healthcare, as well as a profound change in society's perception of, and support for, these patients.

Conclusions

This study revealed the many complexities of euthanasia in the context of psychiatry, due to the many differences in patients' background characteristics, in their motives for requesting euthanasia, and the multi-layered aspects of mental suffering that go beyond the field of psychiatry.

Keywords: euthanasia, mental disorders, end-of-life decisions, assisted suicide, psychiatry

Introduction

Assisted dying, defined as the act to end life by providing, prescribing or administering lethal medication at the competent patient's explicit request, is – under certain conditions – legal in an increasing number of countries around the globe.²⁷⁹ 'Euthanasia' refers to the act of a physician administering the lethal medication; 'assisted suicide' refers to the act of prescribing or providing the medication to the patient, who then self-administers it. Belgium is one of the earliest countries to enact euthanasia legislation.¹⁸⁵ Central requirements include having an incurable medical condition, and unbearable suffering that cannot be alleviated. Other eligibility and procedural criteria are listed in the appended Box 1 (see OSF). Belgium's legislation is one of the few – next to the Netherlands and Luxembourg – to make this option available to adults with psychiatric conditions. Canada is currently in the process of considering expanding current legislation to this patient group.²⁰¹

In the last decade, the annual number of reported euthanasia cases involving adults with psychiatric conditions (further referred to as 'patients') in Belgium rose steadily to 45 cases in 2014¹¹⁴, and then decreased to 23 cases in 2019.¹¹² Though these cases make up less than 1.5% of all euthanasia cases, much controversy and scrutiny – nationally and internationally – surrounds them, as some question the eligibility of these patients in principle, particularly with respect to whether and how their medical condition can be deemed incurable and whether suffering can ever be perceived as non-alleviable over a reasonable period of time. Compared to the most frequent euthanasia cases – the terminally ill cancer patient – the situations of these patients are arguably less clear-cut: notwithstanding the higher suicide risk, their death is usually not foreseeable within a short period of time, (the cause of) their suffering is less visible and clinically demonstrable, and it often originates not only from medical problems, but from an interplay of various social factors and a build-up of problems throughout life.^{206,280} For a systematic review of reasons in favour or against euthanasia concerning these patients, see Nicolini et al.¹³⁵

Insight into these factors and underlying life problems is crucial for an informed debate. The empirical picture is still incomplete. Previous research focused on

studying the key aspect of unbearable suffering in these patients who request euthanasia,^{206,250,280} and less on the underlying life experiences that lead them to request euthanasia. Other research has been based on second-hand accounts (e.g., psychiatrists)^{88,131,281,282} or case analyses¹³³, which likely do not fully capture the patients' life history. Therefore, it is important to study the key life events and experiences of these patients from their own perspective in order to fully understand their entire life context and the motives for their euthanasia request.

With respect to the patients' motives, one particularly relevant question (which has not been addressed to date) concerns the relation of a euthanasia request to suicide. The risk of attempted and/or completed suicide has been estimated to be 10 times as high in these patients than in the general population.²⁸³ It has been argued that the option of euthanasia may work to prevent suicide attempts, or may even serve as an alternative to suicide. On the other hand, euthanasia legislation may be seen as a means to regulate suicide legally, which is contradictory to mental healthcare's philosophy of suicide prevention at all costs.^{162,284-286} Therefore, it is worthwhile studying how patients view the option of euthanasia – in terms of its meaning and (dis)advantages – in relation to suicide.

Given the multitude of often non-medical factors involved in the patients' euthanasia requests, the argument can be advanced that certain factors can be prevented and/or managed, and that suffering can be alleviated sufficiently to not have to resort to euthanasia. Though studying life experiences and motives for euthanasia can give some degree of insight into preventive avenues, consulting patients directly and explicitly about their perceptions will provide a more solid body of evidence for practice and policy-makers to consider improvements in prevention, support and response. To date, this has also not been thoroughly researched, let alone with the patients themselves.

Therefore, our aim in this study is to address the gaps that we've noticed, through a qualitative interview study with patients with a euthanasia request. The research questions are the following:

- What are key events and experiences permeating the lives of patients who request euthanasia?

- How do patients phrase their motives for their euthanasia request – in general, and in relation to the option of suicide?
- What could prevent patients from considering death and requesting euthanasia?

Methods

Study Design

The semi-structured interview research design consisted of face-to-face interviews with Dutch-speaking adult patients with psychiatric conditions in Flanders, Belgium, who had their euthanasia request under review, i.e. under assessment by the treating physician in the period 2016-2020.

Participants

The participants were adults with one or more psychiatric conditions as primary basis for their euthanasia request. Patients with a euthanasia request primarily based on somatic disorders and secondarily on psychiatric comorbid diagnoses were excluded from this study. Patients that were – at the time of recruitment – considered by the recruiting physician/caregiver or by researchers MV and KP as emotionally too unstable ($n = 1$) were excluded from the study. No further exclusion criteria were employed.

Recruitment and interview procedure

Purposive sampling was used to ensure diversity and heterogeneity in diagnosis and procedural outcomes (i.e. euthanasia request not granted, under review, granted or withdrawn) and, hence, to minimise the risk of bias. Patients were recruited via different routes, with the assistance of: 1) physicians and caregivers working at the Flemish end-of-life consultation centre 'Vonkel' ($n = 12$); 2) facilitating services of the mental healthcare network of the Belgian Organisation of Brothers of Charity ($n = 1$); 3) members of the Flemish Association of Psychiatrists ($n = 1$); and 4) facilitating services of Zorgnet-Icuro

(a Flemish umbrella organisation for hospitals and care organisations) ($n = 2$). By following this procedure, the team believes the vast majority of patients with psychiatric conditions requesting euthanasia were on the research radar.

The physician or the caregiver gauged the patients' eligibility to participate, and interest in participating, in this interview study. If the patients met the criteria, they contacted MV, KP or KC by phone or mail. The patients were then given an information letter and informed consent form that consisted of 2 main parts (see [OSF](#)).

Using an in-depth interview topic guide (see [OSF](#)), the interviews were not based on a rigid list of structured questions, but about having broad topics and being flexible to make choices along the way, to ensure that research questions are being answered, but without forcing the interviewee into an area that they can no longer express what is most meaningful or important to them, even if it was not included in our topic guide. We did stick to a set of themes, but not rigidly to a set of questions. We used 1) probes and 2) follow up questions to allow for more elaborated answers. The interviewees were thus able to add new topics, especially at the end of the interview, due to the use of the open questions. All interviews were conducted by MV and KP, who both have a background in Clinical Psychology, experience in conducting interviews on end-of-life topics, and affinity with this specific patient population. Interviews were held at the patient's location of choice, except for one interview, which was held online by Whereby²⁸⁷ due to the Covid-19 crisis lockdown regulations. Upon the patient's explicit request, support people assigned by the patient were also allowed to participate during the interview to offer support and to further clarify the patients' perspectives ($n = 1$). Interviews lasted between 1 and 2.5 hours, and were audio recorded. Upon the request of two patients, each received their transcript for additional comments and corrections. As the interviews resulted in rich data, the authors decided to split the results over two papers. Whereas this paper focuses on patient's reflections regarding the meaning of euthanasia and how it relates to suicide, a forthcoming paper will address the impact of the euthanasia procedure on patient's state of mind, clinical trajectory, and social relationships.

Data Management and Analysis

All interviews were transcribed verbatim by MV. After transcription, the audio files were kept under lock and key at Ghent University. The transcribed, anonymized data were stored on a secured Sync folder via encryption and transferred to QualiCoder,²³³ software for qualitative analysis. Only MV, KP and KC had access to the transcripts.

The thematic coding procedure consisted of 4 phases. First, MV identified and coded all emergent themes, with sections of the transcripts, including supporting quotes, highlighted per codes. Second, all fragments were re-read by MV and their codes were put in more abstract sub-categories, and then classified in general main categories. Third, KC and KP independently identified and coded emergent themes of at least 3 transcripts. Fourth, all coding results were compared and commonalities were discussed. All authors were asked to identify which codes needed supporting quotes. We used a model of sampling-based saturation, namely inductive thematic saturation, that relates to the emergence of new themes (no new main themes emerged after the 7th interview).²⁸⁸ We continued to recruit and conduct interviews so that the sample would be heterogenous in terms of socio-demographics, clinical profile, and clinical setting.

Ethical approval

This research project was performed in accordance with the Declaration of Helsinki and the European rules of the General Data Protection Regulation. It received ethical approval from the Medical Ethics Committee of the Brussels University Hospital with reference BUN 143201939499, from the Medical Ethics Committee of Ghent University Hospital with reference 2019/0456, and from the Medical Ethics Committee of the Brothers of Charity with reference OG054-2019-20.

Findings

We succeeded in identifying 16 eligible adults with psychiatric conditions. In total, 16 interviews were held from August 2019 to July 2020. The patients’ main characteristics are listed in Table 1. The sample consisted of 13 women and 3 men, ranging in age from 29 to 60 years. 14 patients were professionally inactive, due to long-term sick leave or disability status. 11 patients lived alone, 1 lived with her parents, and 2 others lived in a residential healthcare centre. The other two patients lived with their partner and / or children.

Table 1: APC’s main aggregated characteristics

Characteristics	N = 16
Biological Sex	
Male	3
Female	13
Age Category	
< 30	2
30 - 40 year	2
41 - 50 year	5
51 - 60 year	7
Stage of the euthanasia procedure	
No formal advice on euthanasia obtained	9
One formal advice on euthanasia obtained	4
Formally accepted for euthanasia	3
APC’s medical condition¹	
One psychiatric disorder	4
Comorbid psychiatric disorders	6
Comorbid somatic disorders ²	3
Multiple psychiatric and somatic disorders	3

¹ Nature of psychiatric disorders according to the DSM-5 categories: Neurodevelopmental disorders (7), Depressive disorders (2), Bipolar and related disorders (3), Somatic symptom and related disorders (1), Disruptive, impulse-control, and conduct disorder (2), Trauma- and stressor-related disorders (3), Anxiety disorders (1), Eating Disorder (2) Adjustment disorder (3), Obsessive-compulsive and related disorders (1), Dissociative disorders (1) and Sexual dysfunctions (1).

² Nature of somatic disorders: Respiratory Dysfunctions, Endocrine Diseases, Chronic/total pain, Development motor disorders, Central nervous system disorder, Visual impairment, Autosomal recessive genetic disorder and Permanent injuries after failed suicide attempts.

Patients were going through different stages in their euthanasia request procedure, ranging from the exploration phase to having obtained multiple advices on euthanasia. 10 patients suffered from more than one psychiatric disorder, with neurodevelopmental and mood disorders as the most common ones. Six patients explicitly mentioned severe and persistent somatic co-morbid disorders.

Key events and experiences permeating the lives of patients who request euthanasia

As listed in Table 2 and illustrated by coded fragments in Box 1 (at the end of this Chapter), the patient's medical burden encompasses the persistent or periodic occurrence of severe, complex or rather uncommon symptoms of their respective psychopathology and comorbid conditions. The medical burden often started in early adolescence and deteriorated precipitously in the long-term course of illness, often resulting in suicide proneness and disability status, with no further expectation of improvement.

Adverse clinical experiences contributed to the burden of the medical disease. Among these, perceived diagnostic and treatment errors, troubled patient-caregiver relationship, and disrespect were reported. Oppressive, disrespectful and abusive practices were mentioned, especially in residential settings, and literally phrased as 'traumatising'.

Alongside the medical burden, the patients described life events during youth and adulthood that contributed to their euthanasia request but did not necessarily relate directly to their psychiatric or comorbid somatic disorder.

At first, most of the patients struggled with the lasting consequences of adversity and unstable caregiving in early life and youth, from parental neglect to violence and abuse. If admitted to adult mental health wards and/or foster care, all experienced failed healthcare (e.g. unstable fostering and maltreatment). Some of these and other patients reported that they felt compelled to act as a caregiver to their own (foster) parent (e.g. due to the latter's depression) or as parent to their sibling.

Most of the patients reported new, or a continuation of similar, adverse events in later life, notably on an intrapersonal (e.g. traumatic events) and interpersonal level (e.g. broken or lost relationships or other dysfunctional relationships such as "*symbiotic relationships*", in which the patient's needs were suppressed as they were continuously being of service or providing caregiving).

Table 2 : Key issues permeating the lives of APC with a euthanasia request

Significant clinical experiences	
Burden of the medical condition	Symptom severity Non-stop or alternating presence of somatic and/or psychiatric comorbidities More complex or 'uncommon' psychopathology features (e.g. subsyndromal mixed features specifier in bipolar disorder, 'total pain') Early onset of symptoms Treatment resistance / minimal progress despite great efforts Deterioration (from bad over worse to the point of no return: invalidity)
Perceived burden of adverse clinical experiences	A long treatment trajectory (e.g. multiple therapies/hospitalisations, multiple caregivers) Diagnostic errors (i.e. misdiagnosis, underdiagnoses or slipped under the clinical radar) Treatment errors /adverse effects (e.g. over- or undertreatment, side effects, minimal effects) Adverse treatment experiences (e.g. compulsory treatment, retaliatory mistreatment) Impaired physician-patient relationship (e.g. physicians' authoritarian/derogatory/indifferent approaches)
Significant life experiences	
Adverse events in youth	Adverse upbringing/parenting (authoritarian/uninvolved/abusive/over-controlling, domestic violence, instrumental and emotional parentification) Dysfunctional families (e.g. harmful family conflicts) / symbiotic relationships Victim/witness of (multiple) traumatic events (sexual/physical/emotional) Loss of important people, no/few supportive figures Failed youth (health) care policies (i.e. inappropriate admissions to adult mental health wards, problems with foster care and education systems: e.g. mismatches/no follow-up) Failed suicide attempts
Adverse events in adulthood	Experienced (multiple) traumatic events (e.g. physical accidents, sexual abuse) Loss of important people/animals (death/relationship breakages) Failed suicide attempts
Effects of significant life experiences	
Negative self-perception	Not being of value Not worthy of living Less resilient to daily life stressors and problems < extreme vulnerability Difficulties associated with sexual orientation (e.g. figuring out sexual identity, being ((partially)) closeted)

Interpersonal difficulties	Perceived failures to live up to the 'standards' of others/society Perceived burden to society Obstructed to (continue to) live a life of one's own (devoted one's own life wholly to others, adjustment difficulties due to major life stage transitions) Difficulties in making/maintaining social relationships (e.g. stigma, self-stigma, poor social communication/understanding skills) Incomprehension for being different or strange Incomprehension of (invisible) suffering No close/meaningful/supportive/reciprocal relationships, burdensome relationships (rather instrumental relationships / feeling bullied, used or deceived by others)
Social difficulties	Thwarted belongingness, solitude, isolation (e.g. loneliness due to too few social connections, absence of reciprocal caring relationships, being prone to frame other's behaviour as 'rejection') No social safety nets available
Societal difficulties	Challenges of being single, loss/burden of work, (e.g. stress, burnout, loss of work ability, discrepancy high job potential though ill-suited for society's expectations) Juridical difficulties Financial difficulties Finding no meaningful place in society (e.g. no social identity, no meaningful civic engagement) Living on the margins of society (invalidating consequences of illness)

A minority reported no significant adverse events before adulthood. Others struggled severely to find a balance after multiple major life-altering events (e.g. being diagnosed and becoming unemployed in later life; or being single after divorce and children having moved out).

Second, difficulties on a self-perception level were reported (e.g. extremely low self-esteem and self-care). Some patients even reported a lack of awareness of their own needs, wishes, and even identity. In all cases, the patients expressed perceived failures to live up to the expectations of others and the societal standards/norms, and, as a consequence, they feel they are a burden to society.

Third, the patients referred to problems with interpersonal relationships. Whilst a minority reported that they had never been in a position to live for themselves or that they had devoted their life wholly to others, all patients reported a range of feelings, thoughts, and behaviours (from self-stigma to others not understanding

why they are different) that resulted in the absence of (sufficient) close, reciprocal relationships.

Fourth, on the social level, all of the patients struggled in later life with both thwarted belongingness and perceived burdensomeness, due to few meaningful social connections and engagements, especially in the absence of social safety nets.

Finally, all of the patients faced a wide range of societal challenges – including the challenges of being single, loss of suitable work, financial and/or juridical difficulties – that led to the perception of not being able to find a meaningful place in society or a life lived in the margins of society.

Motives for patient's euthanasia request, in general and in relation to the option of suicide

As listed in Table 3 and illustrated in Box 1 (at the end of this Chapter), most of the patients stated that, in the early stages, the suffering experiences were not deemed intolerable. However, in the long run, the accumulation of several misfortunes and perceived difficulties in life reached a so-called 'culmination point' that was beyond the patient's capacity to cope with. All felt that their quality of life was progressively diminishing to the point that they felt life was no longer worth living.

However, one completely different motive was distinguished: namely, requesting euthanasia as a means to restoring hope and meaning to life. Some of the patients had been informed by their attending physician that they were in a medically futile situation or not eligible for more intensive therapeutic treatment. They expressed the desire to learn, in the course of ongoing euthanasia consultations, whether there were still treatment options available as well as other means of alleviating their suffering. In addition, euthanasia consultation sessions were also used to seek both comfort and support that could buffer the patient's concerns about dying, death and the afterlife. Some of the patients, however, feared neither death nor afterlife, as they cherished the deepest wish of dying together with their terminally-ill beloved, longed for a reunion with deceased beloveds in the afterlife, or truly believed in a better life after death.

Patients explicitly stated that their current euthanasia request was based on a well-considered request for hastened death (be it tentatively, prospectively, or actually), whereas suicide acts and attempts can be performed out of despair or as a cry for attention. Most of the patients were suicide-attempt survivors and feared (the consequences of) new failed suicide attempts. Control over the time and manner of death, including death rituals, was also a central, recurrent theme. In that respect, euthanasia was perceived as a more effective, softer, and dignified way of dying than suicide.

Euthanasia was also chosen to protect loved ones from complex mourning, from witnessing a suicide death, or/and from making them vulnerable to prosecution. Almost all of the patients were well aware of the existence of international (non-medical) Aid in Dying organizations. Some had even been in contact with these organisations but were put off by the many legal and practical barriers of their proposed means of non-medically assisted suicide.²⁸⁹⁻²⁹¹ As euthanasia often entails a time-consuming decision-making process, it provides their loved ones with time to adjust to the idea of a hastened death and the opportunity to say goodbyes. In addition, euthanasia was the only option for the patients to be eligible for organ donation, an act that was perceived to give meaning to one's own life and to help people in need.

Most of the patients, however, keep considering suicide as one of many options to hasten their death – be it as a plan B should their euthanasia request be denied or the procedure take too much time, or as plan A due to acquired capability (e.g. having access to the lethal means or/and becoming better instructed on how to successfully commit suicide).

Table 3 : Motives for requesting euthanasia, also in relation to suicide

Motives for requesting
<p>Coping capacity exceeded (< accumulation of misfortunes) (e.g. as 'redemption' for non-stop medical suffering and escape from life's suffering)</p> <p>Belief system regarding the afterlife (Symbolic) reunion with deceased loved ones, a better life after death</p> <p>Euthanasia procedure as 'therapeutic tool' providing hope To hear one's <i>ineligibility</i> for euthanasia (temporarily) prevents suicide attempts</p>
Motives related to the specific meaning/advantages of euthanasia versus suicide
<p>Euthanasia = Well-considered/rational/balanced wish to die (>< suicide can be a flash of the moment decision/cry for extended aid)</p> <p>Euthanasia = more dignified/effective/softer/easier way of dying</p> <ol style="list-style-type: none"> 1) it avoids the burden of self-suicide 2) it prevents trauma for loved ones 3) allows support and presence of loved ones OR to die together (symbiotic relationships) 4) Control over one's own death (incl. rituals, farewells) <p>Euthanasia = legal</p> <ol style="list-style-type: none"> 1) it avoids legal implications of suicide for APC themselves and its burden on abettors 2) opens option of organ donation <p>Euthanasia = extra option to reach death, next to suicide Suicide = plan B and may become plan A < acquired capability/modelling</p>

What could prevent patients from reaching the point of considering and requesting euthanasia?

At first, a word of explanation to begin this section with. We considered all responses of participating patients in our study to the question "X" to be direct and relevant answers. Though some may seem far removed from the actual inciting of their euthanasia request, it is what they told us. And as such, we regard these answers as much richer than anticipated in the sense that they reflect experiences, events and problems encountered throughout the life and clinical trajectory that, in a large enough combination, will lead the patients to consider and request euthanasia at some point. This is how these 'preventive factors' are to be read. As listed in Table 4 and illustrated by coded fragments in Box 1 (at the end of this Chapter), the following key players could (have) play(ed) a role in preventing death ideation and the seeking of euthanasia.

Mental Healthcare

Patients reported the need for more accessible and affordable mental healthcare. Hence, they criticized the burden of waiting lists, staff shortages, insufficient or non-reimbursement, information gaps, and the lack of 24/7 access to crisis care in home-based environments. The fragmentation of care was also criticized, as this caused too many patients to slip through the safety net. In addition, the patients advocated for equality of mental healthcare resources, as they detected an oversupply of therapeutic options for the so-called 'easy-to-treat patients' in contrast to an undersupply for the 'difficult-to-treat' and 'forgotten patients' in outdated facilities.

As for the quality of care, the patients expressed the need for a more human-centred, holistic clinical environment, characterised by: 1) continuity of care (non-abandonment) and more tailor-made care; 2) a shift from medical paternalism to shared decision-making, based on values such as respect, connectedness and openness; and 3) congruence with a multidisciplinary recovery approach (i.e. taking into consideration mental, social and existential factors, rather than just the symptoms of the patient's psychopathology).

Finally, the quality of care in the context of end-of-life care should also be enhanced in terms of: 1) embedding talks about death and dying in all clinical care settings (be they residential or ambulatory), as well as in non-clinical care settings, and 2) enhancing the quality of the euthanasia practice in end-of-life consultation centres by increasing the levels of transparency, equality and uniformity regarding euthanasia assessment and procedures.

In addition, personal feuds and quarrels among physicians at the patient's expense should cease and waiting lists shortened.

Table 4: Preventive factors to reduce problems faced in life, death ideation and euthanasia seeking

Mental Health Care in general	
Enhancing mental health care accessibility	<ul style="list-style-type: none"> - Equality of mental health care resources for the easy-to-treat, difficult-to-treat and 'forgotten' patients - Tackling the issue of fragmentation of care - Achieving better access to mental health care (e.g. elimination of waiting lists, 24/7 access to crisis care in home-based environment, more professionals / professional volunteers, low-threshold information) - Reimbursement measures regards alternative treatment options/psychologists/coaches
Enhancing the quality of mental health care in general	<ul style="list-style-type: none"> - Connectedness (providing more time to talk with the patient, active listening and genuine empathy) - Seeing/supporting the patient as a whole - More tailor-made care (empowering individual functional potentials) - Continuity of care (non-abandonment) - Openness (e.g. adequate information on diagnosis/treatment/prognosis) - Non authoritarian approach/Emphasis on dialogue (to enhance treatment adherence) - <u>Interdisciplinary approaches and knowledge</u>
Enhancing the quality of care in the context of end-of-life ideation	<ul style="list-style-type: none"> - Embedding end-of-life ideation and decisions in all residential and ambulant clinical care settings - Embedding end-of-life ideation and decisions in non-clinical care settings (e.g. helplines) - To achieve transparency in euthanasia assessment and procedures (e.g. difficult patient-physician communication, (teams of) physicians not being sufficiently informed, consulted or even scooped by colleagues) - To achieve equality in euthanasia assessment and procedures (e.g. rate of approval depends too much on differences in assessment approaches/on patient assertiveness) - Feuds and quarrels among physicians should never be at the APCs' expense - Elimination of waiting lists with regard to the euthanasia request
Youth Services	
Enhancing youth policies in terms of prevention, adequate care and follow-up	<ul style="list-style-type: none"> - Earlier detection of mental health problems (at primary/secondary school, Centres for Student Coaching) - To avoid children being admitted to adult psychiatric wards - To avoid children being admitted to unmatching foster care without follow-up - To enlarge the amount of youth services (when foster care is unavailable/inappropriate)
Society in general	
Restoring the skewed image	<ul style="list-style-type: none"> - To stop the misrepresentation of the euthanasia practice

related to euthanasia in media	<ul style="list-style-type: none"> - Need for a more nuanced debate on euthanasia (to stop false arguments contra as well as pro) - To stop labelling suffering people as e.g. 'losers'
Tackling societal inequalities	<ul style="list-style-type: none"> - To tackle the under-recognition of mental suffering and breadth of mental health issues, due to its invisibility (cf. physical suffering) - To pay attention to the specific needs of living as a single, +66% disabled - Pay attention to the risk of marginalising people when not fitting societal ideologies (capitalism, consumism, family favouritism) - To pay attention to the loss of high potentials (highly qualified and thus much to offer, but not suited for the rat race)

Youth Services

Each victim of adversity in childhood expressed the need for enhancing youth services and policies in terms of adequate prevention (e.g. early detection of diagnoses and abuse), care and follow-up. Emotional pleas were made to increase the number of (better equipped) youth mental health services to avoid minors being admitted to adult psychiatric wards or being placed in unmatching foster care without follow-up.

Society in general

Patients pointed to numerous societal issues – e.g. the under-recognition of mental suffering and the lack of attention paid to the specific needs of those not following societal norms (e.g. living as a single person and/or in the margins of society).

In the context of euthanasia, patients expressed the need to correct the skewed image of mentally-ill patients in general, to stop the current misrepresentation of the euthanasia practice (e.g. to stop false arguments as if euthanasia centres would rush to judgment and euthanasia performance on the one hand and to stop the romanticised image of euthanasia as the epitome of dignified dying and of sheer self-determination on the other), and to shift to a more nuanced debate concerning euthanasia overall.

Discussion

This interview study is based on the patients' self-reports and offers a deeper understanding of why our respondent patients have requested euthanasia and what could have prevented them from doing so. Our results indicate that the patients were in a state of feeling emotionally worn-out as a result of the many accumulated misfortunes and setbacks, leading to the all-pervasive sense that life is no longer worth living. Patients valued euthanasia over unassisted suicide as being more dignified and acceptable, both for themselves and for their inner circle. Some also noted the potentially therapeutic effect of the euthanasia procedure. Furthermore, the patients declared the need for improved accessibility to, and quality of, mental healthcare, as well as a profound change in society's perception of, and support for, this patient group.

The first research question addressed life events and experiences that the patients phrased as contributing to their euthanasia requests. The results further strengthen and deepen previous research findings that the key issues for patients are often the result of a long and incremental accumulation of avoidable healthcare deficiencies that, over the years, ultimately become a burdensome and unsolvable experiential knot, without any prospect of improvement for the patients.^{206,250,280} In addition to medical factors – which are often an intertwining of mental and physical factors²⁹² – the patients experienced a variety of intrapersonal, interpersonal, social and societal elements in their life, which often started at early age and progressed during the course of life.^{206,250,280}

As these patients endured a long history of serious adversity, often originating in adverse upbringing, some patients concluded that they are suffering more from a chronically problematic life context than from a genuine mental disorder. These results are in accordance with modern theories and approaches to psychiatry (e.g. the Network Theory, Critical Psychiatry), which suggest that mental illnesses tend to result from a variety of biological, psychological, societal and existential factors that cause and/or contribute to the mental illness, and thus must be understood in the multi-layered context of a patient's personal and social life.²⁹³⁻²⁹⁶ This current perspective on mental illness, and the fact that the Law on Euthanasia requires that a patient's suffering stem from a serious and

incurable mental disorder, make it difficult for psychiatry to determine to what extent the illness itself has resulted in mental suffering, which complicates or even transcends medically-driven decision-making on euthanasia.^{162,284}

However, the abovementioned external sources of lifelong adversity did not appear in all cases. Whereas some of the patients reported a lifelong struggle with daily life stressors and social interactions (often the case for patients with neurodevelopmental disorders), other patients struggled predominantly in later life due to various life stage transitions.

Finally, some of the patients reported looking back on their life with satisfaction, and struggled solely from their deteriorating medical condition.

A second objective of the study concerned the main motives for requesting euthanasia and how it relates to suicide. A new finding emerged: namely, that ambivalence towards death ideation did not appear in all cases, as some of the patients longed intently for death, due to, for example, the deep desire to die with a loved one (double euthanasia), to be reunited with deceased loved ones, or the strong belief in a better afterlife. This can be partially attributed to the patient's strong belief system and partially viewed as a coping strategy to deal with cognitive dissonance regarding death and dying. Note that these beliefs were never reported as a central reason for requesting euthanasia, but rather as incidental or tangential.

As regards the tension between euthanasia and suicide prevention, our study revealed mixed findings. On the one hand, euthanasia was perceived as a more dignified and qualitative alternative to dying than non-assisted suicide, for both the patients and their social inner circle. On the other hand, recourse to the euthanasia procedure is not simply an alternative means of realizing death, as some of the patients requested euthanasia to be told of their ineligibility for it and thus to restore hope. In this respect, these requests can be considered as a potential therapeutic tool to prevent patients from giving up hope and attempting suicide. It may also point toward the need for more alternatives to death – e.g., a re-evaluation of the current treatment trajectory, more rehabilitation and palliative care approaches for patients who feel that they run the risk of slipping through the care system's net.²⁴

The third question in this research was to gauge factors that could have prevented the patients from requesting euthanasia. This question resulted in a long list of factors, the majority of which point to the recommendations that have been made in global reports: i.e., to enhance the accessibility, quality and efficiency of mental healthcare resources for adult patients in Belgium.²⁰ These results are not surprising, as roughly only 6% of Belgium's total healthcare budget is invested in mental health, which is below the 10% that is recommended by the Organisation for Economic Cooperation and Development (OECD), despite being one of the European countries with the highest overall costs related to mental health problems, and with the second highest ratio of in-patient psychiatric beds.²⁹⁷ The report points not only to the sector being underfinanced, but also on the poor allocation of these financial means.²⁹⁷ The recommendations also include e.g. better coordination between the various mental healthcare levels (from prevention and early detection to intervention and sheltered living).^{20,298} This is of utmost importance, as most of the patients reported that most mental healthcare resources are invested in the easy-to-treat at the detriment of the difficult-to-treat.

Keeping in mind the many patients who reported having been obstructed in developing their own personality and living a life of their own, as well as the many reported traumatic experiences in psychiatric – often residential – settings, these findings point to the need for more open dialogic and patient-centred approaches in psychiatry. This also resonates with calls from contemporary Critical Psychiatry movements, which not only point out that there are different ways to understand mental illness behaviour, but also to frame and respond to it. At the core of critical psychiatry, the legitimacy of exclusive authority has been challenged.^{296,299,300} Although some of the patients reported that one can accept recourse to paternalism and coercion as necessary and unavoidable in certain circumstances, critical analysis and reflection are deemed essential with regard to when, why and how more authoritarian approaches can be used under which circumstances and to what extent. Moreover, such debate should include the voices of the mentally ill, if only because of their status as psychiatric service users.²⁹⁶

In addition, our results show the impact of many societal factors (e.g., socio-economic inequalities, public stigma regarding mental illnesses, and failed youth

services) that lie beyond the scope of the field of medicine in general and of psychiatry in particular. These results may be interpreted not only as factors that could prevent patients from requesting euthanasia, but also as factors that could prevent vulnerable people from developing a mental illness and a long trajectory in psychiatry in the first place. These aspects need to be addressed as ample literature has indicated the association between low socioeconomic status (in terms of unemployment, financial strain, individual-level inequalities), limited social network and social isolation on the one hand, and psychopathology and suicide risks on the other.³⁰¹⁻³⁰⁷

Finally, our findings point the attention to a much-debated topic in the euthanasia debate concerning these patients, namely whether and if so, to what extent feelings as hopelessness and demoralisation can be ascribed to a realistic perception and appraisal of poor life circumstances and the course of mental illnesses in which hopelessness may become chronic, and not just an acute 'symptom of psychopathology'.¹⁶¹ Whereas some point to the ability of patients to have a realistic perception on the prospect of relief being illusory, others are of the opinion that discussing the probability of euthanasia may reinforce feelings of hopelessness and demoralization, the underestimation and consequently, the rejecting of potential beneficial treatment options.^{161,166} This is an important debate of which the last word has not yet been said.

Strengths and limitations

Confirmation bias was consciously monitored and avoided as much as possible, as the patient's responses were continually re-evaluated and existing clinical assumptions kept at bay. Another strength of this study is the lack of social desirability or acceptability bias, as the interviewers were not involved in the patient's euthanasia procedure and the patients were not pressured to phrase their views and experiences in any direction, which resulted in very rich data. Our study did provide unique and detailed insight into the patient's views towards, and experiences of, the many aspects of end-of-life decisions, including the tension between euthanasia and suicide. Moreover, and in contrast to previous research, the sample can be considered heterogeneous due to the patients being recruited via multiple mental healthcare institutions and organisations. Our sample may seem to lack heterogeneity in terms of gender,

with many women included in this study, however more women than men die by means of euthanasia for psychiatric reasons.^{117,126,131} However, it is not known from official records if more women than men are applying for euthanasia for psychiatric reasons, and if so, to what extent some findings of our study point to the issue of gender inequality. As of today, we have no insights in the total number of patients requesting euthanasia for psychiatric reasons in e.g., private or group practices, in inpatient settings, let alone insight in the global F:M ratio. However, reports from end-of-life consultation centres in Belgium and The Netherlands revealed a skewed gender ratio of women and men applying for euthanasia for psychiatric reasons (approximately 6:4).^{130,308} Hence, we do have reason to assume that more women than men apply for euthanasia. Considering also the 'gender disparities' concerning the nature of psychiatric disorders (whereas more women suffer from mood and trauma-related disorder, more men suffer from substance abuse) and the 'gender paradox' concerning suicide (whereas more men commit suicide, more women undertake suicide attempts)³⁰⁹, the role of gender deserves further exploration.

With regard to limitations, both interviewers expressed difficulties in conducting 3 interviews with patients with neurodevelopmental disorders, where frequent shifts in attention and disengagement from details were noticed. This led to lower success in gaining clear information, called for more assertive prompting, and also created difficulties in interpreting meanings during coding and analysis. Selection bias may have occurred: 1) the study was conducted during a time in which euthanasia in one adult with psychiatric conditions was under heavy public and professional scrutiny, with a criminal trial related to a euthanasia for these patients, and while several guidelines³¹⁰ and an official medical code of conduct³¹¹ – imposing additional due care requirements – had been issued; and 2) the sample was recruited by the patient's physicians, and therefore researchers had no control over selection. More specifically, the researchers had 1) neither access to medical records nor contact with the patient's treating physician to confirm e.g., the patient's mental competence and diagnosis, the perceptions conveyed by the patient, the frequency of prior suicide attempt; and 2) not made use of instruments to assess e.g., the mental capacity themselves or to distinguish between primary and secondary psychiatric diagnoses. Hence,

there was little control over patient selection, which may have interfered with the purposive sampling goal of their recruitment process.

Implications for further research, policy and practice

This study revealed the many complexities of euthanasia in the context of psychiatry, due to the many differences in the patient's background characteristics and in their motives for requesting euthanasia. Further research is needed to develop a full and undiluted picture of euthanasia requests in the context of psychiatry; and additional studies need to keep in mind the complexities and subtleties of mental illness from (neuro)biological, psychological, existential and societal perspectives. As written in previous studies, particular attention should be paid to patients suffering from autism spectrum disorder (ASD) and intellectual disabilities and seeking euthanasia, as their suffering was described differently than other patients, in terms of their lifelong condition of being misunderstood, rather than their psychiatric illness.^{312,313} As evidence^{112,126,127} points to the large proportion of patients with ASD seeking euthanasia in Belgium (compared to the number of ASD in The Netherlands) and both the interviewees examined differences between some patients with and without ASD as regards perceptions and reactions to stressful (daily) life events and social functioning, this definitely requires more research. Quantitative research studies should map the differences in the profiles of all patients requesting euthanasia and study factors that may lead to a euthanasia request being rejected, granted or withdrawn. Further research could also focus on integrating these insights into existing and/or novel models for a systematic understanding mediators and moderators towards wishes to die in patients. But first and foremost, future research needs to focus on a better understanding of the factor of 'existential demoralisation' in these patients as 'fatigue' was reported by patients and attributed/ascribed to the consequences of the long duration and the 'bumpy' course of the clinical and life trajectory in which adversity was key and which contributed to feelings of increased hopelessness. In that respect, reflection is needed on how to adequately prevent this '(treatment) fatigue'.

Demoralization is a mental state of low morale and poor coping, characterized by feelings of perceived failure, incompetence, hopelessness, pointlessness, and the loss of meaning and purpose in life.³¹⁴ Its clinical importance relates to its mediation of suicidal thinking, leading to a desire to die.³¹⁵ After controlling for psychiatric disorders, studies have shown a two-fold risk of suicidal thinking in patients with demoralization.^{316,317} Although widely studied in other parts of Europe³¹⁸, demoralization is a worthy subject of future research in Belgium, especially when psychiatric patients request euthanasia.

As regards policy and practice, specific attention should be paid to how to interpret and assess the legal criterion of causality between the patient's medical condition and suffering. In addition, more specific attention is needed on how to interpret, assess, and deal with the legal criterion of 'irremediable suffering', given the 'uncertainty' in psychiatry³¹⁹ or the odds of spontaneous recovery versus the odds of suicide deaths. Both outcomes have been reported in patients considered eligible as well as in patients approved for euthanasia.^{126,320-322}

Notwithstanding the added values of the Belgian deontological and other guidelines^{310,311} on how to implement the legal criteria in psychiatry, there is little mention of how to deal with the multi-layered aspects of mental suffering that may complicate medical decision-making. However, the role of the psychiatrist cannot be underestimated, as our findings suggest that euthanasia can be seen as a therapeutic tool with potential to restore hope. Nonetheless, there were mixed findings regarding its tension with suicide prevention. Finally, our study also presents the need for a serious ethical debate on society's responsibility to tackle these societal inequalities and failures, instead of passing the buck to the – underfunded – field of psychiatry. Ensuring accessible, high-quality and more dialogic approaches in mental healthcare and practices, better equipped youth services, and more societal support for patients should be priorities. Our findings suggest that specific strategies and interventions are sorely needed to address the concerns and needs of these individuals, e.g., the long-term unemployed living with low financial allowances, the socially isolated and the 'forgotten patients' in residential patient settings.

BOX 1: List of Coded Fragments

<p>Burden of the medical condition</p>	<p><i>"Um, when you feel really depressed every day or really agitated, very manic, your heart rate that's beating a bit more, um, your head that can't settle down, um, sleepless nights and with that I mean really not sleeping at all, just nothing. I have problems with my teeth which caused me to lose 18 kilos. I can't eat a lot because my stomach has been reduced. I've also had technical problems with my mouth. It's just too much."</i></p> <p><i>Female, 54 years</i></p>
<p>Burden of adverse clinical experiences</p>	<p><i>"Um, they had the habit that each time I was allowed out, that I could take a walk in the garden. Every time I returned to the ward, I had to undress completely nude. E-very time. And that was pure intimidation. E-very time, both male and female nurses. Indeed, every time, everything had to come off."</i> <i>(Interviewer: And the explanation for that?)</i> <i>"Ah, doctor's orders".</i> <i>(Interviewer: But with your past? Well, regardless, regardless of the past, it's never OK).</i> <i>"It's never OK. But those are things [that happen]. (Whispers: every time, every time.) I lost it, I stood there crying, every time. Like: 'Oh no, not again.' I cried and I cried there. Eventually you also didn't feel like going outside, of course, every time that comedy."</i></p> <p><i>Female A, 55 years</i></p>
<p>Adverse events in youth</p>	<p><i>"And then you wind up in institutions, also in adult institutions as a child, um, you name it. How many times I, as a child, had to sit among grown-ups in psychiatry, that they sedated me with the dose of an adult and I was an underweight child. I was bedridden for more than 2 weeks and then afterwards I got all sorts of symptoms from that and that they then had to give me a shot each time because I as cramping up from the side effects. Normally they should never have done that, but it was that or the isolation cell. They thought that the isolation cell would be more traumatic! Well, they're both equally traumatic but anyway." [..] "And then um, then after that you end up in a bad foster family where you are mistreated in all sorts of ways and the committee [the Belgian Committee of Special Youth Care] knows about it and does nothing."</i></p> <p><i>Female, 29 years</i></p>
<p>Adverse events in adulthood</p>	<p><i>"But I then also experienced a rape [in my early thirties]. And then I actually...it started to go wrong again. And then I started psycho-analysis. And which eventually resulted, in [year], in a first psychiatric admission. And it actually never stopped from there."</i></p> <p><i>Female A, 55 years</i></p>
<p>Personal / Existential difficulties</p>	<p><i>"And yes, for me that was something like, well, that was something, that was hammered in with us, you know, like 'I am not worthy that you should enter under my roof, but only say the word and my soul shall be healed', huh?"</i> <i>(Interviewer: I know it (laughs).)</i> <i>"And do you know the 'forgive me my sins' and na-na-na. So for myself I was a sinner, and all guilt with myself also... That is in</i></p>

	<p><i>any case more part of my character, I think. (Sighs) I have those texts from that time. I'm a bad sister and a bad daughter. I'm a bad person. Pages full, huh, and really like 'I want to die. I want to die.' 'I'm not worthy of being alive'. Really pages full, already at that age. Sometimes I still go in very easily, still toward 'See, I'm worth nothing.'</i></p> <p><i>Female, 33 years</i></p>
Interpersonal difficulties	<p><i>"And like: 'I'm sick and they won't find me valuable anyway or such'. And little by little that improves. I was also a little bit because of the admissions, I called myself 'socially handicapped' because the interaction with normal people or... Yes, because that had become very limited as well and started to feel very awkward after time, because you're not used to it anymore. And you feel shy and ashamed. Because you know...people see your scars and they know you're in psychiatry or they know indirectly. And you think they look at you strangely and 'What are they thinking about me now?' and 'How are they now against me?' [...] During my second admission my youngest sister came to visit. And she had a teddy bear with her for me, which I still sleep with by the way. But she also said: "You're no longer my sister." (Interviewer: You're no longer my sister?) "Yes, because I was in psychiatry. And then for years, for many many years I didn't yet want to be in contact with her. With the others I was no longer in contact anyway, they have stood far from me anyway. But my youngest sister was someone with whom I had a good contact as a child. Contrary to the others. Yes, and then. Those are also things that affect someone, of course huh. It wasn't said so jokingly huh."</i></p> <p><i>Female A, 55 years</i></p>
Social difficulties	<p><i>"Yes, friendship is very important to me. I also have a really great need for it, probably because I hardly have anyone. It's not nice at all to realize that you don't have many friends. Do you know the book 'Alone in the world'? Well, that's often how I feel, and that's not a nice feeling at all. It's also not a nice feeling if you don't seem to belong anywhere."</i></p> <p><i>Male, 29 years</i></p>
Difficulties related to neuro-development disorders (e.g. autism)	<p><i>"My psychiatrist before, the first one, used to say, 'Yes, working somewhere longer than two and a half days is actually not so good for someone with autism, because then it becomes too difficult. Not for you, but for the others.'" I say, "After two and a half days? I have to do it 24 hours a day, 365 days a year to live with someone else, who is different and then 8 hours a week is more than enough? How flexible do I always have to be to meet your requirements? Well, I'm not talking about you, huh?" (Interviewer: No, no, I know, I know. I know very well what you mean.) "I'm talking about people in general. I can't gauge anything, I can't feel what that something is like, I miss that. I have to reason through everything. And then of course, mistakes happen when you reason through everything. But I think, with you, with 'feeling a lot', that a lot of mistakes also flow from that. That I thought, I felt it that way, but apparently it isn't like</i></p>

	<p><i>that. Well, that's what I notice about how people sometimes react. Because I don't feel (to fit) in this world. I just feel like an observer of how this works here, but I don't feel like a participant in society."</i></p> <p><i>Female B, 55 years</i></p>
Societal difficulties	<p><i>"Yes, the psychiatrist and the general practitioner and psychiatrists all say, "(name), we're really going to keep you at home, we don't see many problems with it, with the health insurance fund, because you have a long career behind you, you've done your best, you tried to start again three times." And um, she says "Yes, but yes, you don't have to anymore." And I'm actually quite safe financially because I have a high-grade disability allowance, I've always worked in the (sector). And she says: "Then you definitely don't have to take that risk anymore". I say, "Yes, but then I feel so useless like I'm taking advantage of society and..." and then cry, I'm getting it again now, I get a lump in my throat like yes, but I do want to mean something, I do want to leave a footprint when you leave the world here, you know?"</i></p> <p><i>(Interviewer: Yes yes yes)</i></p> <p><i>"Then she really had to convince me like: "(name), you can also do that in a different way than by working, right? There are things like friendships, like family and volunteering, like uh, where you can mean a lot and where you can find a lot of satisfaction." But that's a real quest for me. Because also, and certainly in the past year I lost a lot of friends because it was too intense for them and they really, yes, backed off, well, stepped back. Many have given up, have given up on me, let's just say and that also makes it extra painful."</i></p> <p><i>Female, 52 years</i></p>
Motives for requesting euthanasia	<p><i>"But if you can no longer find a way in your discomforts, then, then... yes, or if the way... How should I explain it? If you have to climb a mountain every time to be able to enjoy something. By the time you get to the top, you've come such a long way. Well, isn't worth it anymore that you say phew... Too exhausted to enjoy anymore."</i></p> <p><i>Female, 50 years</i></p>
Motives related to the specific meaning/advantage of euthanasia/being death	<p><i>"In 2012, I lost my child and started the fight for euthanasia. Then it also sticks in the back of my mind about euthanasia, that I will be with my little one again."</i></p> <p><i>Female, 29 years</i></p>
Motives related to the specific meaning/advantages of euthanasia versus suicide	<p><i>"Actually, as a certainty of 'I know, I know that this will work'. The certainty of OK, if euthanasia, well, is carried out in accordance with the rules, then I will effectively be dead. While suicide depends on a number of factors whether it will be successful or not. And then the alternative is another suicide [attempt] and then the risk is that it will fail again or that you will come out badly damaged. So that's then from... you don't want it anymore. That you say, "I don't want that, that trajectory, because then you'll be in intensive care and the whole process will start again."</i></p> <p><i>Female, 43 years</i></p>

<p>Enhancing mental health care accessibility</p>	<p>"Because that is one of those paradoxes, of the sector, where the more severely someone suffers and the more help they need from the system, the less money is made available. Right? The people with mild depression who briefly enter a [psychiatric institution], a lot of money is thrown at that and that presents well in the statistics, because they improve and they are successful in therapy, but do they actually need that? Do they need it that so much money is being spent? But people with severe defective psychoses, then there is hardly any money left for that? Yes, hmm. I have my ideas about that, but I don't know whether that still has anything to do with the euthanasia debate."</p> <p>(Interviewer: But then you're saying that the more care someone needs, the less care there actually...)</p> <p>"Yes, but is that a reason to use euthanasia more? It should be a reason to allot more money to those people. And whether that would take away the euthanasia request, that I don't know, but I do think it, it would make life more bearable so that the euthanasia request could become less..., but they will probably remain in a state of having exhausted all treatment, to use that ugly term. But then there is more money available to let them live, more humanely, in their way, whatever is still possible for them, huh?"</p> <p>Male, 56 years</p>
<p>Enhancing the quality of mental health care in general</p>	<p>"There is just, many more care providers are needed and if there is a care provider, that they also (receive) more intensive care and attention... Just more people, more time, more care providers, plain and simple. Because at that moment you just want, you just want to be carried. At that moment, you just don't have enough energy to stand on your own legs. So, to me that's really important and uh, the taboo that's still hanging around or floating, huh? It's just really, really hard to open some doors, in any case, but also to make that decision and to look for it too. Because that information isn't thrown in your lap when you need it, really not."</p> <p>(Interviewer: The information of which...?)</p> <p>"For example, in my case, [the social welfare centre] option, but actually all forms of assistance, the entire broad, the very broad palette."</p> <p>Female, 51 years</p>
<p>Enhancing the quality of care in the context of end-of-life ideation</p>	<p>"That is, as of that moment you can be refused in hospitals, if you have a request for euthanasia."</p> <p>(Interviewer: Can they refuse you? In terms of treatment, you mean?)</p> <p>"Yes, and I would eliminate that, that people have the attitude like 'I'm not spending any more time on you'. Just because you have a request for euthanasia doesn't mean that the request for euthanasia is justified. And in any case, people whose request for euthanasia is justified are also entitled to it. And at the moment in psychiatry there are a number of hospitals that no longer want to treat you. And likewise some individual psychologists or therapists. I think, that should be legally regulated now. If it isn't already, I'm not sure about it, if one now has a request for euthanasia, that it shouldn't be reason to refuse someone. Just as it shouldn't be reason to refuse someone on the basis of religion or race or ... that all of that isn't allowed, that shouldn't be reason to refuse someone with a</p>

	<p><i>request for euthanasia, yes. (...) Yes, to put it squarely. Either a treatment is meaningful and then you don't even get a chance, or there is no longer any chance of a meaningful treatment and then you get the message that yes, you are a 'walking dead' as they say in America. You are in fact dead, psychologically, but you are not physically dead yet and we are not putting any more time into it. I think that's such a filthy, ugly message. I think that should be banned, yes."</i></p> <p><i>Male, 56 years</i></p>
<p>Enhancing youth policies in terms of prevention, adequate care and follow-up</p>	<p><i>"Well, if they had maybe recognized it earlier, then maybe they could have done something with it earlier and I'm not, eh, playing catch-up, 36, 37 years catch-up, huh? That you can only, have to, work on it now, huh? Yes, yes, yes, yes. That it might have been easier had they seen this before, but could they have seen this earlier? Did people so many years ago already pay attention to it, I don't know either. Early 80's, I don't think they were already concerned with it then. So, you've got a number of things that you think like, if only, if only they... but then again, that won't help me now. So, if I was angry at one point, it was more because why have the GP and the medical center, why has a school never done anything about it."</i></p> <p><i>Female A, 43 years</i></p>
<p>Restoring the skewed image related to euthanasia in Media</p>	<p><i>"My reasoning and I always say that. There are people, without wanting to name names, but... There are people who make it appear in the media as if here in Belgium, gosh, that there are doctors here who, one after the other almost, huh, a shot here, a shot there. While if you look at the numbers that, well, if you then look at the Committee report [the most recent biennial report of the Belgian Federal Control and Evaluation Committee on Euthanasia, ed.d.], right, and you look at the numbers. And you know that in those numbers of psychological suffering, that it's not just people with a psychiatric disorder, right? But that there are people with MS, they are also included. If you'd then exclude those, right? Then how many people do you have per year? Hey? Well? So no, it's an exception. That is an exception that is made. So yeah, and with exceptions or like it is in physics anyway and I hope it's like that in general, when it comes to exceptions you have to look at cases individually. And every file is different and OK if they absolutely want to write a sort of guideline or protocol for that, the Brothers of Charity and, and, and [Network of Healthcare Organisations], OK, but in the end it comes down to that, right? You have so few people that you just have to say 'each case is actually a stand-alone something and that has to be looked at individually, thoroughly, of course yes, naturally. But...then the doctors who deal with that should also be given the opportunity to do so."</i></p> <p><i>Female, 33 years</i></p>
<p>Tackling Societal inequalities</p>	<p><i>"At that moment you are really in a hopeless, at that moment you are in a hopeless position, but really huh? At that moment it is total hopelessness, because there is simply no one. There's just no one there at that moment. Okay, you have hotlines that you can call, but for all we know they don't even know that hotline exists, they don't have call credit for whatever reason, they haven't had internet and wifi for years. They can't read</i></p>

	<p><i>and write. Doesn't matter, but at that moment there is simply no one for them. There's no one to pick them up just for a little bit and carry them and just whisper 'Hey, you know what, I may not be expert enough to listen to you and I definitely won't, I won't have the correct responses. But there are people who do have that and among other things, there is the suicide line for that, among others there are psychologists, the CGG [Flemish Centre for Mental Healthcare], a psychiatrist, a doctor, a general practitioner or other institutions that I now...' And they have to be available then and not like yes, OK, we have registered your call, in due time we will contact you again for help."</i></p> <p><i>Female, 51 years</i></p>
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CHAPTER 7 :

THE IMPACT OF THE EUTHANASIA ASSESSMENT PROCEDURE: A QUALITATIVE INTERVIEW STUDY AMONG ADULTS WITH PSYCHIATRIC CONDITIONS

Verhofstadt M†, Chambaere K†, Pardon K, Mortier F, Liégeois A, Deliens L, Audenaert K. The Impact of the Euthanasia Assessment Procedure: A Qualitative Interview Study among Adults with Psychiatric Conditions. *BMC Psychiatry*. 2021 (in revision)

† shared first authorship

More detailed information is posted in the Open Science Framework repository accompanying this paper: <https://osf.io/j9fvz/>

All the whole time you live, you purloin from life and live at the expense of life itself. The perpetual work of your life is but to lay the foundation of death. You are in death, whilst you are in life, because you still are after death, when you are no more alive; or, if you had rather have it so, you are dead after life, but dying all the while you live; and death handles the dying much more rudely than the dead, and more sensibly and essentially.

Michel De Montaigne (That to study Philosophy is to learn to Die)

Abstract

Background

Assisted dying for adults with psychiatric conditions (APC) is highly controversial but legally possible in a few countries, including Belgium. Previous research has suggested that the complex euthanasia assessment procedure may cause additional suffering in APC but may also induce positive experiences. This study reports on the impact of the euthanasia assessment procedure as experienced by APC on 3 counts: 1) their mental state, including death ideation; 2) their treatment trajectory; 3) their social relationships.

Methods

We performed an in-depth qualitative interview study with APC in Flanders, Belgium, who had voiced a euthanasia request between 2016-2020.

Findings

Euthanasia assessment procedures brought out a plethora of experiences in 16 APC, both favourable and unfavourable. Whereas thoughts of suicide remain present to a certain extent, being in the assessment procedure prompts some APC to reconsider alternatives towards life, and also to attempt new treatment options. However, many APC experience ambivalence about the supposedly inherent desirability and dignity in euthanasia. Worries also surfaced about the rationale behind, and the effects of, involvement of the APC's social circle, and about the impact it could have on them.

Conclusion

Further research, including other stakeholder perspectives, is recommended with a view to maximising favourable and minimising unfavourable impacts for all involved. Attention to these impacts is paramount in clinical practice, and clear communication and management of expectations between physician and patient seem appropriate in addressing the many ambivalent experiences that accompany APC during the euthanasia assessment procedure. In this regard, policy attention could go to clarifying certain sources of ambivalence and issues that are insufficiently addressed, such as modalities of relatives' involvement.

Keywords: euthanasia, mental disorders, end-of-life decisions, assisted suicide

Introduction

Assisted dying – defined as the act to end life by providing, prescribing or administering lethal medication at the competent patient’s explicit request – is, under certain conditions, legal in an increasing number of countries around the globe.²⁷⁹ The Netherlands⁷³, Belgium¹⁸⁵, Luxembourg⁶⁹ and Spain⁷⁴ are the only countries in the world to enact legislation that does not rule out adults with psychiatric conditions (APC) as sole or primary underlying conditions. Canada is currently also considering expanding current legislation to APC.^{201,323} Although euthanasia (the act of a physician administering the lethal medication) has been legal and implemented in Belgium for almost two decades, it remains highly controversial when applied to APC.

Since legalisation, 315 cases of euthanasia in APC have been carried out in Belgium, 1.4% of all reported *performed* euthanasia cases.^{113,114,117,324} This is only a fraction of all APC *applying* for euthanasia: a recent annual report from one Belgian end-of-life consultation centre revealed that only 12% of euthanasia requests by APC lead to euthanasia¹²⁷, as around half of them put their request on hold or die through suicide or palliative sedation (1%).¹²⁷ The reasons for these outcomes are largely unknown – but, as scarce research shows, these might be related in large part to the often highly complex life and treatment histories of the APC, as well as continued controversy about assisted dying in this patient group, and perhaps also ambivalent feelings about the wish to die in the APC themselves.^{88,135,325,326}

Several mental health organisations have recently published advisory texts^{310,311}, in which existing legal criteria are strictly ‘operationalised’ and a number of further due care criteria are expressed for APC. For instance, the ‘incurability of the disorder’ criterion is defined as ‘no reasonable treatment perspective’ and a number of clinical conditions that need to be met were set. Emphasis is also put on the importance of extending the 1-month reflection period either to 6 months or 1 year, of engaging a minimum of 2 advising psychiatrists (instead of 1), and of engaging the APC’s other relevant caregivers and social inner circle in euthanasia assessment procedures. A recent survey among Belgian psychiatrists showed that these additional due care criteria are already implemented in practice, with the entire assessment procedure of requests culminating in the

performance of euthanasia spanning, on average, 13.5 months, and encompassing multidisciplinary consultations, including with family and friends.

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Two qualitative studies have revealed that some APC experience the euthanasia procedure itself as a cause of additional suffering, while, for other APC, it may offer the needed support to find new perspectives on life.^{206,280} However, these studies lacked an in-depth focus on the impact of the euthanasia assessment procedure. In addition, a survey among psychiatrists confirmed that aspects of the euthanasia assessment procedure could be both favourable and unfavourable, as, for example, the psychiatrists reported reduced suicide risk in some, but not all, APC.³²² To date, the APC's first-hand accounts of how they have experienced the euthanasia procedure are largely understudied.

Therefore, this study reports on the impact of the euthanasia (assessment) procedure as experienced by APC. We distinguish impact on 3 counts: 1) impact on their mental state (among others, death ideation); 2) impact on their care trajectory; and 3) impact on their social relationships. This knowledge may provide clinicians and policymakers with insights for minimising negative impacts and fostering positive consequences of exploring requests for euthanasia from APC.

Methods

Study Design and Recruitment

We performed a qualitative interview study among APC who had requested euthanasia in Flanders. Only Dutch-speaking APC who had made a request for euthanasia in the years (2016-2020) were included. Purposive sampling was used to ensure diversity in terms of heterogeneity in procedural outcomes (that is, diversity in terms of requests being neglected, rejected, put under review, or granted by the physicians involved, or put 'on hold' by the corresponding APC).

We also ensured diversity in terms of diagnoses and age range, as we suspected that the impact of the euthanasia assessment procedure and the role of the social inner circle could vary according to these different patient characteristics.

No further inclusion or exclusion criteria were employed. The APC were recruited via different care organisations, each of which had publicly expressed or published their own vision on how to adequately deal with euthanasia requests from APC: 1) the Flemish end-of-life consultation centre Vonkel, 2) the Belgian Organisation of Brothers of Charity; 3) the Flemish Association of Psychiatrists; and 4) Zorgnet-Icuro (a Flemish umbrella organisation for hospitals and care organisations).

When their respective physician approved an APC's participation in the study, the APC could contact the researchers (MV, KP, KC) by phone or mail, and they were given an information letter and informed consent (see [OSF](#)).

Interview procedure

MV or KP interviewed the APC at their location of choice for 60 to 180 minutes, except for one interview which was held online due to the Covid-19 lockdown regulations. An interview topic list was used (see [OSF](#)). The following 2 key themes were addressed: the impact of the actual euthanasia assessment procedure, and, if applicable, the impact of provisional and/or final outcomes (neglected, rejected, granted, put 'on hold') of the euthanasia procedure, in terms of the impact on the APC's immediate mental state, clinical trajectory, and relationships with others involved (i.e. family, friends, caregivers). At the end of the interview, the interviewer checked whether all topics had been covered. The interviews were recorded by an audio recording device and transcribed verbatim by MV. Detailed information on data management and storage can be found in [OSF](#).

Data Analysis

As our study was explorative – i.e., not based on any theoretical framework – MV, KP and KC used an open, thematic coding procedure, consisting of 4 phases; 1) identification and coding of all transcripts; 2) the placing of the codes in sub-themes; 3) the placing of these sub-themes in overarching main themes; and 4) the comparison and discussion of the findings (with all co-authors). We used a model of sampling-based saturation (namely, inductive thematic saturation), which relates to the emergence of new themes. Data saturation was defined as 7 consecutive interviews without new themes. We recruited APC with a view to

obtaining a heterogenous population in terms of socio-demographics, clinical profile, and clinical setting.

Ethics

This research project received ethical approval from the Medical Ethics Committee of the Brussels University Hospital with reference BUN 143201939499, the Medical Ethics Committee of the Ghent University Hospital with reference 2019/0456, and the Medical Ethics Committee of the Brothers of Charity with reference OG054-2019-20.

Findings

Main characteristics of the APC

One APC was excluded from this study, as MV and KP concluded that the APC's mental safety during and after the interview could not be guaranteed. In total, 16 interviews were completed from August 2019 until July 2020. The APC's main characteristics are listed in Table 1, which reveals that the APC ranged in age and suffered from a variety of psychiatric diagnoses, and usually also from psychiatric and/or somatic comorbidity.

8 APC had once had their euthanasia request neglected or explicitly rejected. At the time of the interview, euthanasia requests from 9 APC were under review, and 3 of them had already obtained at least one formal positive advice. Finally, requests from 3 other APC had been formally granted.

Table 1: Characteristics of the study sample of adults with Psychiatric Conditions' (APC's) having experienced the euthanasia assessment procedure

Characteristics	N = 16
Biological Sex	
Male	3
Female	13
Age Category	
< 30	2
30 - 40 year	2
41 - 50 year	5
51 - 60 year	7
Stage of the euthanasia procedure¹	
No formal advice on euthanasia obtained (yet)	9
One formal advice on euthanasia obtained	4
Euthanasia request formally granted	3
Former/Provisional/Final outcomes of euthanasia procedures^{1, 2}	
Neglected ³	4
Rejected	4
In assessment procedure	9
No formal advices on the euthanasia request obtained	6
One formal advice on the euthanasia request obtained	3
Granted (at least two positive formal advices obtained)	3
Put on hold for a definite or indefinite period of time ⁴	4
APC's medical condition^{1, 5, 6, 7}	
One psychiatric disorder	4
Comorbid psychiatric disorders	6
Comorbid somatic disorders	3
Multiple psychiatric and somatic disorders	3

¹ Information retrieved from the APC during the interview, not from their medical file nor from their recruiting physician/caregiver

² Some APC had applied for euthanasia more than once. Seven APC reported ≥ 2 outcomes, e.g., rejected by first though accepted by the second advising physician, granted by the physicians involved but put on hold by the patient herself.

³ One APC had requested euthanasia before the law on Euthanasia came into effect. For reasons of clarity, all data, except for (the impact of) this one neglected euthanasia request were included in this study.

⁴ All APC cited to have "put their euthanasia request on hold for an indefinite period of time" instead of having it "withdrawn", as mentioned in our topic list, and as literally phrased by both the interviewers.

⁵ Nature of psychiatric disorders according to the DSM-5 categories: Neurodevelopmental disorders (7), Depressive disorders (2), Bipolar and related disorders (3), Somatic symptom and related disorders (1), Disruptive, impulse-control, and conduct disorder (2), Trauma- and stressor-related disorders (3), Anxiety disorders (1), Eating Disorder (2) Adjustment disorder (3), Obsessive-compulsive and related disorders (1), Dissociative disorders (1) and Sexual dysfunctions (1).

⁶ Nature of somatic disorders: Respiratory Dysfunctions, Endocrine Diseases, Chronic/total pain, Development motor disorders, Central nervous system disorder, Visual impairment, Autosomal recessive genetic disorder and Permanent injuries after failed suicide attempts.

⁷ All APC (had) dealt with suicidality. Thirteen had committed serious suicide attempts.

The impact on the APC's mental state, including death ideation

As shown in Table 2 and illustrated with quotes (BOX 1 at the end of this Chapter), and regardless of whether the APC were (dis)satisfied with their actual therapeutic and social relationships, *neglect* of the euthanasia request had an adverse impact on the mental state of all of the APC who had experienced it. They were unanimous feeling misunderstood, that their suffering was not being taken seriously, and that they had not been guided in finding physicians for open discussions on euthanasia. Some stated that they had considered suicide again.

When asked about their accounts of their euthanasia request being *rejected* by their own treating physician or opposed by an advising physician, all of the APC echoed immediate disturbing feelings and thoughts of anger and indignation similar to a neglect. Unwillingness of their own treating psychiatrist or physician to perform the euthanasia itself was received with more immediate understanding.

Some of the APC reported that the *neglect or rejection* of their request gave them the advantage that they did not have to notify their loved ones about having requested euthanasia, so the latter would not be burdened by this knowledge. When loved ones had been informed, two divergent discourses emerged: whilst the APC reported some relief in no longer having to discuss the subject or to burden the loved one with it, others struggled with their loved ones' attempts to discourage them from persisting in their request for euthanasia and seeking new physicians. The APC expressed concerns about their loved ones bottling up their own emotions for the APC's sake.

Regardless of the status of their euthanasia request – under review, refused, or granted – the APC reported ambivalent feelings throughout. The ambivalence for the APC who had their euthanasia request under review was based, on the one hand, on their ability to talk openly about their death wish without fearing involuntary (re-)admission to a psychiatric ward. They felt recognized in their suffering experiences and problems. If the first positive advice had been obtained, the APC reported being in a state of 'contentment', 'intense happiness' or even 'euphoria'.

Table 2: Impact of the euthanasia procedure on Adults with Psychiatric Conditions' state of mind, including death ideation, in the context of the euthanasia request being neglected (N), rejected (R), under review/being assessed (A), granted (G) or put on hold (P)

MENTAL STATE		
	Favourable outcome	Unfavourable outcome
Feeling heard	<p>Feeling recognised/heard/understood</p> <ul style="list-style-type: none"> - Relief of being enrolled for future euthanasia assessment (A, P) - Being recognised/heard as regards the burden of suffering/problems in life (A, G) - Being seen as a whole (not only sick) person (G, P) <p>Immediate impact at having request granted (G)</p> <ul style="list-style-type: none"> - "euphoria", "intense happiness", "contentment" 	<p>Not feeling recognised/heard/understood</p> <ul style="list-style-type: none"> - Being fended off (N, R) - Not being taken seriously/heard (N) - Being misunderstood as regards the burden of (invisible) suffering/problems in life (N, R)
Fear for adverse events	<p>Less fearful of unwanted events (A, G)</p> <ul style="list-style-type: none"> - No (more) fear for involuntary admissions to a psychiatric ward - Less burdened with 'self-destructive ideation and behaviours' - Increased ability/willingness to suppress suicidality <p>Relief for loved ones when no formal advice on the request has been obtained</p> <ul style="list-style-type: none"> - not to have burdened loved ones (N, R, A) - not to have burdened one self with further discussions on the subject (N, R) 	<p>More fears/thoughts regarding death and dying</p> <ul style="list-style-type: none"> - Fearful of new (failed) suicide attempts (N, R, A) - Ambiguity about dying (fear of dying, afterlife) (A) - Time-consuming ruminations regarding *(unregulated) suicide (N, R, A) vs *euthanasia (A) - Time-consuming practical preparations for euthanasia (A,G) <p>Distress about consequences of having request granted</p> <ul style="list-style-type: none"> - stigma/labelling if APC does meet the legal criteria (A) e.g. jeopardise potential opportunities in life - ambiguity about dying (fear of dying, afterlife) (A) - Uncertainty < probability of the window of opportunity narrowing/closing: (A,G) <ul style="list-style-type: none"> *professional backing out * legislation change *validity period of obtained positive advices (e.g. physician's retirement)
Creating Perspective, empathy	<p>Better understanding of/empathy toward others' perspectives</p> <p><u>*Towards physicians</u></p>	

	<ul style="list-style-type: none"> - Understanding/empathy towards rejection <ul style="list-style-type: none"> *from treating psychiatrist (R, A) *from performing physician (A, G, P) - Understanding/empathy towards physicians as regards the difficulties faced and the necessity of building sufficient reflection time (A, G, P) - Understanding/empathy towards physicians entrusted with euthanasia assessment (A, G, P) <ul style="list-style-type: none"> *Towards the social inner circle - Understanding/empathy: regained ability to take important others' perspective into account (A) - Regained ability to deal with different perspectives and reactions (A, G, P) 	
Perceived control	<p>Ability to plan a good death</p> <ul style="list-style-type: none"> - e.g. planning and exchanging goodbyes, memorial celebration (G) - Reframing the death wish (A, G, P) <ul style="list-style-type: none"> e.g. 'euthanasia' as potential safety net >< acute death request 	<p>Feelings of powerlessness, having no control (A, G)</p> <ul style="list-style-type: none"> - Burden of pleading tribunal hearings' (A, G) (pleas instead of requests for euthanasia) - Perception of being given the run-around (A, G) - Experiences of broken promises/physicians getting cold feet (A) - Distress about the uncertainty of the outcome (A) <ul style="list-style-type: none"> *the probability of broken promises, tightening of the law (A) <p>(Di)stress when the outcome turns out negative</p> <ul style="list-style-type: none"> - despair, hopelessness (N, R) - indignation (R) - Feeling left in the dark/to their fate to find new physicians (N) <p>Burden of the quest in finding physicians open to euthanasia (N, R)</p>
Fairness		<p>Feelings of injustice, unfairness (A, G, P)</p> <ul style="list-style-type: none"> - Unprofessional behaviour of physicians involved <ul style="list-style-type: none"> *violation of medical secrecy/confidentiality * poor communication skills (induced false hope, lack/little transparent communication between physicians involved) - Inequality of the euthanasia procedure and outcomes associated with <ul style="list-style-type: none"> *patient characteristics

		<p>i.e.. the highly intelligent, verbally skilled APC and those who have important other's approval are in the advantage</p> <p>* the absence of one single standard protocol approach</p> <p>i.e.. law versus a variety of guidelines</p>
Emotional drain		<p>Procedure itself is emotionally draining</p> <ul style="list-style-type: none"> - Reluctance/burden of (repeated) self-disclosures (A, G, P) - Assessment procedure is hard/too time-consuming/over-burdening (while being exhausted) (A, G) - Being the victim of dissensions between EOL centres/played out by the dissensions between strong opponents and proponents (A)
Distress about loved ones	Relief not (yet) to burden loved ones (N, R)	<p>Distress about consequences of the euthanasia procedure on loved ones</p> <ul style="list-style-type: none"> - Burdening loved ones (A,G) - Concerns about bottled up emotions inside loved ones (N, R, A, G, P)

On the other hand, they also reported distress, mainly due to the many uncertainties, including the probability of rejection. Some of the APC with a request under review also struggled with the probability of a granted euthanasia request and its consequences for treatment options, as the 'official' label of having an irremediable psychiatric condition could potentially compromise their possibilities for treatment, social relations, and societal rehabilitation. Similar findings emerged regarding the APC's death ideation: whilst some reported decreased suicidality, others continued to consider suicide as a plan B (e.g., if the euthanasia procedure would be too burdensome and/or time-consuming), or, for some of the APC, even as plan A. Only the APC who had their euthanasia request granted or on hold reported feeling less burdened with 'self-destructive ideation and behaviours', which they attributed to the feeling of being recognized and treated as a person (and thus not only as mentally-ill).

Ambivalence was also found in APC with a *granted* request. They literally said that they were in an immediate state of 'intense happiness', 'being blessed' and/or 'intense relief'. However, after some time, ambivalence re-appeared. This may be understood as no longer having to ponder how to die (by means of suicide or euthanasia) which, on the one hand, allows more time to try out alternatives to death (i.e., euthanasia as a safety net). On the other hand, the APC also have to deal with preparations for euthanasia (e.g., when, where and with whom), as well as with many perceived uncertainties, such as the validity period of obtained positive advices (in the case of a physician's retirement or a change in legislation). Some of the APC mentioned more peace of mind to suppress suicidality, and hence more time to take all aspects of dying, or alternatives to death, into account. The latter result is explained as follows: the benefit of following a two-track approach during the whole procedure, in which not only the APC's eligibility for euthanasia had been assessed, but also alternatives to death, including rehabilitation, always in dialogue with the APC. Others remained torn between their wish to die versus the burden of leaving behind bereaved relatives. However, some other concerns remained, like finding a performing physician or, when found, the likelihood of her change of mind, retirement or passing away. In addition, uncertainty was experienced regarding the term of validity of the advice obtained.

Impact on death ideation

All of the APC applied for euthanasia on the assumption that they would have some control over their own process of dying, leading to a dignified death. However, most of the APC, even those with a granted euthanasia request, reported that, during the long and exhausting assessment procedure, they had come to see the idea of a self-chosen death as an illusion, and they considered euthanasia as a medical favour that they had to plead for. They further tackled the following as undermining the assumption of euthanasia as 'dignified death': 1) poor communication between the physicians involved and towards the patient (ranging from physicians and caregivers inducing false hope regarding the duration and outcome of the procedure, to the violation of confidentiality), 2) the inequality of assessment procedures within and between different institutions, and 3) the uncertainty about the outcome of a recent euthanasia case being subject to criminal investigation (e.g., possibly leading to future changes in physicians' attitudes, to broken promises or to future changes in legislation at the APC's expense).

Most of the APC held that the euthanasia procedure is too time-consuming and overburdening, due to (for example) the many self-disclosures that have to be expressed repeatedly to at least 3 physicians during what some literally phrased as 'pleading at the tribunal hearing'. Finally, they criticized the perceived unequal assessment favouring highly intelligent, verbally proficient APC and APC with less complex clinical pictures – even if they themselves were the ones being advantaged. Also, although the procedure was experienced as highly burdensome, some did not seek the easy way to get their wish fulfilled, as some APC were willing to have at least 2 formal *positive* advices for the performing physician's sake.

The impact on the APC's clinical trajectory

As shown in Table 3 and illustrated with quotes (BOX 1 at the end of this Chapter), all of the APC whose request had been *neglected* (e.g., the request falling on deaf ears) reported that neglect of their request had damaged the actual therapeutic relationship, resulting in treatment noncompliance, and eventually in quitting the current therapy. The APC who felt dismissed by their

physician reported an irreparable mistrust in their physician's professionalism and immediately quit their current therapy.

When the APC's treating physician *rejected* active engagement in the euthanasia request, the impact this had on the APC's clinical trajectory varied. Some of the APC reported being verbally attacked, wrongly informed about the legal aspects of euthanasia, or deliberately misled by their physician (e.g., suspicion that the physician had referred to another physician, knowing that the latter would also reject the APC's euthanasia request). Irreparable mistrust, and discontinued therapy were also cited. Other APC reported no changes in treatment adherence, once their primary emotions and disturbing feelings were processed and the reasons for rejection were thoroughly discussed with the treating physician. These APC also appreciated their physician for being open to holding serene talks about death ideation and euthanasia in forthcoming therapeutic sessions and for meaningful referral (i.e., referral to another physician, willing to be actively engaged in the euthanasia procedure, and holding an open stance towards euthanasia).

Treatment adherence was reported by all of the APC who had their request in review, granted or put on hold, although ambivalence was noted throughout the euthanasia assessment trajectory. As for the sub-group of APC who put their request on hold, some of the APC dealing with ambiguous feelings and thoughts about the meaning of life and death reported having found reassurance in the fact that their euthanasia request and medical file had been registered, handled, and cared for by (at least one) 'competent and trustworthy' psychiatrist. These and one other APC (who had not yet obtained a formal advice on their request) felt sufficiently reassured and empowered to explore new paths of rehabilitation, knowing that they could explore the death track more actively if their personal situation would deteriorate, and their death request would become more enduring and consistent.

Table 3: Impact of the euthanasia procedure on APCs' clinical trajectory, in the context of their euthanasia request being neglected (N), rejected (R), assessed (A), granted (G) and put 'on hold' (P)

IMPACT ON THE CLINICAL TRAJECTORY	
Favourable	Unfavourable
Continuity of care (R, A, G)	No continuity of care (R) <ul style="list-style-type: none"> - Treatment abandonment by the patient (N) - Treatment abandonment by the caregiver (R)
Open discussion about the death track within treatment trajectory <ul style="list-style-type: none"> - discussion of death ideation and euthanasia encapsuled in therapy (with respect, honesty and integrity) (R, A, G) - Being able to express the request and have it assessed (A, P) - Serene/caring talks about death (A, G, P) - Dialogic, compassionate approaches (A, G, P) 	No discussion of the death track within treatment trajectory <ul style="list-style-type: none"> - talks on death ideation/euthanasia not being encapsuled in the existing treatment trajectory (R, A)
New referrals & treatment approaches <ul style="list-style-type: none"> - Meaningful referral (R, A, G, P) <ul style="list-style-type: none"> *to new/additional treating physicians *to additional caregivers - Meaningful advices/suggestions (e.g. new diagnosis/reframing death ideation) - preparedness to continue treatment (R, A, G, P) - preparedness to halt acquired treatment resentments (G) - Encouraged/empowered to undergo further/additional diagnostic testing/ treatment options (A, G, P) 	Referral & further treatment burden <ul style="list-style-type: none"> - no meaningful referral (R, A) - Burden of additional psychodiagnostics testing/therapy (A, G) - Poor patient-commitment, just undergoing additional testing/treatment to get file approved/hiding behind irrelevant diagnoses/events/occupational therapy (A)
	Souring patient - physician relationship during euthanasia trajectory <ul style="list-style-type: none"> - Directive approaches of physicians involved (A, G) - Breakdown in relationship with treating physician (e.g. when verbally attacked by the physician, being disinformed, useless referral) (R, A) - Mistrust in physicians involved (A) (cf. instrumental burden + in case of violation of confidentiality)

One of the APC, who had already obtained (more than) the two required legal advices, felt empowered to explore new ways of living only once the euthanasia request had been granted with the physicians' reassurance that it remained an option to fall back on.

The impact of the euthanasia procedure on the APC's treatment is illustrated by the following experienced changes to their clinical trajectory: 1) adequate help and treatment for a new diagnosis, 2) a transition from a rather restrictive to a more patient-centred care model, with a focus on rehabilitation, in which self-destructive behaviours could be reframed when identifying remaining functional potentials, and 3) additional support for not only medical but all problems faced in life (e.g., autism coaches helping them with administrative issues).

However, whilst some of the APC felt empowered to give alternatives to death a fair chance of success, others perceived the suggestions on additional psychodiagnostics, additional treatment, and other rehabilitation options as overburdening and futile. These APC consented to proposed additional treatments only with a view to obtaining approval for euthanasia.

The impact on the APC's social life

As listed in Table 4 and illustrated with quotes (BOX 1 at the end of this Chapter), whereas some of the APC took the initiative to inform their loved ones about their euthanasia request and procedure, or to involve them to a certain extent, others were urged to do so by their physicians. For some of the APC, somehow involving their relatives was unjust toward themselves (e.g., for fear of violating medical confidentiality or that strong opposition would compromise their chances of euthanasia), unnecessary (especially in the case of a tentative euthanasia request), or even undesirable (because of the emotional burden and responsibility it places on intimates as well as the possible conflicts it provokes between relatives who were or were not informed or more deeply involved).

Table 4: Impact of the euthanasia procedure on APC's social life, also in the context of their euthanasia request being neglected (N), rejected (R), assessed (A), granted (G) and put 'on hold' (P)

IMPACT ON SOCIAL LIFE	
Favourable	Unfavourable
<p>Receiving understanding & more emotional support</p> <ul style="list-style-type: none"> - Increased attention, compassion (R, A) - More serene talks about death (A, G) (with respect, honesty and integrity) - Opportunity to share the emotional experience (A, G) - Received blessing (A, G) - Additional support/understanding from 'similar' peers (e.g. from experts by experience) (A, G) - Ability to learn from 'similar' peers (e.g. joined forces to make life more bearable/to see alternative options) (A, G) 	<p>Not being supported or understood</p> <ul style="list-style-type: none"> - No/little understanding for APC's perspective (A, G) - Adverse attempts to change APC's mind (R, A) - Negative reactions/conflicts (R, A, G) - Non-committal approaches/reactions (R, A) - No mutual understanding due to conceptual confusion (legal terminology) (A)
<p>Rebuilding social relationships</p> <ul style="list-style-type: none"> - Opportunity for rehabilitation of existing social relationships (deeper connection) (A, G) - Empowered to open-up/build new relationships (G, P) 	<p>Crumbling relationships</p> <ul style="list-style-type: none"> - Resignation from family and other 'social obligations'/ further erosion of the network (R, A) - Decreased sense of belongingness (R, A) - Increased feeling of being 'alienated' (R, A)
<p>Receiving more practical support</p> <ul style="list-style-type: none"> - Offering e.g. transport and shelter after consultations with physicians (A) - Suggesting potential helpful/comforting books/movies (A) 	
<p>Support for important others possible</p> <ul style="list-style-type: none"> - Opportunity for loved ones to receive support (A) 	
	<p>Difficulties with involving and managing interactions with important others</p> <ul style="list-style-type: none"> - No/little advice/guidance on how to inform the inner circle - Informing relatives is deemed unfair (A) *wrong as it is only a measure to protect physicians from

	<p>deontological/ juridical complaints</p> <ul style="list-style-type: none"> *unjust to exclude (eligible) APC from euthanasia if someone/some members would strongly oppose to it *it puts a heavy burden on the few one's involved *it may provoke conflicts/ruptures after APC's death <ul style="list-style-type: none"> - Reluctance to hurt loved ones needlessly (e.g. when informed in an early stage) (R, A) - Incompatible objectives patient versus relatives or among relatives (A) - Practical difficulties of informing the inner circle (i.e. how, when and where to inform whom) (A) - Emotional difficulties: <ul style="list-style-type: none"> • to cope with mixed reactions/stages of grief (A, G) • when reactions within the social circle (A, G) • fear of/difficulties to cope with meddlers outside the close inner circle (A)
	<p>Comparing own situation with fellow peers (mirror-window)</p> <ul style="list-style-type: none"> - Concerns regarding fellow APC making precarious use of the euthanasia procedure (A, P) - Difficulties to cope with the loss of fellow peers in inpatient settings (suicide and euthanasia), especially in case of omerta rule giving (P) <p>i.e.. APC were 'forbidden' to talk to fellow peers about their own or another fellow peer's euthanasia request/euthanasia procedure/attempted suicide/suicide)</p>

When loved ones had been informed or involved during the euthanasia procedure, divergent reactions emerged. Some of the APC experienced informing, or even involving, loved ones as positive, provided there was a serene atmosphere during the euthanasia procedure, based on reciprocal understanding and empathy. These APC valued the opportunity to share this emotionally difficult trajectory with loved ones and to support each other through the euthanasia procedure. As mentioned earlier, this reassured them that their loved ones would not have to keep their feelings bottled up. Rehabilitation of existing troubled social relationships or broken relationships was reported by some, but not all, of the APC with euthanasia requests rejected or in review. The opposite also occurred, which resulted in a decreased sense of belonging or an increased feeling of being 'alienated'. Some of the APC reported new relationships with understanding and supportive peers, from whom they could learn how to make life more bearable.

The reasons there was reticence to inform or involve the inner circle were the following: 1) the lack of tools and support for APC to engage in the conversation with their loved ones (i.e., how, when and where to inform whom), 2) anxiety about hurting loved ones, 3) the burden of having to cope with the inner circle's emotional reactions (whether absent, negative, mixed, or with disagreements), and 4) concerns about having to deal with potential meddlers from outside the close inner circle.

The following experienced disadvantages were reported in the relationships with other APC: 1) concerns regarding peers making frivolous use of the euthanasia procedure (e.g., the perception of euthanasia used as a cry for attention), 2) the difficulties of coping with omerta rules in inpatient settings (i.e., when the APC were 'forbidden' to discuss a euthanasia request or procedure with peers), and 3) concerns regarding coping with the loss of fellow peers, whether by suicide or by euthanasia.

Discussion

This qualitative study revealed a multifaceted impact of the euthanasia assessment procedure on APC. Whereas thoughts of suicide remain present to a certain extent, being in the assessment procedure allows some APC to

reconsider alternatives towards life, and also to attempt new treatment options. However, many APC experience ambivalence about the supposedly inherent desirability and dignity of euthanasia. Worries also surfaced about the effects of involving the APC's social circle, and about the impact that could have on them.

Strengths and limitations

To the best of our knowledge, this is the first study to emphasise the impact of euthanasia procedures on APC. As previous studies among APC have focused on the reasons APC request euthanasia,^{172,206,250,327} this study has systematically investigated the impact such requests have on their mental state, current care trajectory, and social relationships.

Another strength of this study is the minimal risk of socially desirable answers, as the interviewers were not involved in the APC's euthanasia procedure, full confidentiality was guaranteed, and the APC were not pressured to phrase their views and experiences in any direction – which resulted in very rich, unique and detailed data. Moreover, the sample can be considered heterogeneous in terms of clinical diagnoses, age ranges, different stages in the euthanasia procedure, and the APC being recruited via multiple mental healthcare institutions and organisations. Thematic data saturation was reached, as no new themes emerged after the 7th interview.

A limitation of this study is the potential lack of thematic saturation *per outcome* of the euthanasia assessment procedure. Furthermore, selection bias may have occurred as: 1) the sample was recruited by the APC's physicians; and 2) the euthanasia procedure of most of the APC interviewed was affected by recent and potential changes in euthanasia practice, due to the recently published deontological code recommending more strict due care criteria³¹¹ (e.g., obtaining formal advice from at least 2 instead of 1 psychiatrists) and the legal and emotional consequences regarding one high-profile euthanasia case being brought to court. Given these limitations, external validity of the findings may have been limited.

Interpretation of main findings

The APC clearly benefited from being listened to, being recognised in their suffering and valued as a person, and having their euthanasia request taken

seriously. This finding supports the so-called 'therapeutic effect' of euthanasia assessment procedures, as it may suppress suicidality^{126,172} and may even offer sufficient peace of mind to give alternatives to death a fair chance of success once the request is positively advised or granted.^{126,172} However, this does not apply to all APC, and even when it does, it seems to have only an ephemeral effect, as most of the APC continued to struggle with ambivalence, irrespective of the (provisional or final) outcome of their euthanasia assessment procedure. The ambivalence was present on 3 counts: 1) ambivalence toward longing for death, 2) toward euthanasia as a desirable alternative to suicide, and 3) toward euthanasia as a dignified way of dying.

First, ambivalence toward death can be partially explained by different motives for requesting euthanasia. A previous study, also based on interviews with this sample of APC, revealed that, whilst some APC make an active euthanasia request, others request it in a more tentative, exploratory or prospective way.³²⁷ Those euthanasia requests may be considered a cry *of* unbearable pain and suffering – instead of a 'cry for help to exit life' – as these APC seem to seek the physician's help in recognizing and alleviating their burden of suffering. Second, ambivalent feelings toward euthanasia and suicide suggest that APC view both as means to the same end – with euthanasia being more dignified and preferable than suicide, but very difficult to obtain. Building on this, our findings suggest a growing realization that they are in control of neither the euthanasia procedure nor the outcome, which leads them to doubt whether euthanasia is a dignified way of dying for them. Almost all of the APC interviewed, even those who had their request granted, experienced the whole euthanasia trajectory as an emotional tug-of-war, due to the many self-disclosures and 'pleadings', to (the difficulties of dealing with) outcome uncertainty, and the presumption of unequal assessment procedures. The latter may point to a tension between the physician's autonomy to opt for strict adherence to the legal conditions or the implementation of additional due care criteria on the one hand, and the burden of these non-uniform procedures on the APC.

Another main finding is that the treating physician's rejection of the euthanasia request does not necessarily compromise the therapeutic treatment, provided there is: 1) good physician-patient communication in which the reasons behind the rejection are well-motivated, 2) a meaningful referral, and 3) openness to

discussing the (ambivalence toward the) death ideation and the euthanasia procedure in upcoming therapeutic sessions. In contrast, neglecting the euthanasia request seems to have only unfavourable consequences. This finding suggests that both psychiatrists and APC may benefit from open and serene discussions about death and euthanasia. The scenario of losing a patient to either another therapist or to death seems more likely to happen if the euthanasia request goes unheard or faces a wall of impenetrable incomprehension.

With regard to the impact of the euthanasia procedure on APC's social relationships, divergent discourses emerged. While some APC reported valuing some relatives being involved in the euthanasia assessment procedures, others raised concerns or strongly opposed their involvement. The stronger position and (informal) role for the APC's social inner circle is not a legal requirement, yet it is strongly recommended by the recently published advisory texts and effectively implemented in today's euthanasia practice as an additional due care criterion. Motives for engaging relatives are many. The triadic dialogue between the APC and their physicians and relatives may enhance the quality of the euthanasia assessment. Heteroanamnesis can be of great value for physicians, as it can further elicit the family history and lead to a better understanding of the APC and their relational and situational context. In turn, relatives may gain deeper understanding of the APC's suffering and the meaning of their euthanasia request, and their involvement may soften their mourning if the euthanasia is performed. Of course, psychiatrists may also welcome the involvement of the APC's relatives in order to avoid disgruntled relatives after the fact. APC themselves may find additional support from loved ones, which may lead to further social rehabilitation.

However, some APC expressed critical concerns about the feasibility and desirability of involving relatives, because (for example) practical advice on when and how to involve which relatives to what extent, and how to manage potential conflicts, is lacking. This would seem to be a subject of thorough discussion between patient and physician. In addition, we are left uncertain as to whether all relatives would be willing to be informed and engaged during the euthanasia procedure.

Implications for further research on psychiatric practice and policy

As our study illuminates the fact that the euthanasia assessment procedure may be beneficial or/and detrimental to APC's mental state, suicidality, and their current care trajectory, further research should elicit the determinants of when and why the euthanasia procedure may have a therapeutic effect on some, but not on all, APC. In addition, research should further explore the notion of ambivalence towards *whether* and *how* to die and how this relates to the concepts of (for example) being in search of control, dignity, self-determination and connectedness in dying, and also to what extent this phenomenon befalls non-APC populations requesting euthanasia. The perspectives of physicians, caregivers and the APC's social circle should also be studied regarding this matter.

With regard to practice, it is essential for psychiatrists to anticipate the emotional impact of euthanasia procedures on APC. As our findings confirm that APC need to feel listened to, be taken seriously, and recognized in their suffering, it is recommended that psychiatrists embrace the two-track approach, as suggested by advisory texts³¹⁰. This two-track approach is characterized by focusing both on the *life track* – by means of continuity or reassessment of treatment, for example – and on the *death track* – by means of assessing the APC's euthanasia request. The rationale behind this two-track approach is that it should not be ruled out that the euthanasia request is the expression of an APC not seeking help to die but to alleviate the suffering or to anticipate future suffering. For that reason, while on the *death track* the reasons for, and the eligibility of, an APC's euthanasia request are explored, a *life track* is pursued simultaneously, in which alternatives to death are explored from a medical and psychological, as well as from a social and existential, perspective.

As our study reveals the negative impact of a neglected euthanasia request on an APC's mental state and treatment trajectory (see Table 2), it is highly recommended that treating physicians who would rather not actively engage in the euthanasia assessment focus on the *life track* and refer in a timely manner the APC to a colleague willing to further explore the APC's request. Meaningful referral to a colleague or experienced institution – e.g., an end-of-life

consultation centre – is legally enforceable since the revision of the Belgian Euthanasia Law in 2020.¹⁸⁵ Following this 2-track approach implies additional safeguards to the legal criteria (e.g., non-abandonment of treatment), as recommended by the Belgian guidelines that have been published in recent years.³¹⁰

But even if a psychiatrist is willing to actively engage in an APC's euthanasia procedure, expectation management seems to be of utmost importance. Through clear and careful communication, it should be explained to the APC that euthanasia is not an enforceable right nor a subjective medical decision but encompasses the assessment of stringent legal criteria. A proactive approach, in which the whole procedure is explained and all potential outcomes discussed before the assessment procedure is initiated, is considered to be necessary to prevent severe distress that compromises the treatment trajectory. For this reason, the Dutch guideline stipulates that physicians need to respond to death requests from APC with a '*No, unless...*' statement.³²⁸

If the request is rejected, it should also hold the engagement that, in the future, there is the possibility of having the request re-evaluated if circumstances have changed.

It is of utmost importance to explore and deal with the emotions of disappointment, anger, and despair. This should be dealt with in the parallel consultation sessions (i.e., on the life and death track) to prevent negative impact on the ongoing treatment. Given that suicide remains on an APC's mind in some cases, this possibility must also be taken seriously – but it must be made explicit that threatening suicide compromises sound decision-making and therefore an APC's chances of having their request granted. In the condition of either granting or rejecting the request, the impact of spill-over in the parallel treatment sessions must be minimized.

With regard to policy, the main issue that needs medical-ethical and regulatory attention and reflection is if, when, how and to what degree to involve the patient's relatives. It goes without saying that engaging in an APC's euthanasia procedure is emotionally and professionally very demanding, especially as the physicians involved usually want to take the needs of the APC's loved ones into account.^{170,322} Our findings also revealed ambivalence in some APC who are torn

between their death-seeking behaviour in order to alleviate their suffering and their reluctance to make their relatives suffer from their death-seeking behaviour. However, whereas some APC value their relatives' involvement, others reflected on the reasons not to strengthen the role and position of relatives. Other issues that, according to our study, deserve consideration due to their impact on APC are: differences in policies between organisations; differences in assessments based on the APC's verbal and cognitive abilities; validity periods and the conditions of positive advices and granted requests.

BOX 1: List of Coded Fragments per Table

	MENTAL STATE	
	Favourable	Unfavourable
PROCEDURE-related		
Feeling heard	<p>Feeling recognised/heard/understood <i>"Finally, I felt heard, I felt understood, I felt supported, I felt I was being carried."</i></p> <p>Female, 51 years</p>	<p>Being fended off <i>"Ohhh, he really cursed and shouted and yelled at me so much that I came out weeping"</i></p> <p>Female, 45 years</p>
Fear for adverse events	<p>Less fearful of unwanted events</p> <p><i>"But on the other hand, I do feel that I am stronger than I was a while ago. Do you know why? I'm here with a huge amount of medication lying around, and it hasn't occurred to me to take an overdose and that's a huge difference. Before, in an emotional crisis, I used to take a whole box of anything and everything until I was lying here in a coma and the ambulance had to come to pick me up, and things like that. And now I can leave all that behind. I'm not going down that road anymore. So now I'm like, 'I'm going for survival, and I've got to try and stay strong now and not give in to self-mutilation and self-destructive behavior.' Even though I'm so used to that and it's so easy to give in to that because it became so normal... that threshold has been so lowered... Yes, well and now I have that... Now I have like some sort of power within me to say no to that. I'm not going to do that anymore, I'm not going to start with impulsively swallowing pills, taking the whole box of meds and ending up in intensive care. That is my strength, at this moment."</i></p> <p>Female, 55 years</p>	<p>Fear of actually dying, afterlife (Ambiguity about dying)</p> <p><i>"Ah yes, what I did notice when I applied for euthanasia, and these are two things I have never read about in the euthanasia debate... First, I have a very strong fear of death, I must overcome something terrible in me for that, and I have never really succeeded to do so; so as soon as I asked the question 'I want to die, give me euthanasia', I was at the same time afraid of 'what if he immediately approves and goes along with it? That is because I am so afraid of death. And secondly, what I also never read about: it is an unknown fact what would happen after death and who knows, the afterlife may be even worse. No one has ever returned from death. It is assumed that the suffering stops then, but no one, no one has ever returned from it. Who says it won't get worse or that there will be another form of life after this, life that nobody knows about? I am agnostic, so I don't know what might come afterwards. And those two fears also relate to one another. My fear of death relates to me not knowing what may come after death. And then, I am actually taking a gamble, aren't I? That is how I feel. The gamble is that I hope that the suffering would stop after death, but that is not a certainty, is it? And I've never read anything about that in</i></p>

		<p><i>the euthanasia debate, even though I think it's a logical question, don't you?</i></p> <p>Male, 54 years</p> <p>AND</p> <p>Distress about consequences of having request granted</p> <p><i>"I do see an impediment, don't you? At this moment, once you obtain the approval for euthanasia, the approval is valid for an indefinite period of time. As I understand it, the attending physician will always seek confirmation, will assess if the euthanasia request is still justified, but shouldn't this approval be limited in time? The one person I just spoke about, the one who received the approval so quickly and this for more than five or seven years now, well, this person is still alive, he also wants to continue living, but he also feels the hindrance of the obtained approvals, because it renders many things impossible in his actual life. (Interviewer: Yes? Even nowadays? So you can still see the impact...) Yes, I talked to him about the idea of a romantic relationship, and he said to me 'well, that's no longer an option for me, nobody wants me anymore'. The people that I know, like [name of another fellow peer], yes well, assume that she would meet a nice man and fancies a relationship with him, then that man would be troubled by the idea 'I'm having a relationship with someone who suffers unbearable and irremediably. Personally, as a partner, I think I would not be able to bear that either, with my partner. So, I think to myself, she is making it difficult for herself to live. (...) You'll block off a lot of things for yourself by already having obtained that approval, yes.</i></p> <p>Male, 54 years</p>
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<p>Perspective taking/empathy</p>	<p>Better understanding of/empathy toward others' perspectives</p> <p><u>*As regards physicians</u></p> <p><i>"I had, in good conscience, decided together with my general physician, who wanted to be the performing physician and still wants to be, that we had to obtain POSITIVE advices. Because, and I think that this is very important and something that a lot of people still underestimate... My... The fellow peers that I have known and still know, uh, we are really concerned about the welfare of the physician who is going to help us, aren't we? Because I hear that a lot in the media and each time again, it hurts me a lot, that one is saying like, 'yes, but well, those POOR physicians who...'. First of all, they are not compelled to do it. If my GP had said 'no, I don't want to do it'. I always told her that. If you don't want to, then just say so. We have been very transparent about that, from the beginning. And that's the only way to handle it, I think. You have to be very honest with each other and ask 'Are you ready for this?' "Yes, okay then, but take some time to think it through, and if you don't want to, I'll seek someone else, right?"</i></p> <p>Female, 33 years</p> <p><u>*As regards the social inner circle</u></p> <p><i>"So that weight fell off my shoulder and was replaced by so much inner space. Suddenly I had the opportunity to empathise with, for example, what my mother felt, what my sister might feel, what my brother might feel, what my neighbour might feel, yes, and my friends and acquaintances. Suddenly, there was enough space to reflect about this and that was a great relief, that I had received the necessary recognition from [name of 1st advising physician who</i></p>	
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	<p><i>gave the positive advice]. I got that relief and recognition from her, and she gave me the gift of also being able to give recognition to others. I did not have that space before. On some practical level I could still see that, uh, my mother was going to lose one of her children, so from a practical perspective, I could see that, but I could not empathise with it, emotionally I could not... I didn't have that space. I didn't have that space to evoke that emotion, or create it, or to get it or feel it or whatever."</i></p> <p>Female, 51 years</p>	
Perceived control	<p>Reframing the death wish e.g. 'euthanasia' as potential safety net and not an acute death request</p> <p><i>"The right not to be forced to be here, but to be allowed to be here, is what made me stay here. It ensured me that I could be here, that I could continue to live here. That's really how it was for me, the right not to be obliged to live here made it possible for me to live. And I have put the procedure on hold now, but still, I know it is not far out of reach and knowing that still helps me. It is not out of reach and knowing that helps me out in the most difficult moments."</i></p> <p>Female, 47 years</p>	<p>Feelings of powerlessness, having no control (A, G)</p> <p><i>"No, (the procedure) is beyond your control. You have to comply with anything and everything."</i></p> <p>Female, 43 years</p>
Fairness		<p>Feelings of injustice, unfairness (A, G, P)</p> <p><i>"Yes, all these conversations with all these physicians. I don't call these 'conversations' anymore. I call them: going to plead your case, going to argue your case. I think, if you can uphold it well, that is, if you can explain it well, that you will get it. And if you have the right people around you, you will get it. And if you don't have the right people around you, you won't get it."</i></p>

		<i>Female, 45 years</i>
Emotional drain		<p>Procedure itself is emotionally draining <i>"Yes, it is a very long procedure. You must be very patient and when do you apply for it? At a time when you really feel exhausted, then you ask for it. And then they expect you to go everywhere, to have all those conversations, but you don't have that energy anymore, they... But that is what they expect. I think, someone who has a physical problem and already receives palliative care, they're not going to say: "Okay, you'll get euthanasia, but first you have to run a marathon, huh, so you better start going to the physiotherapist." They don't do that, but we are expected to do so, we still have to be able to do everything, that's deemed normal."</i></p> <p><i>Female, 50 years</i></p>
Distress about loved ones		<p>Distress about consequences of the euthanasia procedure on loved ones <i>"Because I felt that [name of the life partner] was keeping a lot to himself and that hurt me. I didn't want him to carry on like that. I wanted him to be able to express his feelings and thoughts and... to openly speak about it and... But that was difficult for him."</i></p> <p><i>Female, 55 years</i></p>

THE CLINICAL TRAJECTORY	
Favourable	Unfavourable
Continuity of care	No continuity of care (R)

<p><i>"With Dr [name attending physician], I can have these conversations about euthanasia about five times a year. And just that, just knowing that I could discuss it with him every time, without getting a stigma, huh? Knowing that it might be possible one day, might even be a manner that enables you to continue to live, eh? That you are being taken seriously, that you are indeed allowed to talk about it and that, because of that, you don't get a certain label of "What a strange patient is this? Do you really have to put me through this? Does she really have to burden me with this? It's not what a physician is meant to do." So that you have a safe setting somewhere where you can go to and have it discussed, and when you leave, that you can also step back into your life. And I realise that this is very strange and difficult to understand, even if you were to tell people about this, because on the one hand, you are on a heavy therapeutic trajectory, in which you put every focus on life, and in which you make all kinds of plans for the future and advancing your future, but then, on a parallel track, you are on a trajectory in which it is possible that I might take that turn towards euthanasia. So, I am actually following a two-track trajectory."</i></p> <p><i>Female B, 43 years</i></p>	<p><i>"Yes, first I followed day treatment twice and after that, I went to a revalidation centre for psychosocial revalidation purposes. And uhm, yes, well, because I talked about euthanasia, I wasn't allowed to stay there anymore, because normally, well, they need to get permission from the RIZIV [Belgian National Institute for Health and Disability Insurance]. And normally, depending on your diagnosis, you can stay there for a year and a half to two years. And I had already been there for one year, but they didn't want to make a new application for me because they thought that applying for euthanasia would mean to be ruled out for rehabilitation by the NIHDI. And then I think, well, all those people who are suicidal, they are allowed to stay, can't they, so why can't we? Well, apparently that isn't really taken into consideration."</i></p> <p><i>Female, 43 years</i></p>
<p>Open discussion about the death track within treatment trajectory</p> <p><i>"That one could ask for it, that there was room to discuss it, that there was at least a possibility for other people to engage in it, to assess the urgent need, the despair that you feel at a certain moment in your life: 'I can't do this anymore', 'I can't bear it any longer', 'This is too much', 'This takes too long', 'This is all way too painful'. The fact that, that you can apply for it, that gave me so much peace of mind."</i></p> <p><i>Female, 55 years</i></p>	<p>No discussion of the death track within treatment trajectory talks on death ideation/euthanasia not being included in the existing treatment trajectory</p> <p><i>"I think it was something of a no go for [name of the treating psychiatrist], that he was like: 'I'm not going down that road. For me it's a subject I don't want to discuss', right? And then I actually started looking for a place where I was able to discuss it and then I switched physicians, didn't I? [...] Dr. [treating psychiatrist] then said: we are ending our therapeutic trajectory now, yes well, we both felt that the therapeutic relationship was depleted."</i></p> <p><i>Female B, 43 years</i></p>

<p>New referrals & treatment approaches</p> <p><i>"And I was like "Okay, yes, that's fine, I'll get tested". And yes, the testing did indeed reveal the diagnosis of ASS and, well, the thing is that people who are more highly gifted intellectually, especially women, well, they unconsciously learned to camouflage it. But that takes so much energy and that was exactly what made me... Because, for example, eating and so on is still a problem for me, but now that I know that I am not able to notice a feeling of 'hunger', that this kind of stimulus does not reach me, just like, uhm, I do not get the notion of 'pain' either. But on the other hand, I am extremely sensitive to medication. So now I know all of that, and, well, okay, at that time I was like, okay, at least we know that now."</i></p> <p><i>Female, 33 years</i></p>	<p>Referral & further treatment burden</p> <p><i>"And then they said: 'Look, this [medication] isn't working out, let us try something else?" "Well, yes, of course" I had to rapidly say yes. Uhm, so yes, the former medication was phased out as quickly as possible, and we did a few blood tests. "And yes indeed, one drug has a different impact, its impact differs from one person to another, so let's try something else, he said." And I said, okay, let's try something else, as I'm still willing to consent, I still want to be cooperative, uhm, okay, the new medication dose was increased, and it didn't work out. The side effects were so intense and very burdening me, but for me, the only goal remained to comply with the conditions set by (name advising physician) to get the approval. And then he asked me: "Do you want to try something else? It was then that I said, "Well, no, I don't really need to, because I think I've proven and shown enough that I'm willing to consent and give it a try, so yes, I think of myself that I've done everything that was noted on the to do list. I have done what you asked me to do, I've done my homework, and marked 10 out of 10."</i></p> <p><i>Female, 51 years</i></p>
	<p>Souring patient - physician relationship during the euthanasia trajectory</p> <p><i>"My (treating therapist) also wrote this in a report. She wrote a report about the fact that I was following behavioural therapy for 2 years now and she also wrote that 'whatever decision she makes, I support her in her decision.'</i> <i>(Interviewer: And how did that affect you?)</i> <i>Well, I was very happy until...! Then she had a talk with my psychologist, with my general physician and, uh, she also had Dr. (the first advising doctor) on the phone... and, uh, they all said, so all my doctors, they all said that they take me seriously, but that they don't think I'm eligible for euthanasia. And that contradicts the report of my (therapist). She wrote "whatever (...) decides, I'll support her". A month later, she said that to me</i></p>

	<p>and I was devastated. She said, "Well yes, I don't think you qualify for euthanasia now". So, I was shocked and I said "You are turning your back on me. First you say that you'd support me and then you say, yes, well, the doctor doesn't know you well enough. And then she said "Well, the diagnosis, we have to be critical about that too and have it examined. And I thought, shit man, I felt so angry inside. You can't play with people like that. They don't realise that sometimes. "</p> <p>Female, 54 years</p>
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SOCIAL CIRCLE	
Favourable	Unfavourable
<p>Ability to learn from peers (e.g. joined forces to make life more bearable/to see alternative options)</p> <p><i>"In the end, you must look at it this way: there are eight or at least seven fellow peers there (in a rehabilitation-oriented group consisting solely of people with a euthanasia request), who all have a wish for euthanasia or a wish for death, and they either have approval or they haven't obtained it yet, or they are in the process of obtaining approval. And they are all people who have tried a ridiculous amount of things during their lifetime. You can't have a greater resource of little tools... Yes, and that is, uhm, what I've heard there sometimes, eh? Yes well, please do try this now or try that and then I think: 'Oh, but that's a great idea, I'm going to try that too, yeah! Or for example, 'I tried this, and it didn't work out for me but maybe it will for you'. So, there you have the largest source of self-help and experiences with therapies and psychiatrists and doctors and everything you want, all together in one single group of fellow peers. Nowhere is that kind of resource so huge."</i></p> <p><i>Female, 33 years</i></p>	<p>Not being supported or understood</p> <p><i>"No, unfortunately it's not up for discussion, both mum and dad don't want to hear about my wish for euthanasia, so it's difficult. Not only my mother and father, but my whole family also doesn't want to hear about it. I also have uncles and aunts, but they don't want to hear about it, none of them. (Interviewer: And did you tell them yourself at a certain point or...? Yes, I tried several times, and when I noticed that I couldn't do it verbally, I did it in writing, I did it in every possible way, but they don't want to talk about it. (Interviewer: Is that what they say, 'I don't want to hear about it?') No, no, they don't even say that, they just run away or they just ignore it."</i></p> <p><i>Male, 29 years</i></p>
Empowered to open-up/build new relationships	Crumbling relationships

<p><i>"And then by chance, in springtime, I think it was February or March, I encountered someone who had become a coach, who also danced with us in (name dancing therapy). But in (name dancing therapy) no talking is allowed during the dance session. (Interviewer: Ah?) Yes, that is to be able to stay connected to your feelings and, yes, I found out by accident that (dance coach) had to stay at home for 15 years, also due to a (psychiatric disorder). And (dance coach) said "I was against medication for 15 years and at some point, I had to give in to it, but it's often a long search before you find the right meds. And then I asked what did you take then? And (dance coach) gave me the names of the drugs, it was a mix of everything, and (dance coach) still came through. And then (dance coach) studied to become a coach and now (dance coach) works as an independent coach. (dance coach) says: 'you need to start thinking about it and open up to give it a try. So I took the list of named medications to my psychiatrist and gave it a try. Uhm, and I'm also going to a meditation group now, those people have also joined in my life, yes. So, yes, what has left my life is about to get replaced, some new people and new things fill in the places left empty".</i></p> <p><i>Female, 52 years</i></p>	<p><i>"And I, uhm, it actually ended up with quite a lot of people saying, 'I love you, but I have to let you go'. Yes well, so I don't have any contact with a lot of friends, a lot of people from the past, anymore. (Interviewer: Okay, but could they just let you go, or have difficulty doing so?) Yes, well, they just didn't understand, or they just went on with their lives, right? I mean in the sense of making their own living, their own home, starting a family, and so on."</i></p> <p><i>Female, 33 years</i></p>
<p>Receiving more support in life</p> <p><i>"But my daughter has been incredible because she also said, a few days after I had told her about my request for euthanasia, "That must have been terribly difficult for you". I said "yes, it still is terribly difficult". But they didn't say to me "You can't opt for euthanasia" and "you can't...". Afterwards, my daughter said "(name interviewee), I have seen how far you can go in your lows. I love you when you are manic, but now in December, I have seen that being extremely manic is a danger to you, that the urge to kill yourself is so high that you would actually do it." And therefore, she is now determined to stay</i></p>	

<p>more alert to the signals, like "Ha (...) you're manic, you're the active mum now." (Interviewer: Is she going to keep a closer eye on it and try to tone it down?) Yes, she will."</p> <p>Female, 54 years</p>	
<p>Opportunity for loved ones to receive support (A)</p> <p>"And euthanasia, well, you can say goodbye, the people who will stay here can be prepared for that moment. I would do anything to achieve that. I wanted them to meet with my psychologist. I wanted them to have guidance during the procedure, yes. Saying goodbye also, I, I, knew who I'd allow to stand at my bedside, yes, I found that, I found that so much more serene than just leaving by surprise."</p> <p>Female, 47 years</p>	
	<p>Difficulties with involving and managing interactions with important others</p> <p>"My daughter started crying and said "yes, but that means that, I won't have a mum any more within a year or two". And that was terribly confronting for her. My son said "Yes, then you might as well commit suicide now, than that I have to sit here and wait another two years to see you go, and what are you going to do in the meantime?" (Interviewer: So, 2 different kinds of reactions really?)</p> <p>Yes, and yet, a week or two later, my daughter said "Well, for me euthanasia and suicide are the same thing". (Interviewer: Yes?) Yes, and I said "No, I can say goodbye if I opt for euthanasia. And she said "Yes, but in both cases you will be dead. The outcome is death." (Interviewer: But your son had more difficulties with euthanasia?) Yes, yes. He literally said to me, "I'd prefer you to die within the week than in 2 years." He just finds that terrible, another 2 years from now."</p> <p>Female, 54 years</p>

Comparing own situation with fellow peers

"The people I know who have already obtained the approval, for some of them it has been given so quickly, so easily, yes, not quickly, but easily. (Interviewer: You mean the approval?) Yes, so easily given, and what I notice, these people, they don't have it carried out. Like (example in the media), they don't go that far and have it carried out. And one of those people I know, when he came back from the consultation with the approval in his pocket, when he came outside from the consultation with, I don't know which psychiatrist or doctor, and when he went back home, he thought, I don't want to die. (...) - I'm not going to make him identifiable now - he told me that he had only had one conversation with those two physicians, three physicians were mandatory, and in those days, you weren't even supposed to have two (advising) psychiatrists. And they would have told him something like 'we're not going to force you to live' and that he then obtained their approval.

Interviewer: After one conversation? With the first psychiatrist he consulted, I don't know how many conversations he had, but this man still says to me 'they almost threw their approval in my lap'."

Male, 57 years

PART THREE:

PSYCHIATRIST PERSPECTIVES

Chapters are based on the following publications:

Chapter 8

Verhofstadt M, Audenaert K, Van den Broeck K, Deliens L, Mortier F, Titeca K, Pardon K, & Chambaere K. Belgian psychiatrists' attitudes towards, and readiness to engage in, euthanasia assessment procedures with adults with psychiatric conditions: a survey. *BMC Psychiatry*. 2020.

doi:10.1186/s12888-020-02775-x

Chapter 9

Verhofstadt M, Audenaert K, Van den Broeck K, Deliens L, Mortier F, Titeca K, Pardon K, De Bacquer D, & Chambaere K. The engagement of psychiatrists in the assessment of euthanasia requests from psychiatric patients in Belgium: a survey study. *BMC Psychiatry*. 2020.

doi:10.1186/s12888-020-02792-w

Chapter 10

Verhofstadt M, Audenaert K, Van den Broeck K, Deliens L, Mortier F, Titeca K, De Bacquer D, & Chambaere K. Euthanasia in adults with psychiatric conditions: A descriptive study of the experiences of Belgian psychiatrists. *Science Progress*. 2021;104(3):003685042110297.

doi:10.1177/00368504211029775

CHAPTER 8 :

BELGIAN PSYCHIATRISTS' ATTITUDES TOWARDS, AND READINESS TO ENGAGE IN, EUTHANASIA ASSESSMENT PROCEDURES WITH ADULTS WITH PSYCHIATRIC CONDITIONS: A SURVEY

Verhofstadt M, Audenaert K, Van den Broeck K, Deliëns L, Mortier F, Titeca K, Pardon K, & Chambaere K. Belgian psychiatrists' attitudes towards, and readiness to engage in, euthanasia assessment procedures with adults with psychiatric conditions: a survey. *BMC Psychiatry*. 2020.
doi:10.1186/s12888-020-02775-x

More detailed information is posted in the Open Science Framework repository accompanying this paper: <https://osf.io/fg3ys/>

“Death is more merciful than hope itself! There is nothing surprising in this, for death is divinely appointed, while hope is the creation of human folly. Both end in frustration. Am I destined to lead a life of endless frustration?”

Naguib Mahfouz (The Beginning and the End)

Abstract

Background

Although the Belgian assessment pathway for legal euthanasia requires the engagement of at least one psychiatrist, little is known about psychiatrists' attitudes towards euthanasia for adults with psychiatric conditions (APC). This study aims to gauge psychiatrists' attitudes towards and readiness to engage in euthanasia assessment and/or performance procedures in APC.

Methods

This cross-sectional survey study was performed between November 2018 and April 2019. The survey was sent to a sample of 499 eligible psychiatrists affiliated to the Flemish Association for Psychiatry, a professional association that aims to unite and represent all psychiatrists working in Flanders, the Dutch-speaking, northern part of Belgium. The Association's members comprise an estimated 80-90% of all psychiatrists active in Flanders. Only psychiatrists working with APC (83% of the association's total membership) were included. Factorial Anova and Chi Square tests were performed to examine if and to what extent psychiatrists' backgrounds were associated with, respectively, their attitudes and their readiness to play a role in euthanasia procedures concerning APC.

Results

184 psychiatrists completed the questionnaire (valid response rate 40.2%); 74.5% agree that euthanasia should remain permissible for APC. However, 68.9% question some of the approaches taken by other physicians during the euthanasia assessment and only half consider euthanasia assessment procedures compatible with the psychiatric care relationship. Where active engagement is concerned, an informal referral (68%) or preliminary advisory role (43.8%) is preferred to a formal role as a legally required advising physician (30.3%), let alone as performing physician (< 10%).

Conclusion

Although three quarters agree with maintaining the legal option of euthanasia for APC, their readiness to take a formal role in euthanasia procedures appears to be limited. More insight is required into the barriers preventing engagement

and what psychiatrists need, be it education or clarification of the legal requirements, to ensure that patients can have their euthanasia requests assessed adequately.

Keywords: euthanasia, mental disorders, assisted suicide, psychiatry, survey study

Background

Since 2002, Belgium has provided a legal framework which – under certain conditions – enables patients suffering illnesses, including psychiatric disorders, to choose to die by means of euthanasia. No former Belgian research study has focused on the attitudes of psychiatrists towards euthanasia for adults with psychiatric conditions (APC). This is striking, as the Belgian legal procedure for euthanasia assessment requires the consultation of at least one psychiatrist for this specific patient group and research outside of Belgium has revealed strong reservations among psychiatrists toward euthanasia in APC.

Euthanasia (the administering by a physician of life-ending drugs to the patient at the latter's request) and/or physician-assisted suicide (where a physician prescribes and provides life-ending drugs to the patient, at their own request, for the patient to self-administer) is legal in a small number of countries worldwide and some US states, and mainly applies to those who are terminally ill.^{187,188,329} There are only a few European countries (Belgium, Luxembourg, Switzerland and the Netherlands) where euthanasia requests from non-terminally-ill patients can be granted when based primarily on psychiatric conditions.³²⁹ In Belgium, the act of euthanasia is only legal when all the legal criteria are fulfilled. The Belgian law does not explicitly cover physician-assisted suicide. However, in its information brochure for physicians, the Federal Control and Evaluation Commission for Euthanasia has stated that, in their opinion, physician-assisted suicide is also covered by the Euthanasia Law as the Law does not prescribe how euthanasia should be performed.⁷² In any case, physician-assisted suicide is extremely rare in Belgium.

Since the Belgian Law on Euthanasia came into effect in 2002, reported euthanasia rates based on psychiatric conditions (other than dementia) have risen from five cases in the first five years of the euthanasia law and 72 cases in the second to 181 cases in the third.^{112,117} The numbers represent a proportional increase from 0.25% of all reported euthanasia cases in APC between 2002 and 2005 to 2.1% in 2015, with a decrease to 1.2% between 2016 and 2017.

The increasing number of euthanasia cases based on psychiatric conditions has generated increasing ethical and societal debate. Public media have reported on

controversial euthanasia cases based on psychiatric conditions – three of which were referred to Belgian or European Courts ¹⁹⁵⁻¹⁹⁷ – and some observers have expressed concerns about potentially overly-permissive approaches in some instances, in terms of the assessment of eligibility.¹⁹⁸ Therefore, health care institutions and ethical and professional organisations have recently developed and published guidelines on the assessment of euthanasia requests in APC emphasizing the need for careful scrutiny in euthanasia decision-making procedures.³¹⁰

Psychiatrists are key players in euthanasia as regards APC ^{162,286,330}, as the Law on Euthanasia clearly states that they should be involved, at least as advising physicians, when patients request euthanasia in cases of non-terminal (neuro)psychiatric disease. However, to date, little is known about how they feel about euthanasia in APC, and to what extent they are prepared to be involved in such procedures.

Currently, only the Netherlands provides information from periodic evaluation and survey studies on euthanasia practice involving APC from a psychiatrist's perspective and results show that although the number of euthanasia cases performed has increased over time, the Dutch professional body of psychiatrists has become more reluctant to engage in or grant euthanasia requests from APC over the years.^{88,169} Recent cross-sectional studies gauging Canadian and Swiss psychiatrists' attitudes to such cases also show this reluctance.^{321,331} This is commonly attributed to the complexity and difficulty of adequately assessing all legal substantive criteria in APC.^{131,169}

This study aims to complement both the little knowledge that exists and the current debate with findings from Belgian euthanasia practice. We will address the following research questions:

- What are Dutch-speaking psychiatrists' attitudes towards euthanasia and the practice of euthanasia in APC? To what extent are their attitudes related to their personal and professional characteristics?
- To what extent would Dutch-speaking psychiatrists consider being involved in the assessment and/or performance of euthanasia procedures regarding APC? And to what extent is their willingness/unwillingness to be

involved in such euthanasia procedures related to their personal and professional characteristics?

Methods

Study design

This cross-sectional study consisted of a paper and web survey on psychiatrists' attitudes towards and readiness to be involved in euthanasia requests and procedures for APC.

Participants

As Belgium is divided into Flanders (the Dutch-speaking region in the north), Wallonia (the French-speaking region in the south), and Brussels (the capital, which is officially bilingual), the survey was launched among the Dutch-speaking psychiatrists. According to the latest report of the Federal Control and Evaluation Commission for Euthanasia, the ratio of performed euthanasia cases in the French-Speaking versus the Dutch-speaking region has been 20/80.¹¹²

The total eligible sample consisted of 499 psychiatrists, all members of the Flemish Association for Psychiatry (Vlaamse Vereniging voor Psychiatrie, VVP), a professional body that aims to unite and represent all psychiatrists working in Flanders, the Dutch-speaking northern part of Belgium. VVP-affiliated psychiatrists made up approximately 47% of the total professional group of psychiatrists in Flanders (1,286, of whom 910 were registered in the database of the National Institute for Sickness and Disability Insurance.³³² The distribution of the survey was limited to Dutch-speaking psychiatrists affiliated to the VVP for practical reasons (see [OSF](#)).

Survey Instrument

For this study, survey questions on psychiatrists' attitudes and readiness to be engaged in euthanasia procedures in APC were taken from a larger survey instrument that is posted in the Open Science Framework repository (see appendix A and B in [OSF](#)) accompanying this paper (in Dutch). The larger survey not only aimed to examine psychiatrists' attitudes, but also their concrete experiences and whether they can see themselves taking part in euthanasia

procedures based on psychiatric conditions in the future. The instrument was developed on the basis of five existing questionnaires^{88,97,169,333,334}, and adjusted to the context of current psychiatric clinical practice in Flanders.

The draft survey was presented at a meeting of 15 psychiatrists from the psychiatry ward of Ghent University Hospital for cognitive validation purposes (i.e. for participants to identify potential problems as regards item interpretation, item redundancy, completeness of the survey, feasibility to generate correct answers, and time estimation). Finally, the survey was revised by the members of the broader research group (for more details, see the research protocol in [OSF](#), appendix C).

For this specific study, the following 12 items of the larger survey (see [OSF](#), appendix D) were selected and divided into three main parts: 1) seven items covering the psychiatrist's personal and professional background; 2) one item consisting of 13 statements on attitudes towards euthanasia, to rate on a 5-point Likert scale, ranging from 'totally disagree' to 'totally agree', e.g. 'euthanasia should be legal for psychiatric patients'; 3) three items on psychiatrists' readiness to take up one or more roles in euthanasia procedures concerning APC (as e.g. the treating, advising and/or performing physician in the future; see Box 2 for a helpful glossary, explaining each of the active roles a psychiatrist could be engaged in); and 4) one open-ended question at the end of the questionnaire, consisting of a comment box, in which responding psychiatrists could clarify their answers if necessary.

Ethics

This research project was performed in accordance with the Declaration of Helsinki and received ethical approval from the Medical Ethics Committee of the Brussels University Hospital with reference BUN 143201837302 and the Medical Ethics Committee of the Ghent University Hospital with reference 2018-1165.

Procedure

Data collection

The VVP members were invited by e-mail to participate in the study. A link to LimeSurvey's online platform³³⁵ was included and the information letter (see

OSF, appendices E and F, in Dutch) attached. Data were collected between November 2018 and April 2019. Non-responders received a first reminder by e-mail, two weeks after the initial invitation. A second reminder, including a paper-and-pencil version of the questionnaire, was sent by post three weeks after the survey was launched.

Analyses and criteria

Data were imported from LimeSurvey into SPSS version 25 and cleaned according to the principles of a data analysis plan (OSF, Appendix G). The SPSS database was supplemented with data gathered from the returned paper surveys. Missing data were excluded from analyses.

To describe the sample, we calculated aggregated descriptives on the psychiatrists' personal and professional characteristics that were also used as independent variables in further statistical analyses. Factorial Anova and Chi Square tests were performed to examine if and to what extent psychiatrists' backgrounds were associated with, respectively, their attitudes and their readiness to take a role in euthanasia procedures concerning APC. See appendix G in OSF for the syntax used for hypothesis testing. The open question at the end was checked for relevant answers, thematically analysed and included in the findings.

Results

Description of the Sample

The VVP consisted of 600 members; 101 members were not professionally active as psychiatrists and/or had no work experience with adult psychiatric patients. The response sample consisted of 201 out of 499 psychiatrists (valid response rate 40.2%). The data from 17 psychiatrists were excluded from further analysis, for example due to no explicit agreement regarding informed consent or too many missing answers. The responses of 184 psychiatrists were found eligible for further analysis, including data from retired psychiatrists as they can still be involved in euthanasia procedures.

Table 1 shows the characteristics of the responding psychiatrists. Of all psychiatrists, 56.5% were male. The majority (66.8%) worked in a psychiatric hospital care facility, 45.7% in a private practice and 13% in a community mental healthcare centre; 17.9% had less than five years of work experience – they were trainees in psychiatry – and 48.4% had more than 20 years of work experience. Nine (4.9%) had received special training in end of life matters, while 91 (49.5%) felt competent to be involved in euthanasia procedures.

Attitudes to euthanasia

As illustrated in detail in Table 2, a minority of psychiatrists (29.9%) were in favour of restricting euthanasia, as a legal end-of-life option, to the terminally ill. According to the majority of psychiatrists (74.5%), euthanasia should remain legal for APC.

As regards the eligibility of a psychiatric patient's euthanasia request, the majority agreed that APCs can suffer unbearably (94.6%), can make a well-considered euthanasia request (88%), and can find themselves in a medically hopeless situation (83.7%) as a lack of reasonable treatment perspectives can exist (77.2%).

With regard to the assessment of an APC's euthanasia request, about half of the psychiatrists (52.7%) considered a psychiatric euthanasia procedure to be compatible with a psychiatric care relationship. In addition, 58.1% agreed that potentially effective therapeutic treatment options in the future should be taken into account during the euthanasia assessment and 80.9% supported the idea that the assessment should focus on the APC's whole life, and not only on their medical state. As regards suicide, 43.7% of the psychiatrists agreed that euthanasia is an acceptable alternative to prevent the APC from attempting suicide.

Opinions were divided over whether or not physician-assisted suicide is more acceptable than euthanasia. Finally, over two thirds of psychiatrists (68.9%) agreed that in some cases the APCs' euthanasia request was not assessed as thoroughly as they could be.

Table 1: Psychiatrists' demographics and professional characteristics

	Sample (N = 184)	
	n	%
Gender		
Male	104	56.5
Female	77	41.8
Unknown	3	1.6
Age (in years)	n	%
< 30	28	15.2
30 - 40 years	40	21.7
41 - 60 years	65	35.3
> 60	51	27.7
Worked as psychiatrist or psychiatric trainee during last year	n	%
Yes	167	90.8
No	16	8.7
Missing	1	0.5
Clinical setting¹	n	%
Private or Group Practice	84	45.7
Psychiatric Hospital Care	123	66.8
Community Mental HealthCare Centre	24	13.0
Psychiatric Nursing Home	9	4.9
Psychiatric Home Care	6	3.3
Sheltered housing	13	7.1
Other ²	26	14.1
Work experience (in number of years)	n	%
< 5 years	33	17.9
6 - 10 years	20	10.9
11 - 20 years	42	22.8
> 20 years	89	48.4
Ever received special training in End Of Life care	n	%
Yes	9	4.9
No	173	94.0
Missing	2	1.1
Feels competent to be involved in euthanasia procedure	n	%
Yes	91	49.5
No	92	50
Missing	1	0.5

¹ Some psychiatrists had more than one workplace

² Other work places: prison or forensic psychiatric centres, psychiatric and psychosocial rehabilitation centres, psychiatric mobile crisis or response teams, other housing and care centres for other subpopulations (e.g. students, disabled persons).

Table 2: Psychiatrists' attitudes toward euthanasia in general and in psychiatry

Attitude statements	Response in N/% ¹				Combined %	
	Totally disagree	Disagree	Neutral	Agree	Totally agree	Agree + Totally agree
St1: Euthanasia should only be legally allowed for the terminally ill.	40 21.7%	70 38.0%	19 10.3%	32 17.4%	23 12.5%	55 29.9%
St2: Euthanasia should be legally allowed for the non-terminally ill, but only when based on somatic illnesses.	53 28.8%	91 49.5%	20 10.9%	13 7.1%	7 3.8%	20 10.9%
St3: Euthanasia should remain legally allowed for patients with psychiatric illnesses.	17 9.2%	19 10.3%	11 6.0%	68 37.0%	69 37.5%	137 74.5%
St4: A psychiatric patient can suffer unbearably.	2 1.1%	1 0.5%	7 3.8%	37 20.1%	137 74.5%	174 94.6%
St5: A psychiatric patient's death request can be well considered, and not only considered as a symptom of the patient's psychopathology.	4 2.2%	8 4.3%	10 5.4%	92 50.0%	70 38.0%	162 88%
St6: A psychiatric patient can find herself in a medically hopeless situation.	5 2.7%	9 4.9%	16 8.7%	67 36.4%	87 47.3%	154 83.7%
St7: For a psychiatric patient, a lack of reasonable treatment perspectives can exist.	2 1.1%	23 12.5%	17 9.2%	76 41.3%	66 35.9%	142 77.2%
St8: Euthanasia assessment in psychiatric patients is compatible with a psychotherapeutic relationship.	26 14.1%	31 16.8%	30 16.3%	60 32.6%	37 20.1%	97 52.7%
St9: During the assessment of a psychiatric patient's euthanasia request, potentially effective therapeutic treatment options should be taken into account.	7 3.8%	34 18.5%	36 19.6%	74 40.2%	33 17.9%	107 58.1%
St10: During the assessment of a psychiatric patient's euthanasia request, the focus should not only be placed on the patient's medical condition, but also on the patient's whole life context.	6 3.3%	10 5.4%	19 10.3%	77 41.8%	72 39.1%	149 80.9%
St11: Euthanasia is an acceptable alternative to prevent for suicide. ²	35 19.1%	33 18.0%	35 19.1%	64 35.0%	16 8.7%	80 43.7%
St12: In psychiatric patients, physician-assisted suicide is more acceptable than euthanasia.	36 19.6%	41 22.3%	49 26.6%	46 25.0%	12 6.5%	58 31.5%
St13: In some cases, there is mention of psychiatric euthanasia assessment that was too lightly dealt with. ²	2 1.1%	16 8.7%	39 21.3%	66 36.1%	60 32.8%	126 68.9%

¹ Range Likert scale: from 1 "totally disagree" to 5 "totally agree" and for all items: Minimum score = 1 and maximum score = 5

² Missings: $n = 2$ (St9 and St13: $n = 1$, missings from 2 different psychiatrists)

The open question at the end of the survey allowed psychiatrists to elaborate on and clarify their answers. Opposite motives (e.g. a psychiatrist's own norms and values) as regards whether or not euthanasia in APC should remain legal were reported. But irrespective of normative disagreement on that statement, the answers to the open questions revealed scepticism and negative experiences regarding current euthanasia practice concerning APC in terms of a perceived insufficiency of due diligence and care by some colleagues during the assessment procedures.

As listed in Table 3, the results revealed no significant associations between a psychiatrist's attitude to euthanasia remaining legal in APC and their personal or professional characteristics in terms of sex, perceived competence, work setting and work experience.

Readiness to engage actively in euthanasia procedures concerning APC

All psychiatrists, including those who have never been confronted with an explicit euthanasia request from APC in their professional career, were asked whether they could imagine being actively involved in such procedures in the future and if so, what type of role they would assign to themselves. From the 184 psychiatrists who answered the statements on euthanasia, 178 also answered these questions.

As illustrated in Table 4, twenty-nine (16.3%) were not willing to be involved in any active role during a euthanasia procedure concerning an APC in the future. Among those who would consider being involved in such euthanasia procedures (83.7%), respectively 68% and 43.8% would consider for themselves the role of referring or preliminary advising physician (See Box 2 in [OSF](#) for the English version of the glossary); 30.3% would consider being involved as the legally required first or second advising physician. A minority (8.4%) would engage in the performance of euthanasia with their own patient (8.4%) or a colleague physician's patient (4.5%).

Table 3: Psychiatrists' attitude towards euthanasia for psychiatric patients related to their personal and professional characteristics

	N	Mean	SD	F	p-value	95 CI Lower Bound	95 CI Upper Bound
Sex							
Male	93	3.674	.215	.424	.516	3.249	4.100
Female	74	3.804	.173			3.462	4.146
Perceived Competence							
No	86	3.657	.205	.003	.959	3.251	4.063
Yes	81	3.825	.191			3.449	4.202
Work Setting							
Community-based	52	3.451	.274	2.832	.095	2.908	3.993
Hospital-based	115	3.963	.127			3.713	4.214
Work Experience							
< 5 - 10 years (group 1)	51	3.704	.297	.397	.673	3.117	4.291
11 - 20 years (group 2)	39	4.026	.273			3.486	4.566
> 20 (group 3)	77	3.510	1.44			3.225	3.795

Note, Dependent Variable = Euthanasia should remain legally allowed for psychiatric patients
 Note also, R Squared = .181 (Adjusted R Squared = .076)

Table 4: Psychiatrists' Readiness to be involved in the assessment of Psychiatric Euthanasia procedures

	N = 178¹
Readiness²	
Would you consider to actively engage in one or more roles concerning explicitly expressed (distinct?) euthanasia requests of adult patients with (a) psychiatric disorder(s)?	N (%)
No, in not one single role	29 (16.3%)
Yes, as treating physician, who refers the own patient to a colleague-physician for further clarification/advise	121 (68.0%)
Yes, as attending physician, engaged in the clarification of a euthanasia request of my own patient	70 (39.3%)
Yes, as attending physician, engaged in the clarification of a euthanasia request of a colleague-physician's patient	62 (34.8%)
Yes, as preliminary advising physician concerning a partial aspect (e.g. ruling out the existence of an acute depression, assessing mental competence) ³	78 (43.8%)
Yes, as procedural advising physician concerning the legally required 1 st or 2 nd advice	54 (30.3%)
Yes, as performing physician, when being present at, assisting in of carrying out the act of euthanasia in my own patient	15 (8.4%)
Yes, as performing physician, when being present at, assisting in of carrying out the act of euthanasia in a colleague's patient	8 (4.5%)

¹ Missing cases $n = 6$: these missings concern psychiatrists who have filled out the online survey up to and including the 13 statements, but no(t much) further. It concerns psychiatrists that worked as psychiatrist with adult patients during the last 12 months (no retired or child psychiatrists).

² More than one conceivable role could be ticked by the psychiatrists.

³ In some cases, the 'Advising role in a preliminary stage' was chosen by retired psychiatrists and/or members of ethical committees.

Table 5 represents the relation of a psychiatrist's characteristics to their readiness to engage in euthanasia procedures concerning APC. Male and female psychiatrists did not differ significantly in their readiness to be involved in the assessment and/or performance of euthanasia with APC. However, those who felt more competent to be involved in euthanasia procedures more often indicated that they were prepared to consider an active role ($\chi^2_{(1,175)} = 5.140, p = .023$), to give preliminary advice or legally required formal advice, ($\chi^2_{(1,175)} = 10.654, p = .001$ and $\chi^2_{(1,175)} = 26.771, p = .000$, respectively), and to consider a role as an attending physician ($\chi^2_{(1,175)} = 9.498, p = .002$) in an APC's euthanasia procedure.

Years of work experience and older age were significantly and positively associated with not considering an active role ($\chi^2_{(2,176)} = 11.239, p = .004$ for work experience and $\chi^2_{(2,176)} = 18.614, p = .000$ for age range), whereas fewer years of work experience and a younger age were significantly and positively associated with referring the psychiatric patient to a colleague for the clarification of the euthanasia request (respectively $\chi^2_{(2,176)} = 38.765$ and $\chi^2_{(2,176)} = 26.456, p = .000$). Different ranges in years of work experiences were also statistically significant in considering an active role as preliminary advising physician ($\chi^2_{(2,176)} = 11.908, p = .003$).

Anecdotal evidence from the answers to the open question at the end of the survey revealed that the readiness to be actively engaged in a euthanasia procedure concerning APC was based on the following motives: 1) moral and/or religious objection or agreement; 2) concerns regarding the difficulties of these euthanasia decision-making procedures, and 3) concerns about irreconcilable differences with and/or the inappropriate approaches of a colleague physician in current euthanasia practice concerning APC. Reported difficulties in the euthanasia decision-making procedures concerned: 1) some of the legal criteria being vague, as well as doubts about reconciling some legal criteria, such as a medically hopeless situation, due to subjectivities inherent in psychiatry, 2) the influence of transference and countertransference; 3) the lack of adequate courses and training on end-of-life education in regular and post-academic education and 4) concerns about how to reconcile the assessment of an APC's euthanasia request with the current treatment of their psychopathology.

Table 5: Psychiatrists' readiness to be engaged in psychiatric euthanasia assessment related to their personal and professional characteristics

	Can conceive of themselves in the role of... ¹					
	NO ROLE	Referring physician	Preliminary advising physician	Formal advising physician	Attending physician	Performing physician
Sex	<i>p</i> =.060/.067	<i>p</i> =.084/.102	<i>p</i> =.873/.878	<i>p</i> =.098/.134	<i>p</i> =.543/.645	<i>p</i> =.849/1.000
Male (<i>n</i> =98)	21 (21.4%)	61 (62.2%)	43 (43.9%)	35 (35.7%)	49 (50.0%)	10 (10.2%)
Female (<i>n</i> =75)	8 (10.7%)	56 (74.7%)	32 (42.7%)	18 (24.0%)	41 (54.7%)	7 (9.3%)
Age	<i>p</i>=.000	<i>p</i>=.000	<i>p</i> =.091	<i>p</i> =.648	<i>p</i> =.091	<i>p</i> =.106
<40 (<i>n</i> =65)	4 (6.2%)	60 (92.3%)	35 (53.8%)	17 (26.2%)	38 (58.5%)	9 (13.8%)
41-60 (<i>n</i> =64)	8 (12.5%)	42 (65.6%)	24 (37.5%)	20 (31.3%)	35 (54.7%)	7 (10.9%)
>60 (<i>n</i> =47)	17 (36.2%)	17 (36.2%)	17 (36.2%)	16 (34.0%)	18 (38.3%)	1 (2.1%)
Years of experience	<i>p</i>=.004	<i>p</i>=.000	<i>p</i>=.003	<i>p</i> =.240	<i>p</i> =.142	<i>p</i>=.022
<10 (<i>n</i> =51)	3 (5.9%)	47 (92.2%)	32 (62.7%)	17 (33.3%)	32 (62.7%)	9 (17.6%)
10-20 (<i>n</i> =41)	4 (9.8%)	30 (73.2%)	13 (31.7%)	8 (19.5%)	21 (51.2%)	5 (12.2%)
>20 (<i>n</i> =84)	22 (26.2%)	42 (50.0%)	31 (36.9%)	28 (33.3%)	38 (45.2%)	3 (3.6%)
Perceived Competence	<i>p</i>=.023/.026	<i>p</i> =.282/.334	<i>p</i>=.001	<i>p</i>=.000	<i>p</i>=.002	<i>p</i> =.211/.307
Yes (<i>n</i> =88)	9 (10.2%)	56 (63.6%)	49 (55.7%)	42 (47.7%)	56 (63.6%)	11 (12.5%)
No (<i>n</i> =87)	20 (23.0%)	62 (71.3%)	27 (31.0%)	11 (12.6%)	35 (40.2%)	6 (6.9%)

¹ More than one conceivable role could be ticked by the psychiatrists.

Note: In bold: significant *p*-values for Chi-Square tests/Fisher Exact tests

In Grey: One or more cells with expected count less than 5 and thus Chi² does not have sufficient power.

Discussion

This is the first survey in Belgium to study specifically the attitudes and readiness of Dutch-speaking psychiatrists regarding their involvement in euthanasia requests from APC. Almost three-quarters of Dutch-speaking psychiatrists supported the option of euthanasia as a legal end-of-life choice for APC. However, only half would consider an euthanasia assessment to be compatible with a therapeutic relationship and approximately one third (especially the younger generation) would engage in the concrete assessment of euthanasia cases concerning APC. Where active engagement was considered, an informal referring or preliminary advising role in the background was preferred to a formal role as the legally required advising physician, let alone as the performing physician. Finally, concerns were expressed regarding today's euthanasia practice in terms of due diligence and care in the assessment of an APC's euthanasia request.

Strengths and limitations

As outlined above, we carefully constructed and pre-tested a survey, building on existing questionnaires and involving experts from the academic and the clinical psychiatric field, and tested for cognitive validity with a small group of psychiatrists. This pre-test phase resulted in feedback in both form and content. However, we cannot exclude the possibility of misunderstandings remaining as regards the interpretation of individual items.

In order to maximise response rates, we approached our psychiatrists by means of multiple response-inducing techniques.³³⁶ A fair response rate of 40% was achieved (considering the target group of psychiatrists and the delicacy of the topic)³³⁷ and rich quantitative as well as qualitative data were obtained.

However, the results from this study with a 40% response rate from a sample of VVP-affiliated psychiatrists cannot readily be generalized to the full population of psychiatrists in the Dutch-speaking region of Belgium, and must therefore be interpreted with caution. There are avid supporters of as well as opponents of euthanasia for psychiatric patients, and the societal debate on euthanasia itself extends to psychiatrists as part of society. Keeping in mind the extremely sensitive nature of our research topic, we could have missed the answers of

psychiatrists positioned at either end of the euthanasia debate, i.e. the ones strongly opposed to the study and its set-up as well as the ones strongly opposing critical reflections on today's euthanasia practice. However, our study findings revealed both support for maintaining the current law as well as the identification of various scopes of improvement that - in the long run - could lead to sufficiently built-in safeguards integrated to protect against potential wrongdoings. By doing so, our study may contribute to a proper debate about the most appropriate euthanasia practices and as a consequence, may be seen as the first step in order to restore the current lack of trust in and negative experiences of some colleague-physicians in this field.

There is reason to believe that we have minimized the risk of a biased sample. According to email correspondence with the VVP, their database membership comprises an estimated 80 to 90% of all Dutch-speaking psychiatrists. If we extrapolated our response sample of 184 Dutch-speaking psychiatrists working with APC to the estimated population of all Dutch-speaking psychiatrists affiliated to the Flemish Association for Psychiatry ($n=600$) or registered to work with people with psychiatric conditions ($n=910$), it would mean that we had reached close to one third ($184/600$) and one fifth of all registered Dutch-speaking psychiatrists, respectively.

However, it should be noted that the majority of responding psychiatrists were professionally active in a hospital-based setting rather than in a community-based setting. Taking into account that this does not necessarily reflect the general division of private versus hospital-based practices in Flanders (nor in other countries), this suggests that the topic of euthanasia in APC is more pervasive in hospital-based practices, likely due to more severe (consequences of) psychopathology as well as the requirement to engage in intensive treatment programs before APCs can be considered to be in a medically hopeless situation and eligible for euthanasia. This should be further examined in future research.

Interpretation of findings

Contrary to Canadian and Swiss findings^{321,331} but in line with Dutch findings¹⁶⁹, the majority of psychiatrists were in favour of continuing to allow APC to die by means of euthanasia. Most Dutch-speaking psychiatrists agreed that APC can

effectively meet the substantive legal criteria, although this mainly concerns the criteria that can be attributed directly to the patient (e.g. mental competence, unbearable suffering), and to a somewhat lesser degree the criteria attributed to the medical condition (e.g. medically hopeless situation and reasonable treatment perspectives). However, almost one out of three psychiatrists was opposed to euthanasia for psychiatric reasons. This could be due partially to fundamental ethical and religious objections, insufficient competence in handling such requests at a practical clinical and ethical level or a desire for additional or more stringent legal criteria for this specific patient group. As for the latter, the guidelines for adequate euthanasia assessment in APC have only recently been published, so their impact is still unknown (i.e. whether or not these guidelines were sufficiently known and/or sufficiently address the difficulties in the euthanasia decision-making procedure).

Although the majority of psychiatrists were in favour of euthanasia remaining legal for this patient group, only a minority were willing to be actively engaged in it due to the difficulty of the decision-making procedure, e.g. the vagueness of the law and the subjectivities inherent in the medical discipline of psychiatry. However, compared to the Dutch findings, the percentage of psychiatrists supporting this legal option for APC and willing to engage in such procedures was slightly higher in Flanders than in the Netherlands (74.5% versus 70.5% and 84% versus 82% respectively), which may be due to the inclusion of trainees in psychiatry in the sample or to differences in the respective legal end-of-life frameworks. For example, the Belgian law provides stricter legal criteria as regards the non-terminally ill, which may provide more guidance to rely on. It also explicitly assigns a specific role to psychiatrists, as the consultation of at least one psychiatrist is required for euthanasia assessment purposes in APC.³³⁸ In addition, most psychiatrists would rather refer APC to a colleague for the clarification of a euthanasia request where it was deemed difficult to reconcile with the treatment of their psychopathology or with their rehabilitation. On the other hand, conscientious objection by the psychiatrist is also legally accepted and does happen, as shown in our study. This raises questions about how patient referral is organized. Given that only a minority of psychiatrists are willing to engage actively in such euthanasia procedures, it is important to ensure that APC are able to have their euthanasia request heard. The consequences for APC can

be increased suffering and potential suicide (or suicide attempts) when the APC are unable to discuss their wishes concerning death.

It is striking that almost three quarters of the psychiatrists had questions about the approaches of certain colleagues to euthanasia practice in APC. Some expressed concerns about what they saw as the overly permissive approaches taken at end-of-life consultation centres. As only a minority of psychiatrists were willing to engage in the assessment of an explicit euthanasia request from APC, and mostly only as the referring physician, their patients may find their way to these other psychiatrists and centres. However, the concerns expressed about euthanasia requests that are dealt with too lightly may also be interpreted the other way around, as the answers to the open questions also showed worries about some psychiatrists dismissing euthanasia requests too quickly.

Implications for practice, policy and research

More research is needed to further examine the underlying motives influencing the attitudes of psychiatrists towards, and readiness to deal with, euthanasia requests from APC, and to gain insight into the reasons for the discrepancy between their attitudes towards and their readiness to be involved in these cases. Is the discrepancy primarily due to a need for more qualitative education and/or do the legal requirements need more clarification? Further research might reveal more potential study associations between psychiatrists' profiles (e.g. psychiatrists' values in life, beliefs, religiosity and norm systems) in the context of their attitudes and/or readiness to engage in euthanasia assessment regarding APC. In addition, in-depth qualitative studies could further expand our insights into psychiatrists' concrete experiences with such euthanasia requests and assessment procedures.

What can be learned from the lack of trust in other physicians – on both sides of the spectrum – and negative experiences with them, in order to find adequate ways to establish and/or restore this much-needed trust? Our results suggest that psychiatrists who feel sufficiently competent in the assessment of euthanasia requests are more likely to be actively engaged in them as the preliminary or formally advising physician or the attending physician. In this respect, it is noteworthy that only a minority of psychiatrists have received specific training in medical end-of-life decisions, which could affect their attitudes

towards euthanasia in these patients, their perception of their own capacity to engage in them and their lack of trust in and collaboration with experienced colleagues and end-of-life centres. The reasons why the younger generation of psychiatrists seemed more prepared to engage actively in these procedures should also be addressed, as they may give insight into and influence future euthanasia practice concerning APC.

Future cross-national research could provide important insights into the determinants of legal and medical culture regarding differences in end-of-life decisions in different countries, and how they affect the current medical practice of euthanasia. Recommendations for policy and practice arising from this study include budgeting for more in-depth evaluation studies (e.g. to gain insight into the barriers that impede psychiatrists from engaging) and other support that could increase the quality and transparency of today's euthanasia practice with APC, increasing all actors' levels of confidence in this practice, whether by education or by further clarification of the legal requirements.

Conclusions

Although the majority of Flemish psychiatrists indicate that euthanasia should remain legally permissible for APC where the current legal criteria are met, a minority (one third) is prepared to be actively engaged in the assessment of a euthanasia request and fewer than 10% are willing to assist in the administration of the lethal drugs to the APC.

CHAPTER 9 :

THE ENGAGEMENT OF PSYCHIATRISTS IN THE ASSESSMENT OF EUTHANASIA REQUESTS FROM PSYCHIATRIC PATIENTS IN BELGIUM: A SURVEY STUDY

Verhofstadt M, Audenaert K, Van den Broeck K, Deliëns L, Mortier F, Titeca K, Pardon K, De Bacquer D, & Chambaere K. The engagement of psychiatrists in the assessment of euthanasia requests from psychiatric patients in Belgium: a survey study. *BMC Psychiatry*. 2020.
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More detailed information is posted in the Open Science Framework repository accompanying this paper: <https://osf.io/asjvp/>

"The Life you save, may be your own."
Flannery O'Connor (A Good Man is Hard to Find)

Abstract

Background

Since its legalisation in 2002, the number of times euthanasia has been carried out in response to requests from adults with psychiatric conditions (APC) has continued to increase. However, little is known about why and how psychiatrists become engaged in the assessment of such euthanasia requests.

Methods

A cross-sectional survey study was conducted between November 2018 and April 2019 of 499 psychiatrists affiliated with the Flemish Psychiatry Association. Chi square/Fisher's exact tests were performed to examine if, and to what extent, psychiatrists' backgrounds relate to their concrete experiences. The answers to the open question regarding motives for (non-) engagement were thematically coded.

Results

201 psychiatrists participated, a valid response rate of 40%. During their careers, 80% of those responding have been confronted with at least one euthanasia request from an APC patient and 73% have become involved in the assessment procedure. Their engagement was limited to the roles of: referring physician (in 44% of the psychiatrists), attending physician (30%), legally required 'advising physician' (22%), and physician participating in the actual administration of the lethal drugs (5%). Within the most recent 12 months of practice, 61% of the respondents have been actively engaged in a euthanasia assessment procedure and 9% have refused at least once to be actively engaged due to their own conscientious objections and/or the complexity of the assessment. The main motive for psychiatrists to engage in euthanasia is the patient's fundamental right in Belgian law to ask for euthanasia and the psychiatrist's duty to respect that. The perception that they were sufficiently competent to engage in a euthanasia procedure was greater in psychiatrists who have already had concrete experience in the procedure.

Conclusions

Although the majority of psychiatrists have been confronted with euthanasia requests from their APC patients, their engagement is often limited to referring

the request to a colleague physician for further assessment. More research is needed to identify the determinants of a psychiatrist's engagement in euthanasia for their APC patients and to discover the consequences of their non-, or their restricted or full engagement, on both the psychotherapeutic relationship and the course of the euthanasia request.

Keywords: euthanasia, mental disorders, assisted suicide, psychiatry, survey study

Introduction

Since 2002, euthanasia – the intentional termination of life at the patient’s request – has been legal in Belgium, under strict conditions, including for Adults with Psychiatric Conditions (APC).¹⁸⁵ APC encompass two adult patient groups: 1) patients whose euthanasia request is predominantly based on suffering caused solely by their psychiatric conditions, other than dementia; and 2) patients whose euthanasia request is predominantly based on suffering caused primarily by their psychiatric conditions and secondarily by somatic comorbid conditions.

However, euthanasia for APC patients is a highly controversial topic worldwide, and evokes strongly opposing views in the national and international media.^{92-94,339} Extensive research is needed to clarify the way the Belgian Law on Euthanasia is put into practice for APC requesting euthanasia, and how Belgian psychiatrists deal with the roles and responsibilities associated with this practice.

The Belgian Law on Euthanasia places the psychiatrist in the role of gatekeeper, requiring the consultation and formal written ‘advice based on a formal assessment’ (formal advice, in short) by at least one psychiatrist for each request.¹⁸⁵ This psychiatrist is then engaged as a formally advising physician entrusted with the task of giving a formal advice regarding the patient’s (established or potential) eligibility for euthanasia. The formal advice can result in one of 3 determinations: the patient can be considered 1) eligible for euthanasia, 2) eligible for euthanasia, under certain conditions, or 3) not eligible for euthanasia.

To date, this seems to be what happens, as all reported cases include a formal advice from at least one psychiatrist.¹¹⁷ Yet, a recent study demonstrated that, although a majority of Belgian psychiatrists are in favour of euthanasia as a legal end-of-life option for APC patients, only a minority are willing to actively engage in the assessments and procedures involved.³⁴⁰ Nonetheless, the number of reported euthanasia cases predominantly based on suffering caused by psychiatric conditions has increased steadily over time, although these cases still represent a small percentage of all euthanasia cases (i.e. 26 or 1.1% of all 2,309 euthanasia cases performed in 2017).¹¹²

However, the practice of psychiatrists in APC euthanasia remains under-examined, and little is known about why and how psychiatrists become engaged in the assessment of a euthanasia request from an APC patient. Euthanasia in APC remains a matter of serious concern to society, and debates will remain purely theoretical until there is a solid scientific description of the empirical reality. Even if these requests are comparatively rare and seldom granted, they cannot remain unexamined on the grounds of their low rate of prevalence. Therefore, in order to assess the extent to which this issue pervades Belgian psychiatric practice, and to fill in the knowledge gaps described above, this study will address the following research questions:

- During their career, to what extent have psychiatrists in Flanders and Brussels been confronted with, and engaged in, euthanasia requests from APC patients?
- During the last 12 months, what proportion of these psychiatrists have been engaged in euthanasia assessment procedures in this patient group and in giving legally required advice? And what has been the nature of this advice?
- What motives do psychiatrists in Flanders and Brussels cite in refusing or accepting engagement in the assessment of such procedures?
- How does this engagement relate to their socio-demographic and professional background?

Methods

Study design

This cross-sectional study consisted of paper-and-pencil and web surveys on psychiatrists' experiences with APC patients whose euthanasia requests are predominantly based on suffering caused by psychiatric conditions other than dementia.

Participants

The surveys were launched among the professional body of psychiatrists affiliated with The Flemish Psychiatric Association (Vlaamse Vereniging voor Psychiatrie, FPA) in order to gather original data from Flemish-speaking

psychiatrists ($N = 600$). Exclusion criteria were: 1) no work experience as a psychiatrist in adult mental healthcare, and 2) not currently working in Belgium. Taking the exclusion criteria into account, a sample of 499 psychiatrists were eligible to fill in the survey. The survey has been launched in the French-speaking part of Belgium, but results are excluded here as the response rate has been extremely low.

Survey Instrument

For this study, the survey questions on the psychiatrist's concrete engagement in euthanasia cases based on psychiatric conditions were taken from a larger survey instrument, which is posted in the Open Science Framework repository (see Appendices A and B in [OSF](#)) accompanying this paper (in Dutch) and the Supplemental Materials in [OSF](#) (in French and English). The instrument was developed on the basis of five existing questionnaires ^{88,97,169,333,334}, and adjusted to the context of current psychiatric clinical practice in Belgium.

This larger survey was tested for cognitive validation purposes (i.e. participants identifying potential problems with regard to item interpretation, item redundancy, completeness of the survey, feasibility to generate correct answers, and time estimation) via focus group analysis during a meeting with a heterogenous group (with regard to gender, age, and experience in euthanasia) of 15 psychiatrists.³⁴¹ Finally, the survey was revised and tested for time estimation and online technicalities by the broader research group (for more details, see the research protocol in [OSF](#), Appendix C).

The survey questions were preceded by the following sentence: "Part 2: The following questions gauge your engagement in ADULT patients' euthanasia requests that are PRIMARILY based on suffering CAUSED BY one or more psychiatric disorder(s), other than dementia." The words in capitals were deemed necessary from a cognitive perspective, in order to avoid receiving data based on: 1) minors predominantly suffering from psychiatric conditions (as they cannot be considered eligible for euthanasia by law), and 2) adults suffering predominantly from somatic conditions and secondarily from psychiatric comorbid conditions.

For this specific study, the following 16 items of the larger survey (see [OSF](#), Appendix D) were selected: 1) seven items concerning the psychiatrist's personal and professional background; 2) two items on whether and why the psychiatrist agreed or refused to be engaged in euthanasia procedures concerning their own patients throughout their careers; and 3) six items on their specific role in euthanasia procedures during the past 12 months (see Box 2 in [OSF](#) for definitions of the roles a psychiatrist could be engaged in). One open question was checked for relevant additions to the answers that were provided.

Procedure

The FPA members were invited to participate by e-mail. A link to LimeSurvey's online platform³³⁵ was included and the information letter was attached (see [OSF](#) Appendices E and F, in Dutch). According to the GDPR principle of adequate data processing management, a data manager was engaged only to coordinate data collection procedures. Anonymisation of data collection and data entry ensured that neither the data manager nor the researchers were able to trace which answers were given by which participant.

Non-responders received a first reminder via e-mail after two weeks. A second reminder, including a paper-and-pencil version of the questionnaire, was sent by post after three weeks.

Data were collected between November 2018 and April 2019. The data were imported from LimeSurvey into SPSS version 25, and cleaned according to the principles of a data analysis plan (Appendix G in [OSF](#)). The SPSS database was completed with data gathered from the returned paper surveys and cleaned.

As for the handling of missing data, it was determined beforehand that, in cases of too many missing answers (i.e. > 2 missing answers regarding background and > 3 missing regarding attitudes), all data from the respondent were excluded from analysis.

Personal and professional characteristics were illustrated by means of descriptive statistics and used as independent variables in statistical analyses. The answers on the open question regarding motives for engagement or not were thematically coded by means of identifying the main themes of the qualitative data, without a predetermined use of literature references nor background knowledge.

Afterwards, the coded themes were ranked according to the frequency of its mentions.

Bivariate analyses (Chi square test) were performed to examine if, and to what extent, the psychiatrists' backgrounds relate to their concrete experience of euthanasia cases based on psychiatric conditions. If the assumption for the Chi square test was violated, we used Fisher's exact test. Due to the exploratory nature of our study, and in order not to miss out on potentially valuable findings that do not seem significant at first glance but are potentially valuable for further research, no correction test for multiple comparisons has been used. Confidence intervals for a population proportion were reported for the main findings. See Appendix G in [OSF](#) for the syntax used.

Ethics

This research project received ethics approval from the Medical Ethics Committee of Brussels University Hospital with reference BUN 143201837302 and the Medical Ethics Committee of Ghent University Hospital with reference 2018-1165.

Results

Description of the Sample

The FPA database consisted of 600 psychiatrists working in Flanders and Brussels. Of these, 499 are or have been professionally active as psychiatrists in psychiatric care for adult patients. The response sample consisted of 201 of these (valid response rate 40%). The data from 178 psychiatrists were found eligible for further analysis; data from 23 were excluded due to too many missing answers or the lack of explicit agreement regarding informed consent.

Some of the psychiatrists expressed their reasons for non-response as follows: bad timing (n=2), not experienced in euthanasia in APC patients (n=2), survey already filled in during cognitive testing (n=1), not interested in the topic (n=1), and never participate in surveys (n=1).

Table 1 shows the characteristics of our sample. The majority were male (56%) and worked in a psychiatric hospital care facility (67%). Others worked mainly in private practice (45%) and/or in a community mental healthcare centre (12%).

Most (48%) had more than 20 years' experience, whereas 18% were trainees in psychiatry with less than five years of experience. 84% felt ready to engage in euthanasia procedures, and 50% felt sufficiently competent to do so. Only 5% had received specific training in medical end-of-life care.

Psychiatrists' experiences during their careers

As presented in detail in Table 2, during their careers, 80% of the responding psychiatrists (95% CI [74, 86]) have been confronted with euthanasia requests and procedures involving their own patients. Of these, 9% have at least once refused to be actively engaged in the assessment procedures, whereas 91% have never refused (data not shown in the Table).

73% (95% CI [66, 80]) of all participating psychiatrists have been actively engaged in the assessment of a euthanasia request from this patient group, 44% (95% CI [36, 51]) as referring physician (see the Glossary box for an overview and description). 56 (43% of all those ever engaged in a euthanasia assessment procedure) indicated that they have been actively engaged in more than one role other than that of referring physician (data not shown). A minority (23%) have engaged in the role of attending physician in the clarification of their own patient's euthanasia request, and fewer (15%) have taken this particular role regarding a colleague's patient.

22% of the responding psychiatrists reported experience in the role of formally advising physician, and 20% as preliminary advising physician. Fewer than 5% have assisted in the supply or administration of lethal drugs or have been present when a colleague-physician performed the act for their own patient. None reported any experience in this role regarding a colleague's patient.

Table 1: Psychiatrists' demographics and professional characteristics (N/%)¹

Variables	Sample (N = 178) (N° and %)	
Gender		
Male	100	56.2
Female	75	42.1
Unknown	3	1.7
Age (in years)		
< 30	27	15.1
30 - 40 years	39	21.9
41 - 60 years	64	36.0
> 60	48	27.0
Worked as psychiatrist or psychiatric trainee during last year		
Yes	161	90.4
No	16	9.0
Unknown	1	0.6
Clinical setting²		
Private or Group Practice	80	44.9
Psychiatric Hospital Care	120	67.4
Community Mental HealthCare Centre	22	12.4
Psychiatric Nursing Home	9	5.1
Psychiatric Home Care	6	3.4
Sheltered housing	12	6.7
Other ³	26	14.6
Work experience (in number of years)		
< 5 years	32	18.0
6 - 10 years	20	11.2
11 - 20 years	41	23.0
> 20 years	85	47.8
Ever received special training in EOL		
Yes	9	5.1
No	167	93.8
Unknown	2	1.1
Readiness to be involved in euthanasia procedure(s)		
Yes	149	83.7
No	29	16.3

¹ In the online survey tool, explicit consent from the respondent had been asked by inserting the question "Do you agree to take part in this survey?" immediately after the informed consent statement and right before the start of the survey. If respondents clicked the option "no", they have been sent directly to the 'Non-response Questionnaire' and only asked to clarify their motives for non-response. Hence, no other data (e.g. sex, work experience) was gathered nor included in this Table.

² Close to 43% of the psychiatrists (76 out of 178) indicated to be professionally active in more than one workplace.

³ Other workplaces: prison or forensic psychiatric centres, psychiatric and psychosocial rehabilitation centres, psychiatric mobile crisis or response teams, other housing and care centres for other subpopulations (e.g. students, disabled persons).

Table 2: Engagement of psychiatrists in euthanasia, throughout their career

Confronted with euthanasia throughout their career	Sample (N = 178) N/%
Ever confronted with such requests	143 (80.3)
- Ever confronted and never refused to be involved	130 (73.0)
- Ever confronted, but ever refused to be involved	13 (7.3)
Ever engaged in assessment for euthanasia in APC patients¹	
No, never	48 (27.5)
Yes, as	130 (72.5) ²
- referring physician	78 (43.8)
- attending physician	54 (30.3)
with patients from my practice	41 (23.0)
for patients referred to me by a colleague	27 (15.2)
- preliminary advising physician	35 (19.7)
- formally advising physician	39 (21.9)
- participant to the administration of the lethal drugs	8 (4.5)
with patients from my practice	8 (4.5)
for patients referred to me by a colleague	0 (0.0)
- in another role ³	12 (6.8)

¹ 56 psychiatrists (43.4%) indicated that they have been actively engaged in more than one role, other than the role of referring physician. 71 psychiatrists (55% of all 129 psychiatrists ever engaged in such euthanasia procedures) indicated that they have not been engaged in more than one role, throughout their career (46 psychiatrists as referring physician, 13 as attending physician, 7 as formally advising and 5 as preliminary advising physician).

² One of the 130 cases was *not yet* involved.

³ 12 psychiatrists indicated being involved in another role, most of them were *passively involved* as the treating physician of the patient's psychopathology (e.g. discussing the euthanasia request during or after the euthanasia procedure, as well as during crisis confinement), as a member of the psychiatric care facility's ethics committee or as trainee in psychiatry.

Psychiatrists' experiences during the past 12 months

During the previous 12 months, 61% (95% CI [53, 67]) have been actively engaged in a specific role regarding the assessment of a euthanasia procedure for an adult psychiatric patient (Table 3). Among these, 70% have been actively engaged in one or two procedures based on psychiatric conditions, and 8% in more than five.

96% (or 57% of the total sample) have been engaged as formally advising physician during the 12 months prior to the survey; 70% were engaged in not more than two cases. Although asked to give formal advice, 18.6% have refused to do so. More detailed information is shown in Table 4.

Table 3: Psychiatrists actively engaged in euthanasia cases during the previous 12 months

	N/% of all engaged psychiatrists	% total sample (N = 178)
How many psychiatrists were engaged in any role?	108 (100%)	60.6%
In 1-2 euthanasia procedures	76 (70.4%)	42.7%
In 3-5 euthanasia procedures	24 (22.2%)	13.5%
In > 5 euthanasia procedures	8 (7.4%)	4.5%
How many psychiatrists were engaged as formally advising physician?	102 (96.2%)	57%

Table 4: Psychiatrists engaged as “formally advising physician” during the past 12 months

Type of engagement	In 1-2 euthanasia procedures	In 3-5 euthanasia procedures	In more than 5 euthanasia procedures	Total
Giving any advice	76 (100%)	20 (100%)	6 (100%)	102 (100)
Giving Formal Positive Advice	36 (47.4%)	3 (15%)	2 (33.3%)	41 (40.2%) ¹
Giving Formal Negative Advice	26 (34.2%)	14 (70%)	2 (33.3%)	42 (41.2%) ²
Refusing to give Formal Advice	14 (6.3%)	3 (15%)	2 (33.3%)	19 (18.6%) ³

¹ of which 16 psychiatrists (39%) only gave positive advices

² of which 17 psychiatrists (40%) only gave negative advices

³ of which 10 psychiatrists (52.7%) only refused to give advices

Main motives for refusing or accepting engagement

All of the psychiatrists were asked whether they had ever refused active engagement in the euthanasia procedure of their own patient. Table 5 shows the main motives they cited for refusal. The most reported motives were: fundamental objections to euthanasia in APC; the difficulties in adequately assessing the – according to some, unclear and/or subjective – legal criteria; difficulties in reconciling euthanasia assessment within the therapeutic relationship; the ineligibility of the APC patient's request, as it had been expressed prior to euthanasia legislation. Other reported motives included the perceived ineligibility of the APC patient's euthanasia request; complexity of the patient's current life circumstances (e.g. young age and complex family situation); the psychiatrist's perception of being insufficiently competent to engage in such procedures; and previous experiences with APC patients who had withdrawn their request (e.g. unexpected rehabilitation).

Alternatively, motives for accepting involvement mostly concerned the APC patient's right to request euthanasia; the psychiatrist's expertise in exploring, and duty to explore, the meaning of the request and to assess all legal criteria; the possibility that a serious discussion would serve as a therapeutic tool, facilitating further explorations of alternatives to death. In addition, it was stated that an APC patient can be eligible for euthanasia not only due to their poor medical condition but also because of the accumulation of the many misfortunes they had encountered in life.

Psychiatrists' engagement related to their socio-demographic and professional background characteristics

Table 6 represents the relation between the psychiatrists' characteristics and their prior engagement in euthanasia procedures concerning APC. There was more perception of being sufficiently competent to engage in euthanasia procedures in those who had taken up a specific role in euthanasia procedures concerning APC ($\chi^2_{(1,177)} = 10.487, p = .001$), including a role as preliminary ($\chi^2_{(1,177)} = 7.803, p = .008$), formally advising ($\chi^2_{(1,177)} = 23.586, p < .001$), or attending physician ($\chi^2_{(1,177)} = 28.801, p < .001$) and – according to the Fisher exact test – also as performing physician ($p < .001$).

Table 5: Motives for (not) refusing to be engaged in euthanasia assessment procedures regarding APC (sort by frequency)

Motives for refusing to be engaged in psychiatric euthanasia procedures¹
<p>1. Fundamental motives Fundamental objections against euthanasia regarding psychiatric patients (ethical, moral, deontological reasons) Euthanasia is incompatible with therapeutic relationship, but should be topic for further exploration in life track Physicians should never give the sign to the patient of giving up hope Law needs to be re-examined as criteria are unclear or need to be further restricted for this patient group In that specific time, the euthanasia law was not yet effective</p> <p>2. Ineligibility of the patient's euthanasia request Treatment options were still left, including non-medical treatment Substantive legal criteria were not fulfilled Personality disorder as contra-indication</p> <p>3. Complex circumstances Patient's complex family situation Patient's young age Not enough knowledge on the patient and her situation Not enough competence to get actively involved</p> <p>4. Experience of rehabilitation with former patients with withdrawn request</p>
Motives for accepting to be engaged in euthanasia procedures concerning psychiatric patients¹
<p>1. Fundamental motives Fundamental right of the patient to ask for euthanasia Fundamental task of the psychiatrist to take and discuss the request seriously Opportunity to keep on searching for underlying meaning request and treatment options</p> <p>2. Eligibility of the patient's euthanasia request Unbearable and untreatable suffering do exist Specific task of the psychiatrist to be involved in the assessment The euthanasia request is always based on misfortunes in many more domains in life</p>

¹ These motives result from 65 psychiatrists' answers to the open 'What was your motive to (not) refuse to be actively engaged in the clarification of the patient's euthanasia request?'

Table 6: Socio-demographic and professional factors in psychiatrists' engagement in the euthanasia decision-making procedure

Ever performed the role of...¹						
	NO ROLE	Referring physician	Preliminary advising physician	Formal advising physician	Attending physician	Performing physician
Sex						
Male (n=100)	25 (25)	43 (43.9)	16 (16.3)	27 (27)	34 (34)	5 (5)
Female (n=75)	24 (32)	33 (44)	17 (22.7)	12 (16)	19 (25.3)	3 (4)
Age						
<40 (n=66)	23 (34.8)	32 (48.5)	12 (18.2)	4 (6.2)²	12 (18.2)	2 (3)
41-60 (n=64)	14 (21.9)	32 (50)	11 (17.2)	18 (28.1)²	23 (35.9)	4 (6.3)
>60 (n=48)	12 (25.5)	14 (29.2)	12 (25)	17 (36.2)²	19 (39.6)	2 (4.2)
Years of work experience						
<10 (n=52)	20 (38.5)	24 (46.2)	10 (19.2)	4 (7.7)	8 (15.4)	1 (1.9)
10-20 (n=41)	9 (22)	19 (46.3)	11 (26.8)	8 (19.5)	15 (36.6)	4 (9.8)
>20 (n=85)	20 (23.8)	35 (41.2)	14 (16.5)	27 (31.8)	31 (36.5)	3 (3.5)
Perceived Competence						
Yes (n=89)	15 (16.9)³	37 (41.6)	25 (28.1)	33 (37.1)³	43 (48.3)³	8 (9)³
No (n=88)	34 (38.6)³	41 (46.6)	10 (11.4)	6 (6.8)³	10 (11.4)³	0³

¹ In bold: $p < .05$ and *In bold: $p < .01$

² In bold: significant results after Bonferroni test for multiple comparisons, $p < .0033$

³ In bold: significant results after Bonferroni test for multiple comparisons, $p < .005$

In addition, more years of work experience and higher age were significantly associated with more experience in the roles of formal advising physician ($\chi^2_{(2,178)} = 7.506, p = .023$ for work experience and $\chi^2_{(2,178)} = 16.253, p < .001$ for age range) and attending physician ($\chi^2_{(2,178)} = 7.772, p = .021$ for work experience and $\chi^2_{(2,178)} = 11.106, p = .004$ for age range). No significant associations were found based on biological sex. Years of work experience with regard to the role of formally and/or attending physician nor the age range with regard to the role of attending physician did survive Bonferroni correction for multiple comparisons.

Discussion

Over their careers, 4 out of 5 of the psychiatrists have been confronted with a request for euthanasia, predominantly based on suffering caused by their APC patient's psychiatric condition(s), and 7 out of 10 have engaged in the assessment of the request, as referring physician (44%), as attending physician (30%), as formally advising physician (22%), or as performing physician (5%). Over the previous 12 months, 3 out of 5 have been actively engaged in an assessment, 96% as formally advising physician.

Over their careers, 1 in 10 have at least once refused to be actively engaged in an evaluation procedure, due to their own conscientious objection and/or the complexity of assessment in this patient group. The main motive for engagement in euthanasia assessment procedures is the view that the patient has a fundamental right to request and the psychiatrist has a duty to respect and assess these requests.

The perception of being sufficiently competent to engage in euthanasia procedures in this patient group was more common in psychiatrists who have had concrete engagement experiences.

Strengths and limitations

The results of this study cannot readily be generalized and must therefore be interpreted with caution. Although we achieved higher response than anticipated in this target group, only a minority (40%) of the surveyed FPA-affiliated members completed and returned the questionnaire. A strength of this study is the inclusion of a representative group of APC patients, as the psychiatrists were

able to fill in the questionnaire with the following two APC groups in mind: 1) patients whose euthanasia requests were solely prompted by their psychiatric conditions, and 2) patients whose euthanasia requests were primarily prompted by suffering caused by their psychiatric conditions, and secondarily by suffering caused by somatic comorbid conditions. We are well aware that some psychiatrists – positioned at either end of the euthanasia debate – may not have participated in the survey as they are not FPA-affiliated (around 10-20% of all psychiatrists working in Flanders are not FPA-affiliated) or because they are opposed to the study and its set-up (e.g. fearing potential criticism of arguments pro or contra today's euthanasia law and/or practice). Therefore, we cannot exclude the risk of self-selection and response bias skewing the estimates of our survey. In addition, the findings only relate to the Flemish part of Belgium. Unfortunately, a similar survey among French-speaking psychiatrists was unsuccessful and hence we cannot report on this part of the Belgian practice, where previous research shows that requests for euthanasia are dealt with quite differently.³⁴²

In order to facilitate comparison across countries with comparable euthanasia legislation, our questionnaire closely followed the pre-existing Dutch questionnaire in terms of item formulation. Therefore, cognitive testing of the questionnaire was conducted during one focus group session with psychiatrists and their trainees, and not by means of in-depth cognitive interview techniques on an individual level, which might have caused bias. Finally, no established qualitative methods were used to analyse the – concisely written – data. A future follow-up study could make use of these established methods (e.g. literature references).

Interpretation of findings

Our results suggest that psychiatrists in Belgium need to be well informed about the euthanasia law and the assessment procedure, as a high proportion of them have been confronted with such a request. Even if all of the non-responders have never been confronted with such a request, one-fourth of all affiliated FPA-members still have been. Our study revealed that 80% reported that they have been confronted with a request at least once in their career. Among them, 7% had at least once refused to actively engage in a euthanasia assessment, which

means that euthanasia assessments concerning APC involve a larger proportion of psychiatrists than commentators often presume. This is in line with a previous study, based on the same survey, of these psychiatrists' attitudes towards euthanasia in the APC patient group and their readiness to engage in these procedures: that study revealed that a majority are not only in favour of euthanasia as a potential end-of-life option in this patient group, but that they are also willing to be actively engaged in the procedure.³⁴⁰

However, their engagement is mainly restricted to the role of referring physician. This is probably due to the complexity of the euthanasia assessment procedure, which involves other colleagues (not necessarily restricted to the medical discipline of psychiatry) and the assessment of different domains: i.e. the difficulty of interpreting and assessing all legally due care criteria in this patient group, the difficulty of reconciling a euthanasia assessment with the therapeutic relationship, and concern about inadequate approaches towards euthanasia assessment and the lack of safeguards in current euthanasia practice.³⁴⁰ This might also be due to the fear of potential juridical prosecution. In that regard, a number of guidelines and a deontological code have been published recently (2017-2019) in order to support psychiatrists in adequately managing euthanasia assessment. The question is to what extent psychiatrists are already familiar with these guidelines and codes and to what extent they deem them sufficiently useful.

Nevertheless, 'referral' is a minimal engagement that is also embedded in the Belgian Order of Physicians' deontological code, even in cases of conscientious objection. The physician's legal right to refuse engagement in euthanasia procedures is limited due to the patient's legal right to be informed clearly and in a timely manner of the reasons for refusal and to be referred to a colleague physician (not necessarily a psychiatrist) for the further clarification of their request.²¹³ In that respect, it is noteworthy that some psychiatrists cite conscientious objection as a motive for non-referral. On the other hand, some may also sidestep the referral requirement because of a lack of knowledge of this legal criterion or its vagueness, as neither the law nor the existing guidelines provide a sufficiently adequate definition of the term 'referral', let alone 'effective referral' (cf. patients being given the run-around).

Apart from conscientious objection, the fact that the majority of the responding psychiatrists have been engaged only in a referring role might also be due to the fact that they have not been specially trained in euthanasia consultation and practice, and also that one-fifth were working as trainees at the time and were not allowed to act as an advising or attending physician.

Reluctance to actively engage as attending, formally advising and/or performing physician has also been confirmed in Dutch evaluation studies, which have revealed that APC patients' euthanasia requests are seldom granted, and even those that are granted do not automatically result in the actual performance of euthanasia.^{88,169} Former Belgian and Dutch studies attribute this reluctance to the complexity of this specific practice in terms of the difficulties psychiatrists have in determining whether the APC patient meets all legal and due care criteria – with regard to, for example, their mental capacity and the incurability of their disorder (given the unpredictable prognoses and outcomes of psychiatric disorders)^{131,132,134,343} – as well as in integrating a euthanasia request within the therapeutic relationship.^{170,340}

Implications for practice, policy and research

Some of the results regarding conscientious objection and non-referral confirm that, after nearly two decades of legalized euthanasia, it remains a decidedly difficult situation for psychiatrists. More insight is needed to clarify when and why such a referral ends up with the formally advising psychiatrist denying the request, as well as when and why the request is eventually granted.

Furthermore, it remains largely unknown what involvement in a euthanasia assessment means for the psychotherapeutic relationship – does it lead to discouragement, demotivation or even despair, when an APC patient learns that their euthanasia request was not taken seriously, let alone granted, and hence the risk of suicide increases? On the other hand, does the option of euthanasia itself undermine the APC patient's sense of hope and trust in therapy and distract their attention from therapeutic and other options of care that might otherwise be offered?

The fact that psychiatrists are more actively engaged in euthanasia procedures when they perceive themselves as competent in the subject indicates a need to evaluate and reflect on potential thresholds or shortcomings in currently

available training and support initiatives as well as in a handful of recently published (and insufficiently known?) advising guidelines.^{203,209,225,311,344} As these initiatives take a different, and often more restrictive, approach than is required by law (e.g. by stipulating that at least two positive advices should be obtained from at least two psychiatrists, instead of two advices from at least one psychiatrist of which the outcome is not binding), this may lead to unequal treatment of euthanasia requests and/or an unequal course in euthanasia procedures. As these guidelines are not binding, they might have the undesirable consequence that an APC patient's euthanasia request is handled differently according to individual differences in physicians' approaches towards euthanasia assessment and decision-making (whether or not the physician involved also takes the more stringent criteria of the guidelines into account). As a result, this may have an additional undesirable consequence: the patient might immediately search for physicians who presumably hold more permissive stances and approaches regarding euthanasia instead of discussing their euthanasia request with the treating psychiatrist, under the assumption that the latter is inclined to take a more restrictive stance.³¹⁰ Therefore, more in-depth research on what kind of additional support and specific training psychiatrists need regarding the adequate and proper handling of a euthanasia request is recommended.

In addition, further qualitative research should investigate what (non-)referral exactly entails when psychiatrists refuse to engage (e.g. refusing to even discuss euthanasia as an end-of-life option, to refusing to actively engage in a role other than a referring one but remaining open to a sound debate with the patient regarding euthanasia). This can have a great impact on the therapeutic relationship, whether or not the patient's euthanasia request and procedure can still be openly discussed in therapeutic consultations by reciprocally sharing information, concerns and emotions, even when patient and physician have different perspectives, or even different values, regarding medical end-of-life decisions. Just as active euthanasia assessment and decision-making requires excellent communication skills from all physicians involved¹⁷⁰, open discussions about euthanasia can be very demanding, and even burdensome, on an APC patient's treating psychiatrist on a cognitive as well as an emotional level. As previous research has revealed that APC patients' euthanasia requests are less likely to be granted than those prompted by purely somatic conditions, the APC

patients' treating psychiatrists should also be sufficiently empowered to deal with their patients' emotions after obtaining negative advices, and especially after a conditional or definitive refusal.⁸⁸ The scarce literature on this topic has revealed that very few treating physicians discuss or evaluate the patient's death ideation or situation after a refusal.²¹⁹ Therefore, it would be interesting to examine whether this also applies to psychiatrists. In addition, research is needed on whether existing courses on medical end-of-life decisions sufficiently address communication techniques for all actively engaged physicians as well as all psychiatrists handling their own patients' euthanasia procedure, from the moment of the APC patient's first request for euthanasia to the final decision. Moreover, more research is needed to determine whether these courses sufficiently address the ethical value-based aspects of medical end-of-life decisions in addition to the practical clinical, juridical and technical aspects. As for the ethical aspects, insight is needed into whether the ethical principles for guiding good medical practice – e.g. respect for the patient's autonomy, promotion of what is best for the patient versus avoiding harm – are sufficiently interlarded with arguments and counter-arguments based on empirical data, case comparison and thought experiments.

Furthermore, more government-coordinated initiatives could be established (e.g. an optimised budget for more centralised training courses and often-repeated evaluation studies following the example of the Dutch quinquennial ones). However, it must be stressed that, like other new medical practices, factors such as time and experience can also contribute to competence-based practice. This could increase the knowledge and transparency of the entire practice, providing an opportunity to detect and resolve potential shortfalls, and hence offer sufficient medico-legal protection to all actors involved. Future research should also emphasize the perspectives of all actors (including the APC patients and their carers, friends and family) in order to gain more insight into euthanasia practice concerning APC patients as a whole.

Finally, as a previous study based on this survey has revealed that the younger generation of psychiatrists is more supportive of euthanasia in APC patients and more willing to be actively engaged³⁴⁵, future research endeavours might also reveal a potential cohort effect in terms of psychiatrists' concrete experiences and engagement in psychiatric euthanasia assessment.

Conclusions

In their clinical practice, many of the psychiatrists studied have been confronted with requests for euthanasia by APC. However, their engagement is often limited to referring to a colleague-physician for the assessment and possible granting of the request. The assessment of the legal due care criteria stated in the euthanasia law in Belgium seems to be difficult to apply to this specific patient group and it is probably difficult to reconcile within a therapeutic relationship.

More research is needed to identify the determinants of psychiatrists' decision not to personally engage in a role other than referring the APC, on the latter's request, to a colleague-physician willing to engage more fully in the assessment of euthanasia requests, e.g., moral objections, the need for more objective euthanasia assessment approaches, wanting to avoid sending the message of giving up on the patient in order to maintain therapeutic compliance and effectiveness. In addition, this can illuminate both the positive and negative consequences of the treating psychiatrist's refusal or limited engagement for the patients themselves, for the psychotherapeutic relationship, e.g., which motives of (non-) referral may affect therapy compliance, inducing or resolving feelings of hopelessness, and for adequate euthanasia assessment.

CHAPTER 10 : EUTHANASIA IN ADULTS WITH PSYCHIATRIC CONDITIONS: A DESCRIPTIVE STUDY OF THE EXPERIENCES OF BELGIAN PSYCHIATRISTS

Verhofstadt M, Audenaert K, Van den Broeck K, Deliens L, Mortier F, Titeca K, De Bacquer D, & Chambaere K. Euthanasia in adults with psychiatric conditions: A descriptive study of the experiences of Belgian psychiatrists. *Science Progress*. 2021;104(3):003685042110297.
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More detailed information is posted in the Open Science Framework repository accompanying this paper: <https://osf.io/cy297/>

Thank God, we are always at the mercy
Of a sacrifice,
Of a death on credit,
Of a prejudice arisen out of damage,
The sun is escaping,
As a soap suddenly slipping away,
What an adventure, what an adventure
Benjamin Biolay (La Superbe)

Abstract

Objective

To investigate the experience of psychiatrists who completed assessment procedures of euthanasia requests from adults with psychiatric conditions (APC) over the last 12 months.

Method

Between November 2018 and April 2019 a cross-sectional survey was sent to a sample of 753 psychiatrists affiliated with Belgian organisations of psychiatrists to gather detailed information on their latest experience with a completed euthanasia assessment procedure, irrespective of its outcome (i.e. euthanasia being performed or not).

Results

Information on 46 unique cases revealed that most APC suffered from comorbid psychiatric and/or somatic disorders, and had received different kinds of treatment for many years prior to their euthanasia request. Existential suffering was the main reason for the request. The entire procedure spanned an average of 14 months, and an average of 13.5 months in the 23 cases that culminated in the performance of euthanasia. In all cases, the entire procedure entailed multidisciplinary consultations, including with family and friends.

Psychiatrists reported fewer difficulties in assessing due care criteria related to the APC's self-contemplation – e.g., unbearable suffering on top of the due care criteria related to their medical condition; incurability due to lack of reasonable treatment perspectives. In a few cases in which euthanasia was the outcome, not all legal criteria were fulfilled in the reporting physicians' opinions. Both positive and negative experiences of the assessment procedure were reported: e.g., reduced suicide risk for the APC; an emotional burden and a feeling of being pressured for the psychiatrist.

Conclusions

This study confirms that euthanasia assessment in APC entails a lengthy process with diverse complexities, and psychiatrists require support in more than one respect if the assessments are to be handled adequately. Thorough evaluation of

current guidelines is recommended: that is, to what extent the guidelines sufficiently address the complexities around (for example) assessing legal criteria or involving relatives. We formulate various avenues for further research to build on this study's insights and to fill remaining knowledge gaps.

Keywords: euthanasia, mental disorders, assisted suicide, psychiatry, survey study

Introduction

Adults with psychiatric conditions (APC) can be found legally eligible for euthanasia in Belgium if all the legal criteria are fulfilled.¹⁸⁵ As some contest whether and when an APC can meet all legal requirements, the practice remains subject to controversy, fiercely dividing clinical and ethical opinions^{92-94,138,346,347}, and sometimes resulting in legal examination.^{348,349} Meanwhile, the proportion of euthanasia cases in APC within all *reported* performed euthanasias remains small but has increased from 0.2% during the period 2002-2007 to 2.1% in 2015^{114,117} before declining to 1.2% in 2017.¹¹²

Empirical evidence regarding Belgian euthanasia practice with APC is limited. To our knowledge, only two retrospective studies exist, which were limited in scope because one only reported about performed euthanasia cases, and the other only reported about requests from a single practice.^{117,126} One study revealed that the consultation process takes an average of nine months, involving an average of four consultation sessions with multiple actors (e.g., patient, clinicians, family and friends). The study also showed that, whilst 48 of 100 euthanasia requests were accepted, 73% had been carried out, 21% had been withdrawn voluntarily, 2% had to be withdrawn due to imprisonment, and 4% of the requestors died by suicide.¹²⁶

The performed euthanasia cases concerned adults of different ages, mostly women, suffering from multiple chronic psychiatric disorders, mainly major depressive and personality disorders.^{117,126}

A recent Belgian survey study gauging psychiatrists' attitudes and experiences on this topic pointed out that psychiatrists struggle with these practices, due to the difficulties of reconciling euthanasia assessment with the patient-psychiatrist relationship.^{340,345} In addition, almost three out of four Belgian psychiatrists question the adequacy of euthanasia assessment in current practice, which is in line with previous Dutch studies that indicate dissension among physicians regarding whether the legal criteria were/can be met.^{132,133,343}

So far, few Belgian studies have investigated the reasons that APC request euthanasia, and none have focused in detail on the challenge of the assessment for the psychiatrists involved. As psychiatric consultation is imperative and

legally mandatory for determining the APC's eligibility for euthanasia, we in this study use psychiatrists' experiences to gain additional insights into current practices.

This study aimed to come to a description of completed euthanasia assessment procedures by asking a large representative sample of psychiatrists about their most recent experience during the last 12 months regarding: 1) the APC's background in terms of diagnoses and treatment history; 2) the APC's reasons for requesting euthanasia; 3) the main characteristics of euthanasia assessment procedures, and finally, 4) the psychiatrists' perceived difficulties and/or other experiences regarding the assessment.

Methods

Study design and participants

Case-based data on individual APC's completed euthanasia assessment procedures were obtained through a cross-sectional survey of Belgian psychiatrists, consisting of a paper-and-pencil and web survey. The survey was sent to 753 potential respondents: 499 Flemish-speaking psychiatrists affiliated with the Flemish Psychiatry Association (FPA), and 254 French-speaking psychiatrists of the Royal Society of Mental Health of Belgium (SRMMB). The FPA's members comprise an estimated 80-90% of all psychiatrists active in the Flemish-speaking part of Belgium. No estimated percentages could be given with regard to the SRMMB's members, due to a lack of current trustworthy registration of practitioners in the French-speaking part of Belgium.

Only reports from psychiatrists working in Belgium and having been involved in at least one completed euthanasia assessment procedure for an APC in the previous 12 months were included in the study.

Survey Instrument

We based our questionnaire partly on an existing Dutch questionnaire.¹⁶⁹ We validated the final instrument with a selected group of 15 psychiatrists and their trainees for cognitive validation purposes (i.e., for participants to identify potential problems regarding item interpretation, item redundancy, completeness

of the survey, feasibility of generating correct answers, and time estimation) and adjusted it accordingly.

The survey was divided into two parts: one general part to be completed by every psychiatrist, whether or not they had been involved in concrete evaluation of euthanasia requests (see Appendix A in OSE); and one part focussing on their last concrete involvement with a completed euthanasia assessment procedure during the past 12 months, if applicable (see Appendix B in OSE). This study reports on their last concrete involvement (see Appendix C in OSE for the English version of the questionnaire).

The survey questions were preceded by the following sentence: "The questions below relate to your most recent experience with a completed euthanasia procedure (regardless of its final outcome) of an ADULT patient, PREDOMINANTLY suffering from a psychiatric condition, other than dementia, in the past 12 months." Capitals were used to make clear that APC encompass the following two adult patient groups: 1) patients whose euthanasia request is predominantly based on suffering caused solely by their psychiatric conditions, other than dementia; and 2) patients whose euthanasia request is predominantly based on suffering caused primarily by their psychiatric conditions, and secondarily by somatic comorbid conditions.

Procedure

Data collection

Data were collected between November 2018 and April 2019. The FPA members were first sent a link to LimeSurvey's online platform.³³⁵ Non-responders received a first reminder via e-mail two weeks after the initial invitation and a second, including a paper-and-pencil version by post, three weeks after. The SRMMB members were only sent the paper-and-pencil version, by post, as the SRMMB database only contained postal addresses, and non-responders received a reminder two weeks afterwards (See OSE, Appendix D, for a more detailed research protocol).

Data management

Data were imported from LimeSurvey into SPSS, cleaned according to the principles of a predetermined data analysis plan (See [OSF](#), Appendix E), and completed with the cleaned data gathered from the returned paper surveys.

Statistical analysis

No sample size calculation/power analysis was done, as we intended to survey the entire eligible professional group. As duplicate cases could occur (i.e. the same individual euthanasia case being reported by at least two psychiatrists), we performed a manual check to identify euthanasia cases with identical or near-identical data by crossing the values of the following variables: 1) specific characteristics of the responding psychiatrists (e.g. specific role in the euthanasia procedure), 2) specific characteristics of the euthanasia procedure (e.g. the duration of the procedure, the number and nature of formal (and additional) advices obtained, the final outcome), and 3) specific characteristics of the APC (e.g. psychiatric and somatic diagnoses, duration of the treatment trajectory). As the manual check revealed no duplicates, all reported cases were included in this study. All gathered data were analysed by means of standard descriptive statistics, including data that describe the sample of responding psychiatrists. The answers to the open question were used to elaborate further on the given responses by means of thematic analysis.

Ethics

This research project was performed in accordance with the Declaration of Helsinki and received ethical approval from the Medical Ethics Committee of the Brussels University Hospital with reference BUN 143201837302 and the Medical Ethics Committee of the Ghent University Hospital with reference 2018-1165.

Results

The flowchart in [OSF](#) illustrates the response sample procedure of Belgian psychiatrists who filled out the optional part of the survey. Table 1 shows the characteristics of our sample of 46 psychiatrists.

Table 1: Belgian Psychiatrists' personal and professional characteristics (N/%)

Variables	Sample (N = 46) (N° and %)
Gender	
Male	30 (65.2)
Female	14 (30.4)
Missing	2 (4.3)
Age (in years)	
30 - 40 years	4 (8.7)
41 - 60 years	24 (52.2)
> 60	18 (39.1)
Worked as psychiatrist or psychiatric trainee during last year	
No	1 (2.2)
Yes	45 (97.8)
Clinical setting¹	
Private or Group Practice	29 (63.0)
Psychiatric Hospital Care	29 (63.0)
Community Mental HealthCare Centre	7 (15.2)
Psychiatric Nursing Home	3 (6.5)
Psychiatric Home Care	1 (2.2)
Sheltered housing	3 (6.5)
Other ²	7 (15.2)
Work experience (in number of years)	
6 - 10 years	4 (8.7)
11 - 20 years	24 (52.2)
> 20 years	18 (39.1)
Ever received special training in medical End-Of-Life Care	
Yes	7 (15.2)
No	38 (82.6)
Missing	1 (2.2)
Feels competent to be involved in euthanasia procedure	
Yes	39 (84.8)
No	7 (15.2)

¹ Some psychiatrists had more than one workplace

² Other work places: psychiatric and psychosocial rehabilitation centres, other ambulant and residential care facilities (e.g. social welfare care facilities).

Most were men (65%), mainly working in a private or group clinical practice (63%) and/or psychiatric hospital care (63%) for more than 10 years (91%).

Clinical characteristics for APC requesting euthanasia

As shown in Table 2, in 89% of the completed case questionnaires the APC's psychiatric disorders were specified with depressive disorders (N = 23) and personality disorders (N = 18) being the most common.

Table 2: Clinical characteristics of adults with psychiatric conditions with assessed euthanasia requests

	All requests N (%) / (N = 46)	Euthanasia cases N (%) / (n = 23)
Patient's Pathology		
<i>Specified psychiatric conditions</i>	41 (89.1)	21 (91.3)
Depressive disorders	23 (50.0)	9 (42.8)
Personality disorders	18 (39.1)	7 (30.4)
Schizophrenia spectrum and other psychotic disorders	6 (13.0)	4 (17.4)
Trauma- and stressor-related disorders	6 (13.0)	2 (8.7)
Anxiety disorders	4 (8.7)	2 (8.7)
Bipolar and related disorders	3 (6.5)	2 (8.7)
Feeding and eating disorders	3 (6.5)	0 (0.0)
Neurodevelopment disorders	2 (4.3)	0 (0.0)
Substance-related and addictive disorders	1 (2.2)	1 (4.3)
<i>Unspecified psychiatric conditions</i>	5 (10.9)	2 (8.7)
Somatic co-diagnoses		
<i>Somatic co-diagnoses</i>	22 (47.8)	11 (47.8)
Severe brain injury	5 (10.9)	2 (8.7)
Physical deterioration	3 (6.5)	1 (4.3)
Pain, incl. consequences of failed suicide attempts	3 (6.5)	3 (13.0)
Palsy	2 (4.3)	1 (4.3)
Parkinson	2 (4.3)	1 (4.3)
Hearing problem	2 (4.3)	1 (4.3)
Chronic fatigue syndrome/fibromyalgia	2 (4.3)	1 (4.3)
Diabetes/morbid obesity	2 (4.3)	1 (4.3)
Cancer	1 (2.2)	1 (4.3)
Overall multimorbidity	1 (2.2)	1 (4.3)
Patient's treatment history at first consultation		
<i>No active treatment</i> ¹	4 (8.7)	1 (4.3)
Active treatment	42 (91.3)	22 (95.6)
Psychotropics	37 (80.4)	21 (91.3)
Other drugs	13 (28.3)	7 (30.4)
Psychotherapy	31 (67.4)	18 (78.3)
Other interventions ²	14 (30.4)	8 (34.8)
Length of the patient's treatment history		
<i>Mean (Standard Deviation)</i>	10.6 years (9.8)	8 years (6.9)
<i>Median</i>	7 years	5 years
<i>(min-max)</i>	(1 month-32 years)	(1 month-25 years)
<1 year	5 (11.0)	2 (8.7)
1-2 years	6 (13.0)	3 (13.0)
2-5 years	8 (17.3)	6 (26.1)
> 5-10 years	5 (11.0)	3 (13.0)
10+ years	16 (34.7)	6 (26.1)
Missing	6 (13.0)	2 (13.0)

¹ In 2 cases explained as follows: the patient did receive psychiatric treatment in the past.

² Other interventions were specified as follows: neurosurgical treatment and/or electroconvulsive therapy, ambulant and/or residential admittance in a psychiatric unit, nursing and/or other care in a psychiatric home care setting, alternative psychotherapy, mobile team.

Nearly half of the APC (48%) suffered from somatic co-morbidities, from chronic fatigue syndrome to Parkinson's disease to overall multi-morbidity.

At their first consultation for euthanasia, 91% were in treatment, most often including psychotropics (80%) and/or other medical drugs (28%), and/or psychotherapy (67%). The mean and median length of treatment history were 11 and 7 years, respectively.

A similar picture emerges with regard to the euthanasia requests that culminated in the performance of euthanasia ($n = 23$). These cases mainly concerned APC with comorbid disorders (70%), and close to half (48%) suffered from severe physical co-morbidities: e.g., cancer and chronic pain-related problems, some of which were related to injuries incurred by a previous suicide attempt. At the time of their first consultation for euthanasia, all but one APC were in treatment. The mean and median length of treatment history were 8 and 5 years, respectively, with a minimum of one month and a maximum of 25 years.

Main reasons for requesting euthanasia

Most psychiatrists (87%) indicated more than 3 reasons for the request, with a minimum of 1, a maximum of 12, and an average of 6 to 7. Table 3 lists the indicated categories, in descending order of prevalence. No perspective for improvement (87%), a very low level of quality of life, just being in 'survival mode' (72%), and existential suffering (63%) were most often reported, and even to a greater extent if the APC died by means of euthanasia (96%, 83% and 74%, respectively). In the 23 performed euthanasia cases, 'No purpose left in life' (78%) was also more often indicated. When asked to report the 2 main reasons for euthanasia requests, the most frequent were: existential suffering, and no perspective for improvement. Whereas loneliness was ranked third in all reported cases, pain-related problems closed the top 3 ranking with regard to the 23 performed euthanasia cases.

In addition, the open question yielded additional motives for the request: namely, all types of fears other than suicide (e.g. potential repetitive traumatic events), being finished with treatment (due to, for example, treatment resistance on the level of the APC's psychopathology, even if the APC is improving on the physical level), complex grief, self-hatred and financial difficulties.

Table 3: Reasons for requesting euthanasia in adults with psychiatric conditions¹

	All requests N (%) / (N = 46)	Euthanasia cases N (%) / (n = 23)
Indicated reasons for requesting euthanasia ²		
No perspective for improvement	40 (87.0)	22 (95.6)
No quality of life, only in 'survival mode'	33 (71.7)	19 (82.6)
Existential suffering (suffering from life itself, meaninglessness)	29 (63.0)	17 (73.9)
Stalled on many life domains (work/relationships/...)	27 (58.7)	13 (56.5)
No purpose (left) in life	26 (56.5)	18 (78.3)
Feelings of depression	22 (47.8)	12 (52.2)
Loss of dignity	22 (47.8)	15 (65.2)
Loss of autonomy, control over own life	21 (45.7)	10 (43.5)
Loneliness	18 (39.1)	9 (39.1)
No (longer) wanting to be a burden	16 (34.8)	10 (43.5)
Gradual deterioration	16 (34.8)	10 (43.5)
Total exhaustion	10 (21.7)	6 (26.1)
Fear of suicide	9 (19.6)	4 (17.4)
Disability/Immobility	9 (19.6)	5 (21.7)
Other (e.g. pain)	8 (17.4)	2 (8.7)
Indicated main reasons of the euthanasia request		
Existential suffering	16 (34.8)	7 (30.4)
No perspective for improvement	11 (23.9)	7 (30.4)
Loneliness	7 (15.2)	2 (8.7)
No quality of life, only 'surviving'	6 (13.0)	4 (17.4)
Pain related problems ³	5 (10.9)	5 (21.7)
Fears	5 (10.9)	2 (8.7)
Feelings of depression	5 (10.9)	4 (17.4)
Gradual deterioration	5 (10.9)	3 (13.0)
Lack of purposes left in life	5 (10.9)	2 (8.7)

¹ Psychiatrists could indicate as many predesignated categories as applicable

² The answers on the open question, n° 9: "In your opinion, what were the two main reasons for the patient to request euthanasia?" were tallied. If the answers did not fit one of the categories of question n°8, it was also coded and counted (missings: $n = 3$). This yielded additional motives for the patient's euthanasia request, namely: 1) all kinds of fears, other than the fear of suicide, e.g.: fear of repetitive traumatic events; 2) being through with treatment due to e.g. treatment resistance, even if the patient is improving on the physical level; 3) complicated grief; 4) self-hatred; and 5) financial difficulties.

³ Some pain related problems were ascribed to the consequences of failed suicide attempts

Main characteristics of the APC's euthanasia assessment procedure

Based on the answers of the responding psychiatrists, the mean and median length of the euthanasia assessment procedure were 14 and 7 months, respectively, and, if the patient died by euthanasia, 13.5 and 6 months, with a minimum of 2 weeks and a maximum of 5 years (see Table 4).

Table 4: Characteristics of the euthanasia procedure in adults with psychiatric conditions

	All requests (N = 46) N (%)	Euthanasia cases (n = 23) N (%)
Duration of the euthanasia procedure		
Mean (Standard Deviation)	13.9 months (16.2)	13.5 months (15.9)
Median	7 months	6 months
(min-max)	(2 weeks-5 years)	(2 weeks-5 years)
< 1 month	2 (4.3)	2 (8.7)
1 - 2 months	2 (4.3)	0 (0.0)
2- 6 months	11 (23.9)	5 (21.7)
6 - 12 months	11 (23.9)	6 (26.1)
1 - 2 years	7 (15.2)	4 (17.4)
> 2 years	9 (19.5)	5 (21.7)
Missings	4 (8.7)	1 (4.3)
Involvement of professionals and carers in the euthanasia procedure		
Specific role of the psychiatrist in the euthanasia procedure¹		
Treating physician (of the patient's psychopathology, not regarding the euthanasia procedure)	28 (60.9)	15 (65.2)
Attending physician of the psychiatrist's own patient (actively assessing the euthanasia request)	10 (21.7)	5 (21.7)
Attending physician of a patient from a colleague-physician (idem)	11 (23.9)	4 (17.4)
Preliminary advising physician	5 (10.9)	3 (13.0)
Procedural advising physician	13 (28.3)	6 (26.1)
Performing physician	4 (8.7)	4 (17.4)
Involvement of other professionals		
None	0 (0.0)	0 (0.0)
The patient's general practitioner	29 (63.0)	18 (78.2)
Independent colleague-psychiatrist(s)	21 (45.7)	13 (56.5)
Independent LEIF-physician(s), trained and experienced in end-of-life care issues	15 (32.6)	10 (43.5)
Psychologist(s)	15 (32.6)	8 (34.8)
Nurses	11 (23.9)	9 (39.1)
Other physicians of the patient	9 (19.6)	4 (17.4)
Independent physicians of specialised end-of-life centres	9 (19.6)	4 (17.4)
Ethics committee	8 (17.4)	6 (26.1)
Palliative care team	7 (15.2)	5 (21.7)
(Psycho-)Social service(s)	4 (8.7)	3 (13.0)
Another internal advisory committee	3 (6.5)	3 (13.0)
Others ²	5 (10.9)	4 (17.4)
<i>Involvement of family and/or friends</i>		
No, although the patient did have family or friends	9 (19.6)	2 (8.7)
No, patient did not have family or friends	3 (6.5)	0 (0.0)
Yes, during the euthanasia procedure	22 (47.8)	11 (47.8)

Yes, during and after the euthanasia procedure	12 (26.1)	10 (43.5)
Psychiatrists' opinion on the substantive due care criteria being fulfilled		
Voluntary, sustained and repeated request	41 (89.2)	21 (91.3)
Unbearable suffering	40 (87.0) ³	22 (95.6)
Mental competency	38 (82.6) ³	20 (87.0) ³
Incurability of the disorder	30 (65.2) ⁵	16 (69.6) ⁴
No reasonable therapeutic options left	29 (63.0) ³	19 (82.6)
Medical futility	28 (60.9) ⁶	18 (78.3) ⁴
Outcomes of the procedure		
Formal advices on the euthanasia requests		
Yes, without additional advices	23 (53.5) ⁸	8 (34.8) ⁷
Yes, with additional advices obtained	15 (34.9) ⁸	11 (47.8) ⁷
No	3 (6.9)	0 (0.0)
Don't know	2 (4.7)	0 (0.0)
Nature of advices given or obtained ³		
Only positive advices	30 (65.2)	21 (91.3)
Only negative advices	8 (17.4)	0 (0.0)
Mixed positive and negative advices	2 (4.7)	1 (4.3)
Patient still alive? ³		
No, the patient died by means of euthanasia	23 (50.0)	23 (100)
No, the patient died otherwise ⁹	5 (10.9)	
Yes, the procedure is still ongoing ¹⁰	8 (17.4)	
Yes, the patient had withdrawn the request	3 (6.5)	
No idea (not informed)	6 (13.0)	

¹ Psychiatrists could indicate as many predesignated categories as applicable. For example, at the start or during the course of a euthanasia assessment procedure, the treating physician can decide to also engage as performing physician.

² Others: patient's treating physician (of the patient's psychopathology), colleague-psychiatrists for informal advice, the religious/spiritual caregiver' at the affiliated psychiatric centre, members of the ambulant or residential psychiatric care facility, or the case was distributed at the responsibility of the hospital in question.

³ missing $n = 1$

⁴ missing $n = 2$

⁵ missing $n = 3$

⁶ missing $n = 4$

⁷ the number of advices was not specified in $n = 3$

⁸ the number of advices was not specified in $n = 4$

⁹ in some cases specified as death by suicide. In one case the patient died after having the euthanasia request withdrawn.

¹⁰ In these cases, the assessment procedure is concluded but the final decision is not yet made or the practical modalities are to be discussed, e.g. the decision when or where to die.

The psychiatrist was usually (61%) the patient's treating physician. In all cases, other professionals were consulted, most often the general practitioner (63%) and the psychiatrist's colleagues (46%), and to a greater extent when death by euthanasia was the outcome. Note that, even in the case of performed euthanasia, the palliative care team was involved during the euthanasia assessment procedure (21.7%). In addition, family and/or friends were also

often consulted (74%), and a third of these family and/or friends also during a concluding session after a final decision (54%). When euthanasia was the outcome, the APC's social inner circle was consulted in almost all cases (91%), and in 43.5% also after the final decision had been reached.

According to the respondents, the substantive due care criteria, as prescribed by the law on euthanasia were fulfilled in 61% to 89% of all cases and in 70% to 96% of performed euthanasia cases. The criteria 'medical futility', 'incurability of the disorder' and the 'absence of reasonable therapeutic options', were met to the lowest degree (in 61-65% of all cases, or in 67-70% cases if corrected for missings). Note that, whereas the legal criterion 'incurability of the disorder' was considered sufficiently met in 70% of all performed euthanasia cases (76% if corrected for missings), its operationalized criterion (as suggested in the guidelines on how to adequately assess euthanasia requests from APC) was considered sufficiently met in 83%.

In 4 out of 5 cases, at least 2 legal advices were given or obtained, mostly positive ones (70%). In all performed euthanasia cases, at least 2 positive advices from other physicians were obtained, except in one case in which both positive and negative advices were obtained. In 5 cases, in the responding psychiatrists' opinion, not all of the substantive due care criteria were sufficiently met. The APC's young age, remaining treatment options according to the state-of-the-art protocol, as well as certain clinical conditions (i.e. personality or bipolar disorder) were reported as contra-indications.

In cases in which the APC died otherwise – e.g. suicide (data not shown for reasons of privacy, as $n = 5$, and the cause of death is not reported in all cases), negative advices were obtained more often, or the absence of hopelessness or remaining reasonable treatment options were reported. In 3 of the latter cases, psychiatrists reported an improvement in the medical condition due to a new treatment program.

As for outcomes, 61% of the APC died by means of euthanasia (50%) or otherwise (e.g. suicide). In 26% of the cases, the APC were still alive. In 13%, the reporting psychiatrist was out of the loop regarding the final decision. One psychiatrist reported 2 final outcomes, as the APC had withdrawn the euthanasia request a few weeks prior to suicide.

Perceived difficulties and/or other experiences

As revealed in Table 5, difficulties in the adequate assessment of the substantive due care criteria were in most cases related to the characteristics of the medical condition. One-quarter of the psychiatrists that were involved in the 23 cases that culminated in euthanasia reported having difficulties in the assessment of the legal criteria 'medical futility' (26%) and 'incurability of the disorder' (22%), and with its operationalized criterion 'lack of reasonable therapeutic perspectives' (26%).

Half of the psychiatrists (52%) reported feeling pressured by the APC to approve euthanasia. When they felt pressured by the APC's family or friends, this concerned pressure to decide in favour (15%) or against (9%) approving the APC's request.

The whole assessment procedure posed a heavy emotional burden on the majority of the psychiatrists (72% and 65% for those confronted with performed euthanasia cases) and more than half of the psychiatrists (irrespective of the outcome) sought emotional support to cope with it. Positive effects were also reported, such as a lower suicide risk (57% and 60.9% for the ones that reported on performed euthanasia cases).

Whereas the re-establishment of relationships between patient and significant others was reported to a greater extent by the psychiatrists who reported on performed euthanasia cases (39% versus 26%), new therapeutic opportunities were reported to a lesser extent (9% versus 26%).

After conclusion of the procedure, the attitudes of the majority of the psychiatrists (78%) towards euthanasia had not changed. If it had changed, most psychiatrists reported that they were willing to engage in future euthanasia procedures, albeit more carefully (e.g. by taking more time to reflect thoroughly on the request, adopting more inter- and supervisions, being less quick to refer to end-of-life consultation centres). Others looked back upon the experience more favourably and described it as beautiful and enriching for all actors involved, including for themselves.

Table 5: Psychiatrists' experiences or difficulties perceived during the assessment procedures in adults with psychiatric conditions

	All requests (N = 46) N (%)	Euthanasia cases (n = 23) N (%)
Experienced difficulties in assessing criteria ¹		
Lack of a reasonable therapeutic perspective	16 (34.8)	6 (26.1)
Medical futility	15 (32.6) ²	6 (26.1)
Incurability of the disorder	14 (30.4)	5 (21.7)
Unbearable suffering	9 (19.5)	1 (4.3)
Voluntary, sustained and well-considered request	7 (15.2)	1 (4.3)
Mental competence	4 (8.6)	1 (4.3)
Experienced forms of pressure		
Patient requesting euthanasia under pressure from others	4 (8.7) ³	1 (4.3) ²
Pressure from the patient to approve euthanasia	24 (52.2)	12 (52.2)
Pressure from patient's family or friends to approve euthanasia	7 (15.2)	4 (17.4)
Pressure from patient's family or friends to reject the euthanasia request	4 (8.7) ²	3 (13.0)
Pressure from colleagues to reject the euthanasia request	4 (8.7) ³	1 (4.3)
Pressure from colleagues to approve euthanasia	3 (6.5) ³	3 (13.0) ²
Pressure from the care institute to reject the euthanasia request	2 (4.3) ³	1 (4.3) ²
Pressure from the care institute to approve euthanasia	0 (0.0) ³	0 (0.0) ²
Other experiences		
High emotional burden for yourself	33 (71.7)	15 (65.2)
A lowered risk of suicide with the patient	26 (56.5)	14 (60.9)
New therapeutic opportunities with the patient	12 (26.1)	2 (8.7)
Re-establishment of relationships between patient and significant others	12 (26.1)	9 (39.1)
Fellow patients also requesting euthanasia ²	4 (8.7)	2 (8.7)
Emotional support sought?		
No	21 (45.7)	10 (43.5)
Yes, inner personal circle	14 (30.4)	9 (39.1)
Yes, colleagues	17 (37.0)	8 (34.8)
Yes, external professional help	1 (2.2)	1 (4.3)
Yes, others	1 (2.2)	1 (4.3)
Attitude towards psychiatric euthanasia changed after this specific case?		
No	36 (78.3)	17 (73.9)
Yes ⁴	10 (21.7)	6 (26.1)

¹ This variable was measured by means of a Likert-Scale using scores from 1 to 5, with minimum score = 1 (None) and maximum score = 5 (A great deal). In this table, only the N and % of scores ≥ 4 are presented.

² Missing: $n = 1$

³ Missing: $n = 2$

⁴ In 6/10 cases (or 4/6 cases when $n = 23$) the attitude towards euthanasia in APC changed in a(n) even more risk-averse way. In 2/10 cases (or 1/6 cases when $n = 23$) the attitudes changed in a(n) even more favourable way. Finally, in 2/10 cases (or 1/6 cases when $n = 23$) mixed attitudes due to both favourable and unfavourable experiences were reported.

In addition, qualitative analysis of the answers to the open question 'Would you like to add any clarification or comments about this particular case?' revealed that some psychiatrists, irrespective of their change of mind, expressed the need for a change in law, e.g. implementation of more strict criteria for APC, per the recommendations of the guidelines that were published in the year prior to the survey in order to make these recommendations legally enforceable.

Discussion

Of all 46 completed euthanasia assessment procedures in APC, most concerned patients who suffered from comorbid psychiatric and/or somatic disorders and who had received different forms of treatment for many years prior to their request. 'Existential suffering' and 'no prospect of improvement' were reported as the main reasons for the request. In all cases, the entire procedure entailed multidisciplinary consultations, including family and friends.

Psychiatrists reported fewer difficulties in assessing due care criteria related directly to the APC themselves than in assessing the criteria related to their medical condition (e.g., incurability). Both positive and negative experiences during the assessment procedure were reported: e.g., a reduced suicide risk for the APC vs. emotional burden and feeling pressured by the APC and/or their relatives for the psychiatrist.

As for the final outcomes, half of the completed euthanasia assessment procedures culminated in the performance of euthanasia after at least 2 legally required advices were obtained, all positive bar one.

Interpretation of findings

Our study has shown the complexity of euthanasia assessment procedures in different regards. One noteworthy illustration is that euthanasia assessment procedures may span multiple months or even years. This can be related to the APC not being expected to die in the foreseeable future, and that some mental disorders tend to fluctuate in severity or even resolve over time, which warrants extreme caution. The majority of the APC, irrespective of the outcome, have been treated for their conditions for many years, giving psychiatrists involved in

the assessment a lot of ground to cover. In line with Dutch results^{131,169}, our study confirms that, when euthanasia was performed, the assessment procedure took an average of more than one year, with a few conspicuous exceptions. In two cases, assessment was reported as concluded in less than two weeks. This would be a violation of the Law, which requires a minimum waiting period of one month between the formal request for, and the performance of, euthanasia. However, this is highly unlikely to occur in practice; it is more plausible that the question was accidentally answered from the sole perspective of the individual psychiatrist and their task-specific involvement, instead of for the entire assessment procedure.

Another marked result is that, in 5 of 23 performed euthanasia cases, not all of the legal criteria had been sufficiently met in the responding psychiatrist's perception. This may raise questions about the legality of some euthanasia cases in APC. However, we have not gauged the opinion of the other clinicians involved in those cases, and we do know that the necessary formal advices were obtained in all cases. These cases again illustrate the complexity of the procedures and therefore the likely lack of consensus between the physicians involved,^{340,345} which, according to our study, primarily concerns the incurability of the condition and the lack of reasonable perspectives for improvement.

The psychiatrists also reported specific challenges regarding euthanasia assessment, in terms of the difficulties encountered in determining the extent to which the legal criteria are met in APC cases.

In line with former studies, the APC present with various psychiatric and somatic comorbidities.¹²⁶ As comorbidity is perceived as an important challenge in medicine in general^{350,351}, it also seems to pose a challenge in euthanasia assessment. However, this study confirms former research^{177,206}, which maintains that the reasons for the APC's euthanasia request are not entirely dependent on clinical symptoms alone (e.g. loneliness) and that the APC's problems are deeply rooted and branched into various aspects of the patient's past and current life. These findings point to the responsibility of our societies (and thus not only of the field of psychiatry) to address the problems that confront APC such as loneliness. This multidimensional picture undoubtedly compounds the difficulties for psychiatrists in determining (for example) the incurability of the APC's condition and to what extent there are reasonable treatment alternatives, which

are reported in about 1 in 3 cases (and which may lead to dissensions, as discussed above). Symptoms of psychiatric disorders tend to change over time – even leading, in some cases, to remission and clinical and/or social rehabilitation – and this underscores the challenge to operationalising this legal criterion in the field of psychiatry, as stated in previous studies.^{340,345} The question is whether or not the present guidelines are sufficient to support psychiatrists in these assessments.

Relatively few psychiatrists (9%) reported difficulties in assessing another central legal criterion – mental capacity – which is noteworthy given the predominant focus on competence in clinical and societal debate. A marked finding is that some respondents referred to specific diagnoses as contraindications for APC to be competent, and therefore eligible for euthanasia, a much-debated issue of which the last word has not yet been said.^{138,145,158,343} Ruling out APC for euthanasia on the basis of a diagnostic label can be problematic, as diagnostic classification is often contested due to low reliability and validity.^{352–354} Though the nature of (some) psychiatric diagnoses may indeed affect mental capacity, it has been stressed in all Belgian guidelines on euthanasia³¹⁰ that this cannot be grounds to rule out all APC for euthanasia by definition. In any case, utmost caution is needed; and the perceived absence of mental competence in a few cases might suggest the need for a standardised capacity evaluation. To our knowledge, only one Dutch and one Belgian study on this topic have shown that the assessment of this criterion differs among individual physicians (i.e., to some extent due to their personal values and belief system)³⁵⁵, and, in some cases, seems even flawed, which has led to dissensions among physicians on the evaluation outcome.¹³²

Our study brought an underexposed issue to light: namely, the high emotional strain on almost three quarters of the participating psychiatrists. Our findings suggest that one source of such strain is that the whole euthanasia procedure can be seen as a 'balancing act' in terms of suicide prevention on the one hand and taking sufficient time for rigorous euthanasia assessment on the other. For example, both reduced suicidality and opportunities for rehabilitation during euthanasia assessment were reported, which is also in line with former research findings.^{126,169,206} Anecdotal accounts reveal that suicide risk may be one of the reasons responding psychiatrists feel pressured by the APC into granting the

request. Previous research shows that some patients die by means of suicide, even when the euthanasia request has been granted, which suggests that these APC perceived the euthanasia procedure to be too long and/or too arduous.^{13,26} The relatively high number of negative advices in this group would corroborate this interpretation. However, it is important to note that we gauged neither for past suicide attempts nor for actual suicide risk in this survey. As for the latter, other potential explanations need to be taken into account: that is, for some, the euthanasia procedure itself might reduce the risk of suicide for that period, but for others it could actually increase the risk of suicide. Another likely source of strain is pressure coming from relatives, either to approve or to deny the APC's request.

Finally, it remains unclear whether the support available to psychiatrists is sufficient and which aspects of the assessment cause the most emotional strain. Current research and guidelines predominantly emphasize the implementation of the legal and due care criteria, thereby largely ignoring the moral and personal challenges for psychiatrists themselves.

Implications for practice, policy and research

As for policy and practice, the finding that some legal criteria were not (sufficiently) met in the perception of the psychiatrists involved seems to corroborate concerns about whether requests are always assessed and monitored adequately and rigorously.³⁴⁰

It is deemed quintessential to gauge whether, and to what extent, the recently published guidelines³⁵ have sufficiently addressed and effectively tackled the many challenges regarding decision-making and the abovementioned moral dilemmas. For example, the 'incurability of the disorder' criterion has been operationalized in these guidelines, but there may be a need for further refinement, or maybe even for an alternative legal term that better suits the field of psychiatry. The same could be said about 'reasonable state-of-the-art treatment options' – with the inherent relative proximity of 'therapeutic tenacity' and 'therapeutic negligence' – in the context of psychiatry's lack of objective knowledge regarding prognoses and treatment outcomes. Moreover, the guidelines provide very little on involving and dealing with relatives, while our study revealed that they are often involved and can add pressure on

psychiatrists during the assessment. However, as most of the guidelines were published just a few months prior to this survey, it is yet unclear whether the psychiatrists were familiar with them.

In order to expand upon this study's generated insights, the need for further research is considerable. Qualitative in-depth research into the factors that might further support and enable psychiatrists and other professionals in adequately assessing such requests is needed. This will also allow us to gain deeper insight into the emotional impact these procedures can have on psychiatrists, on the APC and those close to them, and on the therapeutic relationship.²¹⁹ Given that the psychiatrists reported successful rehabilitation in some APC, future research should also focus on protective factors – such as engagement in a supportive social network or acquiring resilience and coping skills – that can lead to increased quality of life which may decrease the wish to die. With regard to the ambiguity of law and the difficulties of its implementation in psychiatric practice, especially in the most complex cases, the research method of casuistry may help to address the unclear legal and ethical challenges. Also, large-scale studies should provide more reliable estimates of requests and granting rates and enable the factors influencing the outcomes of the euthanasia requests to be identified. Of the 46 APC applying for euthanasia in this study, two-thirds obtained at least two positive advices and could be considered formally approved for euthanasia. This result may suggest a high approval rate – but that is misleading, as prior evidence indicates that the vast majority of requests are denied, rejected, or withdrawn before a formal outcome is reached.^{88,126,131,169,356} Moreover, obtaining two positive advices does not automatically mean that the APC have been approved for euthanasia, as the physician entrusted with the clarification of the APC's euthanasia requests may seek to obtain additional (i.e. more than the two legally required) advices. Lastly, future research might also focus on examining the impact and consequences of ungranted requests – as, for example, the APC might be left to their fate with their death ideation, while their physicians refuse to engage in discussion about it.

Strengths and limitations

This is the first study to provide an in-depth analysis of the experiences of Belgian psychiatrists regarding the complexity of euthanasia practice in adults

with psychiatric conditions. It reveals new insights into many aspects of the assessment procedure and the impact it has on the psychiatrists involved. We gathered information on 46 assessed cases and 23 performed euthanasia cases predominantly based on psychiatric disorders that were checked for uniqueness by crossing essential variables. As for representativeness, according to the latest official Euthanasia Review Committee Report, 27 APC died in 2016 and 26 in 2017 by means of euthanasia.^{112(p46)} Assuming that the numbers remained similar in the period of our survey, this may suggest that our study comprises close to all euthanasia cases based on psychiatric disorders. However, given the potential response and selection bias in our study, we cannot make assertions about the representativeness of the captured cases in relation to the entire euthanasia practice in psychiatry.

Though this analysis provides rich insights into psychiatrists' practice and challenges in dealing with euthanasia requests from APC, the authors wish to stress that the data do not readily allow for evaluation of: (a) the legality of performed euthanasia cases, or (b) the factors predictive of requests leading to euthanasia.

Some results should be interpreted with caution due to the potential sources of bias: response bias given low response rates, but also selection bias as we suspect respondents often refrained from reporting about concluded cases where the APC are still alive. Assuming that the psychiatrists were much more inclined to report on euthanasia requests that have been carried out than on those put on hold, we have thus not captured a large proportion of completed evaluations that have not culminated in euthanasia.

This is supported by anecdotal evidence, and annual reports from clinical practice reveal that a large proportion of these patients put their procedure on hold after 1 to 2 consultations.¹²⁷ This combination of potential biases renders the interpretation of half of the requests leading to euthanasia untrustworthy and overestimated, all the more so considering existing sources reporting lower rates.^{130,131,169} Finally, and although the survey was pre-tested for cognitive validity, we cannot exclude the possibility of misunderstandings remaining with regard to the interpretation of individual items.

Conclusions

This study has revealed the complexity of euthanasia assessment in APC, due to the variety of (comorbid) diagnoses and often severe somatic co-diagnoses, the variety of reasons for requesting euthanasia (also appealing to the responsibility of our society), the difficulties in assessing the legal and due care criteria, and the emotional impact of euthanasia assessment on psychiatrists. Not only does it involve people with long histories of medical diagnoses and treatment, but assessment also requires a large amount of time. When the euthanasia request culminated in the performance of euthanasia, the entire procedure spanned an average of 13 months (which is much longer than the legally required one month) and entailed multidisciplinary consultations (e.g., psychologists, palliative care team), including with family and friends (which is not required by law). Our findings indicate that psychiatrists require support in more than one respect if euthanasia requests by APC are to be handled adequately: To what extent can or do the guidelines provide answers to assessment complexities? Is there a need for specific education in assessment? Are legal clarifications in order? Future (qualitative) research can aid by focusing on the psychiatrists' and the APC's experiences and needs in this regard.

Due to the considerable risk of bias, this analysis should be read as an account of the types of cases and issues encountered in psychiatric euthanasia practice, and not necessarily as a reflection of the entire psychiatric euthanasia assessment practice. A more robust mapping of euthanasia assessment procedures in APC would be better achieved through studies with large reliable denominators generating estimates of (for example) granting rates and insight into factors influencing the granting of requests.

PART FOUR:

HEALTH CARE PROFESSIONAL AND VOLUNTEER CARER PERSPECTIVES

Chapters are based on the following submission:

Chapter 11

Verhofstadt M, Audenaert K, Mortier F, Deliens L, Liégeois A, Pardon K, & Chambaere K. Concrete Experiences and Support Needs regarding the Euthanasia Practice in Adults with Psychiatric Conditions: a qualitative Interview Study Among health Care Professionals and Volunteers in Belgium. *Frontiers in Psychiatry*. 2022;13(March). doi:10.3389/fpsy.2022.859745

CHAPTER 11 :

CONCRETE EXPERIENCES AND SUPPORT NEEDS REGARDING THE EUTHANASIA PRACTICE IN ADULTS WITH PSYCHIATRIC CONDITIONS: A QUALITATIVE INTERVIEW STUDY AMONG HEALTHCARE PROFESSIONALS AND VOLUNTEERS IN BELGIUM

Verhofstadt M, Audenaert K, Mortier F, Deliens L, Liégeois A, Pardon K, & Chambaere K. Concrete Experiences and Support Needs regarding the Euthanasia Practice in Adults with Psychiatric Conditions: a qualitative Interview Study Among health care Professionals and Volunteers in Belgium. *Frontiers in Psychiatry*. 2022;13(March). doi:10.3389/fpsy.2022.859745

More detailed information is available online in the Open Science Framework repository (OSF), via this link: <https://osf.io/e8h6t/>

I could just remember how my father used to say that the reason for living was to get ready to stay dead a long time. And when I would have to look at them day after day, "each with his and her secret and selfish thought, and blood strange to each other blood and strange to mine, and think that this seemed to be the only way I could get ready to stay dead, I would hate my father for having ever planted me.
William Faulkner (As I Lay Dying)

Abstract

Objective

Although euthanasia in the context of adult psychiatry is legalised in Belgium, it poses major ethical and clinical challenges for the health care professionals and volunteers involved. This study aimed to address these members' concrete experiences and support needs.

Methods

A qualitative semi-structured interview study was conducted with 16 physicians and 14 other health care professionals and volunteers, with at least one concrete experience with euthanasia requests and procedures concerning adults with psychiatric conditions.

Findings

Concrete experiences concerned the following 8 domains: (1) the impact of euthanasia on the clinical trajectory and (2) on the therapeutic relationship, (3) internal and (4) external collaborative partnerships, (5) patients' social inner circle (non-)involvement, (6) the use of recently published guidelines and, (7) the first criminal trials on this topic, and (8) the act of euthanasia. The following 8 main support needs emerged; (1) protocols addressing specific sub-populations and pathologies, (2) protocols specifically drawn up for non-medics, (3) guidance on how to adequately implement the two-track approach, (4) (after)care for patients, (5) (after)care for the health care team, (6) guidance on the patient's social inner circle involvement, (7) enhanced education measures, and (8) enhanced financial measures, including incentives for holistic, palliative care approaches.

Conclusion

The health care professionals and volunteers reported many positive and negative experiences in dealing with euthanasia requests in adult psychiatry. They reported several support needs across the extensive euthanasia trajectory, pertaining to concrete management of thorny issues that guidelines do not (yet) touch on. Important implications of our study relate to tackling these existing issues, and to paying sufficient attention to the impact of a euthanasia trajectory on all actors, including the patients and their social inner circle, involved.

Keywords: euthanasia, mental disorders, end-of-life decisions, assisted suicide, psychiatry

Introduction

Belgium¹ is one of the few countries – next to the Netherlands⁷³, Luxembourg⁶⁹ and Spain⁷⁴ – that does not exclude adults who suffer predominantly from irremediable psychiatric conditions from medical assistance in dying per definition. Canada considers to expand current legislation to this specific patient group in 2023.²⁰¹ Although adults with psychiatric conditions can be potentially eligible for euthanasia (i.e. the act of a physician administering the lethal medication to a patient), it remains a highly controversial and extremely complex end-of-life practice in terms of whether and when these patients can meet all legal criteria.^{131,135,281} Apart from the difficulties in assessing the legal criteria, these euthanasia assessment procedures are also professionally and emotionally demanding. For instance, physicians have to deal with a higher level of uncertainty in psychiatry (in terms of diagnostics, prognosis, treatment efficacies, and outcome of psychiatric conditions) and the tension between suicide prevention and euthanasia.^{131,135,281} In addition, euthanasia assessment procedures concerning this patient group, may take an emotional toll, as a recent survey study revealed that physicians may feel e.g., pressured by the patient, the patient's social inner circle, colleague-physicians and/or the affiliated institution to (dis)approve the euthanasia request.³²²

Recent empirical evidence revealed that although three-quarters of psychiatrists in Belgium are in favour of euthanasia legislation that does not exclude this specific patient group²⁸¹, only a minority is willing to actively engage in their own patient's euthanasia procedure (39%), to be engaged as advising physician (30%) or performing physician (< 10%).²⁸² The reluctance may be reflected by the decrease in the number of performed euthanasia cases that were reported to the Federal Evaluation and Control Committee on Euthanasia: from 43 adult patients with psychiatric conditions that died by euthanasia in the year 2015¹¹⁴ to 23 patients in 2019³²⁴.

The growing reluctance among physicians may be ascribed to a recent court case in 2020, in which three physicians stood trial for potential offences against the euthanasia law concerning one adult with psychiatric conditions. But even before the court case, it was clear that physicians needed more support in the handling

of euthanasia request based on psychiatric reasons. In the years 2017-2019, several guidelines were published and recommended more strict criteria than required by Law, e.g., the consultation of not one but 2 psychiatrists, the need for 2 positive advices instead of 2 advices of which the outcome is not legally binding, and the need to explore all reasonable alternatives to death, also from a non-medical, psychosocial perspective.³¹⁰ Although these additional recommendations are not legally binding, many physicians are confronted with increased stringency and increased awareness of being prone to court cases. And although these guidelines may offer useful guidance for enhancing clinical euthanasia management in psychiatry, differences in approaches remain, and not all existing bottlenecks have been identified, let alone addressed adequately.³¹⁰

The published guidelines also recommend a stronger involvement of an interdisciplinary team to enhance the quality of current psychiatric euthanasia assessment procedures. Furthermore, end-of-life consultation centres employ other types of health carers than physicians alone, i.e. psychologists, psychiatric nurses, and well-trained volunteers such as buddies. All these people may be involved in a patient's euthanasia procedure and may have an influential role in the euthanasia outcome. Recently, whereas buddy services were established to help these patients to cope with the euthanasia procedure that they may perceive as burdensome,³²⁷ rehabilitation-oriented support groups were established to help these patients with life-and-death considerations. All these health care professionals and volunteers may also have an unacknowledged but influential role in these euthanasia assessment procedures. Unfortunately, the concrete experiences and support needs of these carers have not yet been addressed in in-depth research studies.

Hence, the purpose of this research is 1) to explore health carers' experiences in their involvement in the management, assessment or other additional support of adult patients suffering predominantly from psychiatric conditions with a euthanasia request and 2) to explore their support needs in this regard.

Methods

Study Design

The semi-structured interview research design consisted of face-to-face interviews with health care professionals and volunteers in Flanders and Brussels, Belgium.

Participants

All the participants were Dutch-speaking and had at least one concrete experience with euthanasia requests and procedures concerning adults with psychiatric conditions in the period 2016-2020. No further exclusion criteria were employed.

Recruitment and interview procedure

Purposive sampling was used to ensure diversity and heterogeneity in terms of participants' affiliation with institutions holding different stances on 'euthanasia and psychiatry' and being to a different extent confronted with these euthanasia procedures as regards the amount of experiences (sporadically versus regularly) and the nature of the experiences (e.g. confronted with or engaged in euthanasia procedures that were still under review or that had been rejected, granted, performed or withdrawn).

Participants were recruited via assistance of our contact persons (See BOX 1 at the end of this Chapter) at: 1) the end-of-life consultation centre Vonkel; 2) the Organisation Brothers of Charity; 3) REAKIRO in Louvain; and 4) the REBEL action group. The respective contact persons were asked to inform each associated potential participant about the interview study and to ask them to participate. Participants were also recruited via a notice on the sites, newsflashes and/or in the online newsletters of LEIF (Life End Information Forum), Recht op Waardig Sterven (the Flemish Right To Die with Dignity Society) and Flemish Association for Psychiatry.

Potential participants contacted MV, KC or the study assistant by phone or mail. The participants were then given an information letter and informed consent

form that consisted of 2 main parts (see [OSF](#)). With the use of an interview topic guide (see [OSF](#)), all interviews were conducted by MV, or a study assistant, both of whom have extensive experience in conducting interviews on end-of-life topics. Interviews were held at the participant's location of choice, except for 5 interviews which were held online by Whereby²⁸⁷ due to the Covid-19 crisis lockdown regulations. Interviews lasted between 55 minutes and 2 hours, and were audio recorded (the online interviews were recorded by Whereby's software and immediately transferred in an mp.3 format). Participants' time investment was compensated by means of a gift voucher.

Data Management and Analysis

All interviews were transcribed verbatim by the two interviewers. After transcription, the audio files were kept under lock and key at Ghent University. The transcribed, anonymized data were stored on a secured Sync folder via encryption and transferred to QualiCoder²³³, software for qualitative analysis. Only the interviewers, and co-authors KP and KC had access to the transcripts.

As our study was explorative, i.e., not based on any theoretical framework, MV, KP and KC used an open, thematic coding procedure, consisting of four phases; 1) identification and independent coding of all transcripts (MV), and the coding of 6 transcripts (3 by KC and 3 other transcripts by KP); 2) the substantive discussion on labelling and placing of the codes in subthemes (MV in close discussion with KC and KP); 3) the placing of these subthemes in overarching main themes (KC, MV); 4) the comparison and discussion of the findings resulting coding structure (with all co-authors).

We used a model of sampling-based saturation, namely inductive thematic saturation²⁸⁸, that relates to the emergence of new themes (defined as 7 consecutive interviews without new themes) that was checked for per 3 transcripts. We continued to recruit and conduct interviews so that the sample would be heterogenous in terms of socio-demographics, clinical profile, and clinical setting.

Findings

The main characteristics of the 30 participants are listed in Table 1. The sample consisted of 16 physicians, 7 other care professionals (from psychiatric nurses to mobile support teams), and 7 volunteers, who engaged in one or more euthanasia procedures that were predominantly based on psychiatric conditions. Participating physicians held one or more roles regarding the handling of the euthanasia request:

- refused to discuss the request with the patient on principle grounds ($n = 1$);
- handled the clarification of euthanasia requests from one or more of their own patients themselves (attending physician) or referred one or more of their own patients to a colleague for further clarification (referring physician) ($n = 7$)
- were entrusted with the task to give one of the two legally required formal advices or an additional advice on the euthanasia request (advising physician) ($n = 10$);
- performed the act of euthanasia ($n = 5$);
- held a dissuasive stance against euthanasia in the context of psychiatry but were willing to explore and discuss the euthanasia request with the patient ($n = 3$).

The sample further consisted of 14 non-physicians, among them members holding one or more roles (see Table 1), e.g., mobile teams that provide psychiatric care and support in the patient's home setting ($n = 2$), psychiatric nurses working in a general hospital or in a psychiatric residential setting ($n = 3$), Experts by Experience, i.e. people with a history of mental distress who are trained to provide support for someone who is 'new' to the experience (e.g. entering the euthanasia procedure and/or rehabilitation approaches, $n = 2$), buddies ($n = 3$) and spiritual carers ($n = 3$) entrusted with the task to assist, guide and/or support the patient throughout the euthanasia procedure, and consultants at end-of life information and/or consultation centres entrusted with patient intake ($n = 5$).

Table 1: Participants' Characteristics (N = 30)

Biological Sex		
Male	11	7
Female	5	7
Age Category		
< 30 years	0	2
31-40 years	0	2
41-50 years	1	4
51-60 years	4	3
> 61 years	11	3
Type of work environment²		
Private or Group Practice	5	0
Psychiatric units/Psychiatric Hospitals	7	2
Psychiatric Care Homes	2	3
Specialised end-of-life centres	5	5
Other	0	4
Number of concrete experiences in the year prior to the interview		
1-2 cases	1	3
3-5 cases	4	2
> 5 cases	10	9
Specific role in euthanasia procedures³		
None	1	0
Attending/referring physician	7	0
Advising physician	10	0
Performing physician	5	0
Mobile Teams	0	2
Psychiatric nurses	0	3
Experts by experience ^{4, 5}	0	2
Spiritual carers ⁵	0	3
Buddies ⁵	0	3
(Secretary) consultants at end-of-life centres ^{5, 6}	0	5

¹ The following physicians were interviewed: 10 psychiatrists, 4 general practitioners and 2 other clinical specialists. The interviewed psychiatrists had expertise in e.g. adult and old-age psychiatry, neuropsychiatry, forensic psychiatry, geriatric psychiatry, psychiatric substance abuse care

² Some have more than one work environment

³ Some had experience in more than 1 role

⁴ Experts by experience, i.e. people classified with a (proneness to) mental illness, that are trained to provide support for someone who is 'new' to the experience or entering rehabilitation approaches.

⁵ Among these health care team members, a variety of academic and professional background qualifications can be distinguished, e.g., former or present medics, psychologists, orthopedagogists, and communication scientists

⁶ These people are entrusted with e.g., the patient-intake and referral at end-of-life information or end-of-life consultation centers.

Concrete experiences with euthanasia procedures in the context of psychiatry

Participants' experiences, listed in Table 2, can be captured in eight overarching themes: their experiences regarding 1) the impact of euthanasia legislation and

practice on the clinical trajectory, 2) impact on the therapeutic relationship, 3) the aspect of professional team collaboration, 4) the role and involvement of patients' relatives, 5) the collaboration with end-of-life centres (see Box 1 at the end of this Chapter), 6) the use of recently published guidelines, 7) the impact of recent court cases (see Box 1 at the end of this Chapter), and 8) their experiences with the act of euthanasia. In what follows, we discuss these themes in sequential order.

As regards the first theme, the impact on the 'clinical trajectory', most of the participants reported on the 2-track approach. This 2-track approach is recommended by the guidelines and characterized by simultaneously focusing on the *death-track* by means of the exploration of the reasons for and eligibility of a patient's euthanasia request, and on the *life-track* by means of the intensified exploration of rehabilitation and recovery options on a psychological, physical, social, and existential level, and psychiatric palliative care approaches.

Most participants experienced the 2-track approach as a positive challenge rather than a negative threat. Some of the participants experienced a lack or hampered 2-track approach on two levels: 1) colleagues not establishing a death track, e.g. when refusing to take euthanasia requests seriously or the reason for denying the patients' access to treatment, and/or 2) colleagues not following the life track in which reasonable alternatives to death were insufficiently or not explored, or insufficiently applied, e.g. the perceived remaining basic state-of-the-art treatment options were ignored.

But something happened there, she went to (...) and she was put on a pedestal. A documentary was made of it, it was published in (newspaper), it was published in (popular magazine), so that created a certain, a certain something that left me, that left us, and what we had in mind, without a chance. And that was, that was terrible. Yes, and that has been a turning point, I think. I had the feeling that I wouldn't get another chance, or that we wouldn't get another chance. (...) Yes, and I would like to do that, but yes, I am but a nurse with experience, I would like to make an appeal: please, do not ever do this again, ever! Not with these people, certainly not with these people, with these kinds of problems. That should not be allowed. You are not allowed to do that.

(Psychiatric nurse)

In addition, most interviewees reported on poor rehabilitation options available and insufficiently developed palliative care approaches that could focus more on comfort and holistic care needs than on the medical condition and curation in Belgium.

Some participants described a window of opportunities in the sense that the two-track approach in the euthanasia procedure may serve a twofold therapeutic objective.

In their experience, acknowledging and validating the patient's difficulties in life and thoroughly discussing death ideation in a serene manner (without immediately initiating suicide protocols) may both appease the patient's mind and hence, decrease suicidality (by the prospect of a more dignified way of dying) and empower the patient to further explore the (underlying) meaning of the euthanasia request, to have their clinical trajectory re-evaluated or intensified. Other participants testified that euthanasia legislation closes this window of opportunity due to its discouraging and demoralising effect. In their experience, the option of euthanasia had nudged some of their most vulnerable patients to apply for euthanasia, installed a tunnel vision toward death that discouraged them to give reasonable treatment options a fair chance of success and did not decrease suicidality.

Other participants had experiences with both scenarios and considered euthanasia legislation a double-edged sword: whereas it may encourage and empower a proportion of the patients to refocus on the *life track*, it may discourage or even further demoralise other patients, who feel less motivated to focus on the *life track* and are more swept into the *death track*.

Table 2: Favourable and unfavourable experiences regarding euthanasia in the psychiatric context, reported by health care professionals and volunteers ¹

Theme	Favourable experiences	Unfavourable experiences
Patients' clinical trajectory	<p><u>Benefits of a 2-track approach²:</u></p> <ul style="list-style-type: none"> - continuity of care, - treatment non-abandonment, - turning off 'tunnel vision towards death' (C) - Exploration of rehabilitation options for patients (and relatives) - Empowerment (e.g. increased decision-making capacity and feelings of regaining some control in life) <p><u>Opening window of opportunity</u></p> <ul style="list-style-type: none"> - Serene in-depth discussion about death ideation unravels its underlying meaning (cry for help in dying versus cry for extended aid) - The therapeutic effect of an exit-plan on patients' mindset: patients feel empowered to deal/cope with illness and other problems in life - Re-evaluation of diagnosis, treatment <p><u>Decreased suicidality</u></p> <ul style="list-style-type: none"> - Decreased suicidality 	<p><u>Lack of or hampered 2-track approach</u></p> <ul style="list-style-type: none"> - Euthanasia request as reason for exclusion from ambulant treatment or residential stay - Rehabilitation low on options: understaffed, underfinanced - 2-track approach experienced as double-edged sword: whereas it may encourage some patients, it may discourage others <p><u>Closing window of opportunity</u></p> <ul style="list-style-type: none"> - The law itself inciting patients to fixate on death (discouraging/demoralising factor) - A hampered 2-track approach inciting patients to fixate on death <p><u>Suicidality persists</u></p> <ul style="list-style-type: none"> - No effect on suicidality
Relationship patient – physician/caregiver	<ul style="list-style-type: none"> - Meaningful care - Better 'contextual' understanding of patients (C) - As patients feel heard, understood, respected, caregivers can reach a better connection/trusting relationship 	<ul style="list-style-type: none"> - Difficulty to set personal/professional boundaries (C) - Difficulty to assume an appropriate role (due to inexperience/lack of training or tools)(C)

		<ul style="list-style-type: none"> - Therapeutic relationship threatened in case the euthanasia procedure is completely 'outsourced' (C) - Insufficient (after)care for patients with euthanasia requests rejected/put on hold
Professional team collaboration	<ul style="list-style-type: none"> - Colleague intervision & support - Building up knowledge and expertise - Face & carry the responsibility, workload and/or emotional impact together 	<p><u>Negativity bias</u></p> <ul style="list-style-type: none"> - Physicians willing to engage in the most cautious and careful manner face 'stigma from colleagues' (P) <p><u>Experienced irregularities in the euthanasia assessment procedure</u></p> <ul style="list-style-type: none"> - No meaningful referral - Unmotivated advices, advice without conclusion <p><u>Poor management/follow-up</u></p> <ul style="list-style-type: none"> - Little or no time/space to discuss the case when 'outsourced' (C) - Little or no intervision/supervision (C) - Little or no support (C)
Role and involvement of the patients' relatives	<ul style="list-style-type: none"> - Informing and involving relatives may result in mutual understanding, rehabilitation damaged/soured relationships - Heteroanamnesis = more contextual understanding, completion of 'the puzzle' - Patients take time to prepare themselves and their loved ones for the end 	<ul style="list-style-type: none"> - Relatives not or insufficiently consulted - No/little time/space for aftercare and closing
Collaboration with end-of-life information/consultation centres	<ul style="list-style-type: none"> - offer low threshold for serene talks about death or for these patients whose euthanasia request are more often neglected/ turned down by their treating physician 	<ul style="list-style-type: none"> - Difficult collaboration with end-of-life consultation centres (different approach, ideological bias, etc.) or vice versa (poor physician administration/communication)

	<ul style="list-style-type: none"> - Highly needed and consulted 3rd line partner for the 'individual professional' (support and assistance, expertise, independent partner, death track, objective assessment) 	<ul style="list-style-type: none"> - Lack of collaboration: treating physician/care team side-lined - Unprofessionalism: e.g. some volunteers not trained in the (para)medical field, patients as victim of internal rivalry - Overburdened: long waiting lists, understaffed
The use of guidelines	<ul style="list-style-type: none"> - Helpful in euthanasia assessment - Most concerns addressed by additional safeguards - Deontological guideline experienced as offering an authoritative framework 	<ul style="list-style-type: none"> - Unhelpful (redundant, unpractical/vague, lacking in areas) - Flawed (biased, not uniform, discourages engagement, some paragraphs still unclear)
Impact of court cases	/	<ul style="list-style-type: none"> - Decreased willingness of physicians to engage - knock-on effect for patients with euthanasia request under review (concern request would no longer be assessed) - Missed opportunity for a more nuanced debate
Experiences during the performance of euthanasia	Supportive moments shared with patient and relatives (gratitude, serene atmosphere)	<ul style="list-style-type: none"> - Patients' sudden change of mind (P) - Poor performance on a technical level (P)

¹ (P) when the information was only mentioned by physicians and (C) when only mentioned by other care workers

² The 2-track approach is characterised by simultaneously focussing on the death track by means of exploring the patients' motives for requesting euthanasia and their eligibility for euthanasia on the one hand, while on the Life-track focussing on all alternatives to death, including rehabilitation options. This approach is recommended by the written guidelines and Belgian Order of Physicians' deontology code on how to adequately manage euthanasia requests in the context of adult psychiatry.

Some participants partly ascribed this to the different motives for requesting euthanasia, be it a cry for additional help in life or a cry for help in dying.

"Puff, I think it's also a double-edged sword. On one hand, some people feel heard and get the idea of 'well, now this may be a solution I can choose, isn't it? If it really...' There are many who literally say that, huh: 'plan A is life-oriented, plan B, if I have it approved, then I feel supported, then I feel heard, that's a reason to work even harder on plan A.' But there are also people who will bury plan A much quicker, because they no longer have the courage to follow plan A. So, what I want to say is that it is a double-edged... well, that the outcome actually depends on the person herself. For one person it's, uhm, a solution to continue working on their treatment and to try to obtain a better quality of life, knowing that if they were to fail, they can be receiving euthanasia. And there are also those for whom it is just a lever to say, well, I choose not to do it anymore, uhm (Interviewer: So that it impedes potential treatments?)

Impedes it, yes. I see it a little bit, well, you can compare it somewhat with, uh... There are suicides to life, and there are suicides to death. There are suicides that are clearly appeals to HELP ME, I want to live. There are also suicides that are not a cry for help, but definitely a cry for death.

When you talk to the patients, you can get a clear idea, for example, of the suicides, the way they did the suicides, huh? There are some who will say, yes, well, I cut my arm, 4 months ago. And then I think, yes well, that's not a suicide attempt huh, that's, well, that's self-mutilation and that's actually a cry for help, not for death, but when they tell me, well, a year ago, I took 100 pills and I spent 5 days in intensive care, well, these people really want to die, don't they? They really want to die, don't they?" (Psychiatrist)

Some argued that these different motives were also seen in suicide attempt survivors, be it an acute cry for more attention and help in life or a passionate attempt to take revenge on others, versus a more well-considered, rationalised road to death. Other participants argued that the debate regarding euthanasia on the one hand and suicide prevention on the other should not be mixed up, as

they observed suicide ideation, attempts and deaths in both patients applying and not applying for euthanasia, as well as patients in both groups overcoming suicidality.

"So many things can change. A suicide, for example, can also be a signal. If it supposedly fails, you can notice afterwards, that that signal causes a lot of things that can actually lead to new equilibria and a meaningful balance. Likewise, the journey [*euthanasia procedure*] can actually, due to all those selection criteria, indeed lead to things that result in something meaningful, and so on."

(General Physician)

According to some participants, the discussion on whether or not euthanasia could be considered a potential antidote for suicidality detracts the attention from the real question on the inherent lethality of psychiatric disorders, and suicide and euthanasia as different means to put an end on the long ordeal of suffering.

"Is death not immediately foreseeable with a psychiatric condition? That's the annoying thing, that you don't know that, isn't it? How many suicides do we have here? But well, I do have something against that, when we use euthanasia as a kind of antidote against, uh, against suicide, that's a totally different issue. But death and psychiatry, that is, why do we have all these governmental programmes against suicide, isn't that not dying of a psychiatric condition? Isn't that the second or third cause of death in young people? Is that not dying of a psychiatric condition? A psychiatric condition can be lethal. But we don't know when, right, that varies from one person to the next. We are left to make assessments all the time, how high is the risk of dying, huh, the risk of suicidality. And then that's about the lethality of some psychiatric conditions. If I remember correctly, the life expectancy for psychosis is 10 to 15 years lower than for other people, that's sad, isn't it? And then you have mortality, and you also have suffering. And many of the psychiatric people that I see [as advising

physician], they suffer more than the average person with ALS who has to endure that for three years. 15 to 16 years of hospitalizations, no hospitalizations, I mean, you have these two factors, right? Lethality and suffering."

(Psychiatrist)

As regards the second theme, the impact of engaging in the euthanasia procedure on the relationship with the patient, participants phrased their involvement as an act of meaningful care. Notwithstanding the complexity and need surrounding these euthanasia assessment procedures, they experienced meaningful encounters and a deeper, more intimate, connection with patients, characterized by a sense of mutual respect and mutual understanding on the one hand and the greater intimacy and deeper knowledge of the individual behind the patient on the other due to the intensity of the euthanasia trajectory.

"It is a privilege for a physician to get very close to people in a very short space of time."

(General Physician)

All care workers valued the possibility to offer more holistic, individualized care for these patients that made it easier to help and support these patients in what each of them most needed support with. Although they all valued an even deeper and more contextual understanding of these patients, most of them also experienced its downside in terms of difficulties to set and maintain professional boundaries (e.g., over-involvement, the challenge of keeping a professional instead of a personal role).

Regarding professional team collaboration, the third theme, most participants experienced the added value of inter- and supervision (e.g., support & assistance, learning from other's experiences, to bear the emotional and professional load together). However, the following barriers were also reported, from physicians deliberately hindering the patient from starting the euthanasia assessment procedure by means of false information (e.g. telling the patient that the head of the hospital should give his approval for euthanasia assessment) or obstructing referral to a colleague or institution willing to engage in euthanasia assessment procedures, to physicians handling the euthanasia request with

negligence or complacency due to poor communication (e.g. when not or insufficiently informing/consulting the patient's treating physician or caregivers), poor administration (e.g. providing insufficiently motivated formal advices) or contraventions (e.g. obtaining 1 instead of 2 legally required formal advices).

There was a lot of fuss going on about who would give the approval, and then the approvals were there, but they said, 'if that person is giving approval, I no longer want to be involved'. So, actually the patient finds herself in a certain system that is playing above her head, that was not good, and so I took care of her but because of that situation, she went into a crisis, and I couldn't stand it, I couldn't stand the grief. It's very, very complicated, but of course when you see how it can affect a patient like that, that's just inhuman. Yes, and that's not right. No, no, absolutely not, no, no. So, it's actually a kind of internal conflict between, um, physicians that the patient has to suffer for? Yes and that's not okay. I was with her once when she was fixated in isolation, which we hardly ever do anymore and I think that was one of the last times and even the last time that I saw that happening, a fixated patient, and the sadness was inhuman.

(Psychiatric nurse)

Some of the interviewed psychiatric nurses pointed to the problem of euthanasia procedures that are 'completely outsourced' to external organizations and therefore completely disconnected from the outpatient and/or residential treatment process. As a result, these psychiatric nurses experienced neither guidance nor support to provide appropriate care to these patients and their fellow patients, e.g., regarding the issue of 'contagion', especially among young adults, in terms of imitating the behaviour and death ideation of fellow peers.

The involvement of patients' relatives during the euthanasia assessment procedure, the fourth theme, was experienced as an added value for 1) the physician involved as hetero-anamnesis offers a deeper understanding of the patient's personal, clinical and contextual history, present and future perspectives, 2) the relatives, as being recognised and not being side-lined may help them coping with the euthanasia procedure and – when euthanasia is

performed – soften their mourning, 3) the patients, as they can shoulder along with the relatives in a joint trajectory, and 4) the patient-relative relationship as rehabilitation of soured relationships was reported. Some participants witnessed and criticised that patients' relatives were side-lined. Some physicians wanted to consult the relatives but felt unable to do so due to e.g. strong patient opposition, and/or felt unable to address the need for (after)care.

"When performing euthanasia, I usually say to those who are present, etc., you can always call me, and it may be necessary for, well, and you wouldn't be bothering me, and so on. Some people do call me, but not many. I myself don't take the initiative to take on another 4, 5, 6 people in grief counselling. I think that's the job of the general physician. I think that we indeed don't pay so much attention to that. Beforehand, yes, but after, no, I plead guilty. I don't do that well, I don't have the time and energy for that, I think, actually huh." (...) "Yes, yes, yes, yes, there are already lawsuits, because among others [name physician] has already got a lawsuit about that. A patient who really said, "No I don't want it, I refuse that you inform [family members]." Yes okay, then you have to see. But also in the intervision, during the LEIF-physician training , we are told to try as much as possible and insist, and then you can witness very beautiful things occurring, of being able to say goodbye to those troubled relationships, because that is very important for the children, instead of being informed like, 'hey, my father died, hey, by euthanasia and I knew nothing about it'. That's not easy, is it?"

(General Physician)

In the experience of one physician, euthanasia requests were seldom based on patient's voluntary decision but most often due to pressure of relatives and as a consequence, the physician's duty is to muzzle the relatives' voices and strongly oppose euthanasia in this patient group.

"In a vast majority of cases, people are talked into the psychological suffering, which led the man in question to say under pressure from his family 'alright, let's go for euthanasia then'. I know that because I knew

him so well - well, I'm talking about different cases now – or her as well, whom I knew so well, that I knew this was actually not what she wanted. Because of their weakness, because of their illness, or because of their reduced resistance to go against them. Hence, only people who are so involved with their patients can judge that. Because you've known these people for forty years. And you know very well when they are telling the truth and when they are not. Then you know someone and say 'all of a sudden their character has changed and all of a sudden they have made a request for euthanasia', that I wondered 'how can that be'? And then - but I think there are few people better able to judge than a general practitioner who knows his patients so well. I did feel that – well that was my impression at the end of my practice – that many people did not really want that. But, under pressure from the family-

(Interviewer: Yes. And have you known cases or people whose request for euthanasia was genuine?)

I don't think so. I don't think so."

(General Physician)

Whereas the abovementioned findings resulted from the participants' experiences regarding the euthanasia legislation and -practice in general, the following experiences concern specific aspects that have changed the practice over the years. End-of-life information and consultation centres, the fifth theme, were praised as they offered a low threshold for serene talks about death and for patients whose euthanasia request are neglected or turned down by their treating physician. In addition, end-of-life consultation centres were experienced as a highly needed and consulted 3rd line partner for the 'individual professional'. However, participants working at these centres phrased that 'this low threshold' is threatened by the difficulties to respond to the increasing imbalance between supply (being understaffed and low in options for external referral) and demand (due to an increase in the number of patients applying for euthanasia and hence waiting list enrolment). Other participants reported an experienced lack of collaboration (when being side-lined) or poor professional collaboration with(in) end-of-life centres due to experienced unprofessionalism, e.g., some of the

(peer-) volunteers not being trained in mental health care and/or patients being victim of internal rivalry between these centres.

As regards the role of written guidelines, the sixth theme, for some participants, they provide helpful guidance on translating and implementing the legal criteria in this patient group. The Belgian Order of Physicians' provision of a medical code of conduct recommending more stringent procedural criteria was experienced as 'reassuring' to counter witnessed misuses (as physicians can be suspended). For others, this and other guidelines are deemed insufficiently helpful in terms of some passages being redundant, unpractical or vague (e.g. to what extent do physicians 'have to take negative advices into account') or lacking in areas (e.g. aftercare for patients with rejected requests is not addressed). Some criticized the existence of multiple guidelines as it jeopardises uniformity. Some even consider these initiatives as discouraging physicians to engage in euthanasia assessment procedures as the additional criteria expand the workload (e.g., the recommendation of a roundtable discussion with all physicians involved).

Most participants referred to the negative impact of recent court cases, the seventh theme, in terms of 1) its factual dissuasive effect on (colleague-) physicians' engagement in euthanasia procedures and as a consequence, an increase of patients in already overburdened end-of-life consultation centres, 2) its devastating impact on patients with their request under review, as increased suicidality and even involuntary admission to a psychiatric ward had been reported. Some physicians involved would have suddenly imposed additional criteria going far beyond the ones stipulated in the guidelines (e.g. written agreement from relatives) or withdrawn from their engagement, 3) the legal uncertainty, e.g. on whether or not physician-assisted suicide is part of the law on euthanasia and hence, whether or not it should be reported to the Federal Evaluation- and Control Commission on Euthanasia, and 4) the missed opportunity for a more nuanced euthanasia debate as strong proponents and opponents were pitted against each other.

Finally, when a euthanasia procedure culminates in the performance of euthanasia, the eighth theme, most participants reported that it happened in a serene atmosphere, in which the patient was surrounded by their relatives, who in turn expressed their gratitude to the participant involved. Some unfavourable experiences were also noted on a personal (e.g., the arm-needed patient's

sudden change of mind), social (e.g., lack of serene atmosphere), and a practical-technical level.

Support needs

Eight support needs are distinguished and listed in Table 3. In what follows, we discuss these 8 themes, in sequential order.

As regards theme 1, most of the participants, among whom well-trained physicians and nurses, plead for specific assessment approaches for the following specific patient groups: (1) patients with intellectual disabilities, (2) patients suffering from comorbid disorders and complex clinical pictures, (3) interneers, (4) foreign patients, (5) young adults, and (6) 'difficult patients', e.g., the manipulative patient.

Whereas the non-physicians reported needs for specific protocols to provide them and fellow colleagues with clear information on the euthanasia law and how to best deal with these euthanasia procedures (theme 2), some of the physicians and non-physicians pointed to the need of more practical guidance was needed on e.g., how to find a balance in the 2-track approach to avoid tunnel vision towards death (theme 3).

As regards theme 4, future updates of the guidelines for physicians need to cover areas that are still lacking, e.g., the (after)care for patients with euthanasia request rejected and withdrawn.

Moreover, some non-physicians proposed organisational policies improving, assisting, and supporting them e.g., to help them deal with own grief and emotions (theme 5). To date, the interviewed psychiatric nurses could only rely on suicide prevention policies within their walls. In the event of a suicide death within their walls, this can be discussed and borne *jointly* during team meetings. The opposite occurs if the euthanasia procedure is completely outsourced, precluding such team reflections and support, in turn inflicting an emotional toll on these care workers which in some cases caused these care workers to question their own competence. In such cases, these caregivers went through a difficult grieving process, inciting them to seek external professional help, to take a professional time-out or even to consider a new job.

And I started having doubts about my role as a care worker and so on, and well, that went reasonably well but then she died and I think a year ago, I went to see a psychologist to deal and cope with this, till now. Well, I've been through a lot with this young woman, right, with her attempts to hang herself and her destructive behaviour, I am glad that I can admit to myself that it is okay to go to someone and to talk about it, to discuss it there for a while, and to process and digest it because yes, I do have a sort of 'hangover' and I think that it will always feel like that. (...) But about your own wellbeing, uhm, within such a context, if you lose a patient to suicide, there's a procedure in place where you are allowed to see a psychologist or a psychiatric nurse for three sessions, for example. In the event of suicide, there is a team to which you can go to, but in the event of euthanasia there is no such team.

(psychiatric nurse)

In addition, an ethical debate on the content and interpretation of the recommended 2-track approach and stronger relatives' involvement was deemed needed (theme 6). Examples cited by participants pertained to e.g., exploring the *life track* in light of patients' right to refuse treatment, or involving relatives while patients can legally enforce non-disclosure to relatives.

The need for more educational initiatives (theme 7) was expressed on the regular academic curriculum of all health care professionals (e.g., physicians, psychologists, nurses, social workers). LEIF training should include more training hours on euthanasia requests based on psychiatric conditions, with emphasis on both the hitherto strict due procedures as well as the broad spectrum of rehabilitation. Specific training for volunteers was deemed needed to help them to define their role and responsibilities and to set boundaries.

Finally, more budget for the underfinanced psychiatry is highly needed, including financial resources for proper palliative and rehabilitation approaches in psychiatry (theme 8).

Of course, palliative and rehabilitation approaches follow the same direction; they try to enhance the quality of life. You know, traditional psychiatric therapies are not always tailor-made. If you enter a psychiatric hospital, you must follow their programme, you have to go along with their programme, and if you don't go along with the programme, for example, then they tell you: 'We don't think this treatment is something for you.' and you can go. That's why the importance of tailor-made care cannot be overestimated. That is our basic principle. There is nothing more exciting than to see what the best possible therapy programme is for each individual, and then to refine it along the treatment trajectory. The problem is that there are not enough resources and personnel to do more refining. There are successful therapy models, and I think a lot of so-called rehabilitation departments or recovery departments in traditional institutions are doing everything within their power. But the more traditional departments are not doing so very much.

(Expert-by-Experience)

Discussion

This in-depth interview study among health care professionals and volunteers aimed to explore their concrete experiences and support needs regarding the euthanasia trajectory in the context of adult psychiatry. Their concrete experiences were categorised in eight overarching themes and resulted in their reporting of eight support needs. We'll discuss the following 3 main findings: 1) the use of the guidelines and its recommended two-track approach, 2) the unfavourable experiences and urgent needs of non-medics, with an emphasis on the needs of those working in residential settings, and 3) the particular situation in Belgium following the euthanasia trials.

Table 3: Support needs regarding euthanasia in the psychiatric context¹

TOPIC	REPORTED SUPPORT NEED
protocols for specific pathologies/sub-populations	<p>Specific protocols for adequate assessment regarding the following sub-populations:</p> <ul style="list-style-type: none"> - Patients with intellectual disabilities (P) - Patients with comorbid disorders/complex clinical pictures (P) - Internees (due to the specific environmental context) (P) - Foreign patients (due to e.g. lack of a juridical framework and the many administrative, practical, linguistic, cultural barriers) (P) - Young (<30 or at least <25) patients (C) - Guidance on how to deal with 'difficult patients', e.g. the somatising/manipulative/aggravating ones (P)
Protocols specifically for non-physicians involved (C)	<ul style="list-style-type: none"> - Clear information on the euthanasia law and procedure - How to balance confidentiality/secretcy towards physicians (cf. suicide) - How to assume role as caregiver vs. friend (positioning toward the patient)
implementation of the 2-track approach (P)	<ul style="list-style-type: none"> - Guidance and interpretation of the 2-track approach, e.g., Should these patients be obliged to continue treatment in the life-track, as this would violate the patient's right to refuse treatment? - Practical guidance on how to implement/find a balance in the 2-track approach to avoid tunnel vision towards death
(After)care for patients	<ul style="list-style-type: none"> - More elaborated guidance on care/aftercare for patients with withdrawn euthanasia requests or with euthanasia request rejected
(After)care for non-physicians (C)	<ul style="list-style-type: none"> - Organisational policies on improving, assisting and supporting the caregivers involved in more effective ways
Involvement of patient's social inner circle	<ul style="list-style-type: none"> - More practical and ethical guidance on their (extended) involvement, the viability/feasibility of involving the patient's relatives on who should be informed and the extent of their involvement in the euthanasia procedure
Education	<ul style="list-style-type: none"> - On the academic curriculum of all health care professionals: all EOLC options, including 'euthanasia and psychiatry' - LEIF: more training hours (than 1,5 hour) needed on 'euthanasia and psychiatry', with emphasis on both the hitherto strict due process as well as the broad spectrum of rehabilitation - Specific training for Volunteers (C): role definition and responsibilities
Financial resources and staff	<ul style="list-style-type: none"> - More budget for mental health care <ul style="list-style-type: none"> > More incentives for proper palliative care for the mentally ill > More incentives for holistic therapeutic and rehabilitation approaches in psychiatry

¹ (P) when the information was only mentioned by physicians and (C) when only mentioned by other care workers

Our interview study followed a period in which multiple guidelines and a medical code of conduct were published, to allow these euthanasia cases to be dealt with adequately. Most of the participants experienced the guidelines helpful for euthanasia assessment but questioned whether the one-fits-all approach can be applied in the medical subdiscipline of psychiatry. They expressed the need to diversify for certain psychopathologies and subpopulations, e.g., the younger generation of patients. This issue seems even more relevant, since the recent study of the Dutch centre of Expertise in Euthanasia revealed the trend of an increasing proportion of younger mentally ill requesting euthanasia.¹³⁰ Also, in line with a previous article that made a critical point-by-point analysis of the guidelines³¹⁰, our findings confirm the value of and appreciation for the two-track approach as it may avoid the excesses of a narrowed focus on one single track. Nonetheless, our study found a need for more guidance on correct interpretation and proper implementation of the two-track approach. For instance, issues emerged on how to handle the tension between both tracks in the most effective manner, given the experience that exploring the euthanasia request may empower some patients but may discourage others to give alternatives for death a fair chance of success.

Only one Belgian previous study addressed psychiatric nurses' attitudes and experiences regarding the issue and showed that half of the responding psychiatric nurses had frequently been directly confronted (and 69% indirectly informed) with euthanasia requests predominantly based on psychiatric reasons.¹⁸⁴ Our paper is the first to capture their experiences and needs more in-depth as well as those of many other mental health care workers who are underrepresented in research. As these people often spend more time with the patient (often also with the patient's most involved social inner circle) than physicians normally do, they can be considerably affected by these euthanasia trajectories. Even though all these mental health care workers appreciated the close(r) and deep(ened) relationship with the patient and considered their challenging work an act of meaningful care, most of them reported a lack of education and skills on this matter. In (residential) settings that 'outsourced' euthanasia requests, these care workers faced distress that could exceed their own coping capacity, causing some to question their professional competence. In the event of these euthanasia cases being carried out, the care workers feeling

side-lined during the euthanasia trajectory faced 'disenfranchised grief', grief when incurring a loss that is or cannot be openly acknowledged, validated, and mourned due to (perceived) social norms. Disenfranchised grief is not specific for the euthanasia practice in the context of adult psychiatry, as it is seen in health care workers, after being faced with patient deaths in a palliative care, suicide or covid-19 mitigating context.³⁵⁷⁻³⁶²

Third, and on a broader societal level, this interview study was conducted during a time of increased media attention and debate, following one euthanasia case where physicians stood criminal trial (see BOX 1 at the end of this Chapter). Although increased attention and critical reflections are essential to identify shortcomings and to improve the practice, the Belgian practice seems to be confronted with a negative pendulum swing. None of the participants reported such events to be beneficial, as it complicated or even compromised a serene work atmosphere for physicians engaging in the euthanasia practice. This seems to have resulted in a growing reluctance to engage in euthanasia assessments, evidenced in a recent survey among experienced physicians.³⁶³ A similar trend was observed in The Netherlands.^{171,364} Conversely, those who welcomed the practice being subjected to heavy scrutiny, expressed disappointment that it had not led to a thorough evaluation of euthanasia in adult psychiatry after the trial(s).

Strengths and limitations

This is the first in-depth study that uncovered the concrete experiences and support needs of a variety and relatively large sample of health care professionals and volunteers, with the inclusion of buddies, spiritual consultants, and expert by experience, who are specifically trained and/or experienced in supporting these patients during their euthanasia trajectory. We succeeded in providing a unique and representative sample of participants, varying in gender, age, work setting, expertise and concrete experiences in the euthanasia practice in the context of adult psychiatry.

Our study has also some limitations. Selection bias may have occurred. For instance, there is evidence of the younger generation of psychiatrists being confronted with and (willing to be) engaged in euthanasia assessment procedures^{281,282} but we did not succeed in holding interviews with them. Our

sample of non-physicians did vary in age, but the sample of physicians did not, with most of the physicians older than 60. Finally, due to covid 19-restrictions and potentially also due to the legal and emotional consequences regarding one high-profile euthanasia case being brought to court, a few planned interviews were postponed and ended up cancelled. This led to the voices of e.g., psychologists working in residential psychiatric settings, to be missed.

Implications for future research, policy, and practice

As regards research, more insight is needed on the (dis)advantages of the two-track approach in terms of assets, premises, and potential pitfalls. Our study suggests that the outcome of this two-track approach may be related partially to patients' characteristics. It can also be related to the practical modalities of its implementation in the practice as well as to the feasibility of its implementation in diverse psychiatric settings. For instance, if and to what extent would it be beneficial for the patient (and fellow peers) to have the euthanasia request explored within and/or outside a residential setting? Why are such euthanasia requests outsourced? Why did some participants report being side-lined?

Also, given that these euthanasia trajectories and their outcomes affect so many actors directly or indirectly involved, future focus group studies bringing both the patient population and the health care team, including the patients social inner circle, together, may elucidate how and to what extent one can address and meet other actors' needs. Particularly the perspective of patients' social inner circle is missing, while a Dutch study found a considerable role in and impact of the euthanasia trajectory for them.³⁶⁵

As regards practice and policy, the problem of 'outsourcing' deserves the fullest attention. Not only because our findings reveal that the (understaffed) end-of-life consultation centres are overburdened with patients on growing waiting lists (the same trend is reported in The Netherlands³⁶⁶), but because this outsourcing may be in disagreement with the spirit of the euthanasia law or a shirking of medical responsibility. If the psychiatric nurses from a residential psychiatric setting are indeed side-lined concerning the euthanasia trajectory of an in-home patient, this may have been a violation of the law, that stipulates the consultation between the physician and (members of the) nursing team mandatory if the latter is in close contact with the patient.¹⁸⁵ Also, more resources are needed for

psychiatry to develop proper and sufficient rehabilitation, recovery and palliative care options to strengthen the health carers' capacity to effectively explore the *life track*. In addition, the guidelines' recommendation for strict procedural steps, e.g., the two-track approach, the involvement of all health carers in close contact to the patient, and the involvement of the patients' social inner circle needs to be elaborated in more detail, with respect to feasibility and risks involved, e.g., of violating patients' rights to confidentiality and privacy.⁶¹ Furthermore, our findings revealed that the handling of euthanasia requests require specific knowledge and a range of skills that are not (sufficiently) included in neither the existing academic curricula nor the existing training initiatives. Last but certainly not least, euthanasia policies should also address the need to recognise, validate and address grief in the work context, to properly prevent and manage disenfranchised grief and related consequences, e.g., fatigue, burnout, and low-perceived work ability.

Conclusion

This study yielded insight into the many positive and negative experiences of a variety of health care workers in dealing with euthanasia requests in adult psychiatry. They reported several support needs across the extensive euthanasia trajectory, pertaining to concrete management of thorny issues that guidelines do not (yet) touch on or only superficially. Suggestions to enhance the euthanasia practice relate to tackling these existing issues, to enhancing education and training, to promoting incentives for psychiatric palliative and rehabilitation care approaches, and to paying sufficient attention to the impact of a euthanasia trajectory on all actors, including the patients and their social inner circle, involved.

BOX 1: Milestones in the euthanasia practice in Belgium:

End-of-Life Information and Consultation Centres
<p>I) Recht op Waardig Sterven (Right to Die with Dignity) In the first half of the 1980s, Right to Die Organisations were founded in the Flemish and French-speaking part Belgium, namely <i>Recht op Waardig Sterven</i> (RWS) and <i>L'Association pour le Droit de Mourir dans la Dignité</i> (Association for the Right to Die with Dignity). Their activism resulted in several legislative proposals on euthanasia legislation from 1984 onwards. Since euthanasia enactment, their activism relates to e.g., informing individuals on the medical end-of-life options in Belgium and support them with the administrative paperwork surrounding (some of) these options.</p> <p>II) LEIF (Life End Information Centre) The Right to Die Organisation RWS founded the Flemish organisation Life End Information Forum (LEIF) in 2003. LEIF provides e.g., training for physicians and nurses to increase their knowledge on end-of-life legislation and how to implement it in practice and training for physicians to act as advising or performing physician. LEIF developed and published guidelines on how to handle euthanasia requests and to perform euthanasia.</p> <p>III) End-of-life consultation centres LEIF established three end-of-life consultation centres (ULteam in 2011, LEIF Western-Flanders in 2013 and LEIF.Ghent in 2015) with the aim to effectively engage in euthanasia assessment procedures, especially for those patients confronted with a neglected euthanasia request. These consultation centres consist of an interdisciplinary team of physicians, psychologists, (psychiatric) nurses, ethicists, and legal experts, with extensive expertise in the management of complex euthanasia cases. Due to dissension on how to handle these cases, LEIF.Ghent has been deposed as regional LEIF centre and follows its own course as 'End-of-Life Questions Ghent' (publicly known as Vonkel) since 2017.</p>
Other initiatives
<p>I) REAKIRO Reakiro is a place in Louvain (2020) and West-Flanders (as of 2022) where all individuals considering euthanasia on grounds of unbearable psychological suffering, and their relatives, can go to. The primary focus of Reakiro is rooted in the rehabilitation approach, characterised by an active orientation towards life, towards (re)discovering meaning, purpose and hope in life, <i>without</i> excluding the option of euthanasia. This rehabilitation approach is founded on the following 4 main pillars to qualitative (end-of-life) care: the medical, psychological, social and existential care approach.</p> <p>II) REBEL REBEL is an activist group that consists of Belgian clinicians and academics of all disciplines and philosophies who express their concerns regarding the current euthanasia law and the euthanasia practice, especially in the context of adult psychiatry, and call for the exclusion of adults with psychiatric disorders as sole underlying condition, from access to euthanasia.</p>
Five organisations and their proposed guidelines regarding the management of euthanasia in the context of psychiatry
<p>I) The Organisation Brothers of Charity The congregation of the Brothers of Charity was founded in 1807 as the starting point for the development of a comprehensive mental health care network. Nowadays, the organisation of the Brothers of Charity provides mental health care in 13 psychiatric</p>

centres, 13 sheltered housing initiatives, and one centre for drug prevention and treatment. In March 2017, the organisation of the Brothers of Charity published its 'Vision on euthanasia for psychological suffering in non-terminally ill patients' to be applied in its centres.

II) The Belgian Advisory Committee on Bioethics

The Belgian Advisory Committee on Bioethics was established by the Federal Government in 1993. It has 70 members from different disciplinary backgrounds, including a range of other characteristics reflecting the Belgian population's diversity. In September 2017, its 'Opinion no. 73 – Euthanasia in cases of non-terminally ill patients, psychological suffering and psychiatric disorders' was published

III) The Flemish Association of Psychiatrists

The Flemish Association of Psychiatrists was founded in 2004, with the aim to unite and represent all psychiatrists working in Flanders, to foster the quality of psychiatry as a mental health care specialism, and to inform the societal and political debate regarding psychiatric mental health issues. Close to 700 psychiatrists are associated members of the Flemish Association of Psychiatrists. In December 2017, the Association published its advisory text on 'How to handle a euthanasia request in psychiatry in accordance with the legal due care criteria?'

IV) Zorgnet-Icuro

Zorgnet-Icuro was founded in 2016, with the aim to unite and represent all privately and publicly funded social profit health care organisations in Flanders. More than 775 health care organisations are associated members of Zorgnet-Icuro. In January 2018, its ethical advice on 'End-of-life care for non-terminally ill patients with serious psychiatric disorders' was made public.

V) Belgian Order of Physicians

The Belgian Order of Physicians is an overarching institution that comprises all physicians (over 52,000) who practice medicine in Belgium, either temporarily or permanently. In April 2019, the Association published their deontological guideline a165002 on 'the euthanasia practice concerning patients whose mental suffering results from a psychiatric disorder'.

Court Cases

I) In 2015, the Belgian Federal Control and Evaluation Committee referred the first 'euthanasia case, predominantly based on psychological suffering' to the Belgian Public Prosecutor as not all the legal requirements were deemed met. In 2019, the performing physician was dismissed of further legal proceedings as the Public Prosecutor concluded that the physician's acting was not 'euthanasia' because the patient had drunk the provided lethal drugs herself, knowing it would immediately end her life. As the lethal dose was not injected by the physician, it was not considered 'euthanasia' but 'physician-assisted suicide'.

II) In 2018, three Belgian physicians faced trial before a public jury, as they were accused of unlawful actions during the euthanasia assessment procedure and/or the act of euthanasia itself. In 2020, all three physicians were acquitted from the Belgian court of assise, although the performing physician may still face a correctional sentence.

CHAPTER 12 : GENERAL DISCUSSION AND CONCLUDING THOUGHTS

Author:

Monica Verhofstadt

Everywhere one seeks to produce meaning, to make the world signify, to render it visible. We are not, however, in danger of lacking meaning; quite the contrary, we are gorged with meaning, and it is killing us.

Jean Baudrillard (Simulacra and Simulation)

This final part of the PhD-dissertation consists of: 1) a recap of the research objective and questions, 2) a discussion of the methodology used per research study, including its main strengths and limitations, 3) an overview of the main findings, 4) a discussion of a few important matters deserving the fullest attention, including recommendations for policy, practice and future research, and 5) concluding thoughts.

1. Research Objective and Questions

The overarching objective of this PhD was to establish a more thorough understanding of the euthanasia practice in the context of adult psychiatry.

The following research questions (RQ) were addressed:

Part One

RQ 1: What are the added value and potential shortcomings of the Flemish written guidelines on how to adequately deal with euthanasia requests and procedures in the context of adult psychiatry?

RQ 2: What are the added value and potential shortcomings of Ghent University Hospital's step-by-step protocol on how to deal with euthanasia requests from external facilities?

Part Two

RQ 3: How do adults suffering predominantly from psychiatric conditions, express the nature and extent of their suffering experiences, and what renders their suffering unbearable?

RQ 4: What are their motives for requesting euthanasia, how does it relate to suicide, and what would have prevented them to consider a hastened death?

RQ 5: How do they phrase the impact of the euthanasia procedure on their mental state, their clinical trajectory and their social relationships?

Part Three

RQ 6: What are psychiatrists' attitudes towards and readiness to engage in euthanasia assessment procedures and/or performance concerning these adults with psychiatric conditions?

RQ 7: To what extent have these psychiatrists been confronted with, and

engaged in the psychiatric euthanasia practice?

RQ 8: What can be learned from their latest experience with a completed euthanasia case (irrespective of its outcome)?

Part Four

RQ 9: How do healthcare professionals and volunteers phrase their concrete experiences and support needs regarding the euthanasia trajectory concerning this patient group?

2. Methodology

2.1. THE METHODOLOGY PLAN

The methodology plan consisted of:

- 1) A critical point-by-point reflection of the written guidelines (RQ 1),
- 2) A detailed description of the Ghent university hospital's step-by-step protocol (RQ 2),
- 3) A qualitative thematic analysis on patients' first-hand written or audio-recorded testimonials on what factors render their suffering unbearable (RQ 3),
- 4) A qualitative study for cognitive validity purposes regarding the assessment instrument on 'suffering' (RQ 3)
- 5) A qualitative in-depth interview study with adults requesting euthanasia, predominantly based on psychiatric conditions (RQ 4 & 5)
- 6) A quantitative survey study among psychiatrists affiliated to the Flemish Association for Psychiatry (RQ 6, 7 & 8)
- 7) A qualitative in-depth interview study with healthcare professionals and volunteers, dealing with euthanasia requests from adults with psychiatric conditions (RQ 9)

2.2. STRENGTHS AND LIMITATIONS

Part one: descriptive, critical review of the written guidelines

At the very start of the PhD trajectory, four written guidelines were published in a short period of time. Each of these guidelines primarily aimed to formulate concrete and practical advice to interpret, assess and manage all legal

requirements, and to put forth a series of additional recommendations going beyond these legal requirements. Whereas some of the guidelines were written from a more ethical value-driven approach, others were written from a more practical-implementation approach. In addition, whereas the guidelines contain operationalisations of and additional recommendations to the legal criteria that resemble the ones of the main Dutch guideline, there are differences. Moreover, the Belgian guidelines (slightly) differ from one another.

A critical review was deemed needed to figure a way through the jungle of different recommendations going beyond the legal requirements. The critical review also offered an opportunity to pinpoint the issues that did not provide sufficient guidance to practitioners and the pending issues that were simply not addressed.

Soon after this critical review had been published, the Belgian Order of Physicians (Orde der Artsen) came up with an additional guideline, more specifically a 'medical code of conduct' for physicians on how to deal with euthanasia assessment procedures in the context of adult psychiatry. Due to this overlap in time, the medical code of conduct was not included in the critical review study but will be discussed briefly in this final Chapter.

In addition, we also reviewed the protocol of Ghent University Hospital, that could be seen as an additional initiative for an easy and transparent procedural rule-following for the handling of euthanasia assessment and performance procedures concerning patients from outside their walls. This protocol is not unique. One previous (Dutch) article provided in a purely descriptive summary of the content of the three University Hospitals' protocols, including the Ghent University Hospital's Protocol.⁸⁹ Our paper (Chapter 3) is also descriptive in its essence, but provided more detailed insights in the underlying motives preceding and concerns surrounding the protocol. This additional background information had been gathered during a roundtable meeting with the members of the hospital's ethics committee that had taken the lead in the drafting of the protocol. Nonetheless, as the protocol had been drafted in 2008/09 and received the latest update in 2010, recall bias could have occurred i.e., the accuracy and volume of past memories may have been influenced by subsequent events and experiences, and may have led to participants omitting important details.

Finally, we have not gained access to other written hospital protocols, which had impeded an in-depth comparative analysis.

Part two: qualitative studies on patients' first-hand accounts

When a topic is about to be explored for the first time, qualitative research designs are more likely to precede quantitative ones. Qualitative research studies are simply better suited to explore the new topic of interest in all its aspects, to gain a more complete picture. In addition, qualitative research studies lead to a deeper understanding of human mental states and behaviours that quantitative approaches cannot match. As qualitative research approaches are not only focusing on *what* but also on *how* participants phrase their feelings and thoughts about the topic of interest, they allow researchers to unravel the most complex issues.

The main limitations of this qualitative research can be ascribed to 1) the small sample size, that compromises a claim to generalization, and 2) being more prone to subjectivity and interpretation biases, as the gathered information is subject of further 'interpretive' coding procedures.

These limitations can be minimized to some extent, by means of 1) the use of different qualitative research designs, preferably in more than one or a sufficiently extended research period, and 2) a balanced composition of the research team, with some researchers being more, or less, or not familiar with the topic of interest, the target population, the field of practice and/or the field of academic research. As regards the first, the strict inclusion and exclusion criteria in our research proposal, resulted in the fact that potentially important voices went missing. This concerned – inter alia – people not willing or capable to participate via face-to-face communication, for reasons of privacy and anonymity or their concrete affliction, and people that could no longer participate due to all-hens-on-deck approaches in covid pandemic-related circumstances. As regards the second, we succeeded in the set-up of collaboration partnerships, with authors of many disciplines, of different backgrounds, of whom some worked more hands-on, and others performed an inhibited critical review. We did everything within our power to have potential biases spotted and tackled.

Another issue concerned the complex research context. Two of the main ethical principles of doing research are beneficence and nonmaleficence. In layman's terms these concepts mean that the research (output) must be of (human) value and that the research may not purposely cause harm to potential participants. Asking this potentially extremely vulnerable patient group, who (may) already suffer unbearably, to spend their scarce energy to participate in scientific endeavours could be considered ethically questionable. One possible solution to avoid additional suffering or other burdens for these patients is analysing existing data. That is why the first research study (Chapter 4) made use of already written and video-recorded testimonials, for which the retrospective analysis could not incur any burden for this target population. The fact that patients had presented these testimonials in a spontaneous manner and thus, were not pressured to proceed their writing in any direction by the authors, enjoying total freedom to express and share their thoughts and experiences, may also have prevented bias, and in addition, resulted in very rich data.

An important limitation is that, as the (one-way) testimonials were provided spontaneously, they were profoundly and solely dependent on the individual communication skills of the patient. For some testimonials, the content was written so clearly that it indicated the nature and extent of the patient's suffering in detail, whereas other testimonials were written rather covertly, in a more poetic form. In addition, as patients were depending on the approval of one of the co-authors to get their euthanasia request granted, they might have felt urged to convince the author and overstate the underlying meanings of their euthanasia request as beyond their capacity to cope, while also potentially hiding some other information. Finally, the subtleties and complexities of this topic might not have been examined in such detail as could have been reached via supplementary (open-ended and prompting) questions provided in the method of in-depth interviewing.

As regards the study using cognitive interview technique (Chapter 5), due to the scarcity of studies among the population of patients with both psychiatric conditions and euthanasia requests, there was a lack of knowledge on how this patient population would cognitively and emotionally react during this research project. Therefore, we specifically gauged for participants' experiences on this matter and found that they highly appreciated being involved in the early phase

of instrument development (which was also reflected in the fact that most participants were willing to participate in a follow-up study). Participants acknowledged the study's value and relevance in lifting the taboo of psychiatric euthanasia requests. Participants with euthanasia requests even declared that the nature and duration of the cognitive interview offered them a degree of consolation as they could talk openly while being taken seriously in their unbearable suffering experiences.

Although in line with results of an interview study on respondents' satisfaction, summarised in terms of being heard and making meaningful, relevant contributions via trustful, respectful communication,²⁶⁹ these findings are remarkable as both the research team and Ethics Committees involved had concerns about possible negative consequences for these perceived 'highly vulnerable individuals'. Moreover, the fact that these individuals did not conceal certain aspects of their suffering but clearly discussed even the most sensitive issues emphasizes the value and necessity of keeping them involved in further research endeavours. Also, our study did only study the impact on participants in the short term, based on what the participants told the interviewer. Hence, the impact on the longer term and the risk of social desirability was unclear.

Then, the research team designed a research protocol for in-depth interviews (Chapters 6 & 7), that included measures to meet the ethical criteria of beneficence and nonmaleficence. For instance, the protocol prescribed that a psychiatrist should be on call during interviews, that the interviews should be conducted by clinical psychologists, who were not involved and not able to intervene in the patient's euthanasia trajectory (also to minimise response bias), and that the (mental) safety of the potential participants after the interview should be safeguarded by the provision of the contact details of the research team as well as emergency numbers, to be contacted in case of doubts, bad feelings or further questions.

The qualitative in-depth interview studies resulted in rich data and additional insights in the euthanasia practice. Moreover, and in contrast to previous research, the sample can be considered more heterogeneous as the patients were not recruited by one single practitioner. The main limitation of the in-depth interview study is that selection bias may have occurred due to 1) the researchers having limited control over sample selection; and 2) the study being

conducted during a time in which euthanasia in one adult with psychiatric conditions was under heavy public and professional scrutiny, with a criminal trial related to euthanasia for these patients, and while several guidelines³¹⁰ and an official medical code of conduct³¹¹ – imposing additional due care requirements – had been issued.

As regards the heterogeneity of the sample, the main limitation is that the whole patient group was lumped together, and we were not able to differentiate between e.g., the different age categories or the nature of patients' psychiatric conditions. Finally, a limitation of the study on the impact of the euthanasia trajectory (Chapter 7) is the potential lack of thematic saturation per outcome (i.e., neglected, rejected, in review, granted, or withdrawn) of the euthanasia assessment procedure.

Part three: a survey study among psychiatrists

In this PhD, we developed a research method to gauge psychiatrists' attitudes and the extent of their involvement in euthanasia trajectories in the context of adult psychiatry. Before, only the Netherlands provided information from a quinquennial evaluation and survey studies,^{88,169} followed by recent cross-sectional survey studies from Canada and Switzerland.^{321,331}

Our survey instrument was based on the already existing Dutch one for research and legal evaluation purposes¹⁶⁹ to enable comparison between the results gathered in both countries. However, as the legal framework differs among both countries, the survey had been adjusted to the Belgian legal context. In addition, the Dutch survey consisted of 12 pages and the research team feared that presenting so many pages to be filled in, would reduce the chances to obtain a fair response rate. For instance, the most recently conducted Dutch survey resulted in more detailed information on 9 granted euthanasia requests. We assumed that this low number could be due to the burden of presenting a survey with so many pages to be filled in. Therefore, we decided to develop user-friendly questionnaires, asking a minimum of time and effort from (assistant-) psychiatrists while still yielding the most relevant information for adequate scientific understanding of Flemish psychiatrists' perspectives and practice.

At first and in consultation with three experienced psychiatrists of the Flemish Association for Psychiatry's member board, many items were deleted. The decision was made to divide the survey in two parts: one general part to be completed by every psychiatrist and psychiatrist assistant, irrespective of them being involved in concrete euthanasia cases, and a facultative part focussing on the last concrete involvement in a euthanasia case. Most items consisted of check-box answers, with a minimum number of items containing open answer categories. Finally, the survey draft was presented at a meeting with 15 (assistant-) psychiatrists of the psychiatry ward of the Ghent University Hospital for basic cognitive validation, i.e., to gain unprejudiced feedback on acceptability regarding length, form and content, and exclusion of social desirability.

Nonetheless, and although we did everything within our power (and limited time) to carefully construct and pre-test the survey, the possibility of misunderstandings as regards item interpretation could not be excluded. And although we succeeded in obtaining a response rate of 40%, which is fairly good considering the target group of psychiatrists and the delicacy of the topic,³³⁷ the findings cannot readily be generalized to the full population of psychiatrists in the Dutch-speaking region of Belgium, and must therefore be interpreted with caution. We could have missed the answers of psychiatrists, positioned at either end of the euthanasia debate, the ones being strongly opposed to critical reflections on today's euthanasia practice versus the ones being strongly opposed to the study and its set-up. As for the latter group and to give an example of how complicated the research context is, the executive researcher had been contacted by phone and informed that some people were calling around to discourage colleagues from participating and hence, to prevent the study from being published due to an unacceptably low response rate.

In each case, the risk of a biased sample as such was perceived as minimal, as the database membership comprises an estimated 80 to 90% of all Dutch-speaking psychiatrists. In addition, if we were to extrapolate our sample of responding psychiatrists, with the total sample of Dutch-speaking psychiatrists working in adult psychiatry, it would mean that we have reached close to one third (184/600) of all Dutch-speaking psychiatrists.

Part four: a qualitative study on the concrete experiences and support needs of health care professionals and volunteers

This is the first in-depth study that uncovered the concrete experiences and support needs of a variety and – to existing standards of a sample of 15 to 20 participants in interview studies – relatively large sample of 30 health care professionals and volunteers. Moreover, we had the opportunity to hold interviews with people who are largely unknown to most of the international readership: namely buddies, spiritual consultants, and experts by experience, who are specifically trained and/or experienced in supporting these patients during their euthanasia trajectory. We succeeded in providing a unique and representative sample of participants, varying in gender, work setting, expertise and concrete experiences in the euthanasia practice in the context of adult psychiatry.

Nonetheless, selection bias may have occurred; as most of the physicians were older than 60, we have missed the voices of the younger generation. In addition, due to covid 19-restrictions and potentially also due to the legal and emotional consequences regarding one high-profile euthanasia case being brought to court, a few planned interviews (mainly with psychologists) were postponed and ended up cancelled.

3. SUMMARY OF THE MAIN FINDINGS

3.1. PART ONE: THE WRITTEN INITIATIVES

The point-by-point analysis (Chapter 2) showed that – broadly speaking – the written initiatives based their suggestions on the operationalization of the legal criteria on the Dutch guideline. All written initiatives also advocate additional due care criteria, e.g., the mandatory consultation of not one, but at least two psychiatrists, and the establishment of a two-track policy whereby the focus is given both at the *life*-track (in terms of an assured treatment continuity of the patient's psychopathology on the one hand and exploring rehabilitation options on the other) and the *death*-track (in terms of clarifying the patient's motives behind and eligibility for it, and cautiously complying to the legal and preferably also to the suggested additional procedural criteria). All the initiatives aimed to

provide useful advice for adequate decision-making in a multidisciplinary team. Most of the initiatives also mentioned the importance of a stronger involvement of and the provision of aftercare for the patients' next of kin.

Despite this overlap, differences in the recommendations were also noted. These were attributed to differences regarding its purpose (for practical-clinical versus ethical reflection purposes) and regarding the value-driven framework surrounding it (e.g., a religious versus secular framework). The most notable differences between the compared initiatives relate to e.g., the recommendation (not) to establish an a priori evaluation system and to ensure a mandatory period of reflection between the euthanasia request and its performance (from maintaining the legally required 1 month waiting period to extending it to 6 months or one year).

Shortcomings of the initiatives relate to the lack of recommendations towards 1) how contradictory formal advices from fellow advising physicians on the patient's euthanasia request have to be dealt with; 2) the (after)care for patients, especially in the event of increased suicidality and for those whose request for euthanasia would end up rejected; and 3) how the role and position of patient's relatives should be concretised.

Chapter 3 reveals how the Ghent University Hospital was contacted by a neighbouring psychiatric hospital with the question whether the hospital was willing to handle euthanasia requests and procedures from outside within their institution. This challenged Ghent University Hospital's ethics committee to also consider developing a written policy for the management of euthanasia requests referred to them from any outside facility or institution, based on their 'pluralistic stance' on medical ethical topics but with a clear internal objective in mind: to protect the employees of their department of psychiatry against a possible 'inundation' of 'difficult-to-treat patients' from outside their walls.

The protocol introduces the following 3 additional due care requirements:

- 1) the consultation of their medical ethics committee at each step within the protocol, giving their (non-binding) advice to the psychiatrists involved,
- 2) the entering of a two-track policy 'avant la lettre', which allows the patient's treating psychiatrist to focus on the clinical trajectory and thus the life track, and the Ghent University Hospital's psychiatrists to focus on the death track. That

said, the patient's psychiatrist must engage to a bare minimum (i.e., being at least *passively* involved during the euthanasia assessment procedure and *actually* present when the euthanasia would be carried out) and,

3) the need to obtain 'positive opinions' from at least 3 psychiatrists, of whom at least 1 psychiatrist is affiliated to another university hospital²³.

This protocol goes beyond the legal requirements, given that there are at least 4 psychiatrists involved in the euthanasia trajectory: the patient's treating psychiatrist, the attending psychiatrist (entrusted with the clarification of the euthanasia request) and the two advising psychiatrists (entrusted with the formal advice on the euthanasia request). In addition, the members of the medical ethical committee are also entrusted a(n informal) role too.

The added value of the protocol can be summarized as follows:

(1) the entering of the two-track approach, that offers a way out for psychiatrists working in settings where these requests cannot be managed; it also offers out-patients specialised support and guidance during the euthanasia trajectory without being deprived of therapeutic care. This is of utmost importance as anecdotal and recent scientific evidence (see Chapters 4, 6-7) revealed that an unknown proportion of patients had been excluded or dismissed from psychiatric stays or ambulant treatment, or felt threatened with involuntary commitment, once they requested euthanasia or when a euthanasia procedure was initiated.

(2) the protocol offers a uniform and transparent tool to the psychiatrists engaged in the euthanasia assessment procedures;

(3) it guarantees that the burden of the euthanasia procedure does not fall squarely upon their own psychiatrists (and their anaesthesiologist entrusted with its performance). As regards the latter, the low number of euthanasia requests ($N = 12$) and carried out case ($n = 7$) may suggest that it did prevent an influx of 'difficult-to-treat' patients. The low numbers may also be partially due to the number of institutions that were already prepared to allow euthanasia within their walls and the existence of autonomous end-of-life consultation centres, that have been established from 2011 onwards.

²³ Recent anecdotal evidence revealed that this psychiatrist must no longer be affiliated to a university hospital per definition but can also be affiliated to a general hospital.

Nevertheless, the protocol also has some shortcomings. For instance, the fact that the attending psychiatrist is not involved in the life track could have as an unintended effect that alternatives, such as peer-support recovery-oriented groups, remain underexplored. In addition, the protocol may focus too much on the needs of psychiatrists involved. By contrast, nothing is written on the patients' needs during the euthanasia assessment procedure regarding communication and expectation management (i.e., how to anticipate, clarify and address unrealistic patient expectations, such as the belief that the consultation of a third psychiatrist is a mere formality). Moreover, nothing is written on the patients' and their social inner circle's needs after the procedure, as the protocol envisages neither follow-up appointments after a 'rejection' nor 'a concluding conversation' to the bereaved.

3.2. PART TWO: THE PATIENT'S PERSPECTIVE

3.2.1. *The key criterion 'unbearable suffering'*

The first study (Chapter 4) aimed to provide insights into the suffering experiences with the use of a thematic analysis of 26 spontaneously presented testimonials on how these individuals perceive their suffering. This qualitative thematic analysis revealed that five domains of suffering could be distinguished based on their causes: medical, intrapersonal, interpersonal, societal, and existential. The experience of hopelessness as important contributor to the unbearability of the suffering experience was confirmed.²⁵⁰ A novel additional finding was that the euthanasia procedure itself added extra suffering to the already existing suffering experiences of some patients, due to the reported lengthy duration of and lack of transparency during the procedure, physicians' incomprehension regarding the euthanasia request, and the long-lasting search for physicians willing to accept the euthanasia request and or to perform the euthanasia. On the other hand, encountering physicians who take the euthanasia request seriously was reported as something that made some individuals re-explore new treatment and thus life perspectives.

As a result of this study, a list of aspects defining the nature of patients' suffering as well as a list of descriptors patients used to describe the extent of their

suffering was now available. These lists served the follow-up research purpose of developing an instrument to assess the nature and extent of suffering (Chapter 5). Cognitive validity was established via two rounds of cognitive interviews with adult individuals, all predominantly suffering from psychiatric conditions, some with and others without an (actual) euthanasia request. Results revealed that after completion of a first round of cognitive interviews, most of them perceived the initial NEOSi version as insufficiently comprehensible, non-exhaustive, imprecise, and illogically structured. The initial draft of the assessment instrument to be, was adjusted according to their feedback, which allowed for a further optimisation of its cognitive validity via a second round of cognitive interviews. The results indicated that participants perceived the items of the adjusted NEOSi as sufficiently comprehensible, sensitive to delicate nuances, and all-inclusive. The answer options were perceived as easy and more precise to answer. In addition, a commonly shared preference on layout, item sequence and logical structure was distinguished. Specifically, participants expressed appreciation for the length, explaining that other, shorter questionnaires were often perceived as insufficiently addressing the core of the matter.

3.2.2. Reasons for considering euthanasia, how it relates to suicide, and protective reasons from pursuing a hastened death

As regards the motives for requesting euthanasia (Chapter 6), most of the 16 participants phrased that they felt emotionally worn-out because of the many accumulated misfortunes and setbacks, leading to the all-pervasive sense that life is no longer worth living. However, the abovementioned external resources of lifelong adversity did not appear in all cases. Whereas some reported a lifelong struggle with daily life stressors and social interactions (often the case for participants with neurodevelopmental disorders), others struggled predominantly in later life due to various life stage transitions. Finally, some reported looking back on their life with satisfaction, and struggled merely from their deteriorating medical condition.

Differences also emerged as regards the meaning of euthanasia and how it relates to suicide. Whereas some participants strongly longed for death, others expressed ambivalence towards death ideation, and some even requested euthanasia hoping to be found ineligible, to restore hope and to (re)find meaning

in life. All participants initially valued euthanasia over suicide as being more dignified and acceptable, both for themselves and for their inner circle. Most of the participants, however, kept considering suicide as an option to hasten their death – be it as a plan B should their euthanasia request be denied or the procedure take too much time, or as plan A provided they e.g., gain access to the lethal means or/and become better informed on how to successfully commit suicide).

Regarding protective factors, most of the participants posited the need for improved accessibility and quality of mental healthcare, as well as a profound change in society's perception of, and support for, them and other fellow patients. The most heartfelt plea voiced by the participants was their perception of psychiatry offering a plethora of care options for the easy-to-treat, at the detriment of the so-called difficult-to-treat, i.e., the ones suffering from severe and persistent, often comorbid, illnesses for many, many years. Other heartfelt pleas concern the urgent need to invest in better youth care services, and for more open dialogue instead of perceived authoritarian approaches in youth and adult psychiatry.

3.2.3. The impact of the euthanasia trajectory

The final research question addressed the impact of the euthanasia assessment procedure on the patients' mental state, their clinical trajectory, and their social inner circle.

As regards the impact on patients' mental states, results show that all participants clearly benefited from being listened to, being recognised in their suffering, and valued as a person and having their euthanasia request being taken seriously. This finding confirms the so-called 'therapeutic effect' of euthanasia assessment procedures as it may suppress suicidal ideation and behaviour^{126,172} and may even offer sufficient peace of mind to give alternatives to death a fair chance of success once their request is positively advised or granted.^{126,172} However, this does not apply in all cases and if so, it only seems to have an ephemeral effect, as most patients struggled with ambivalence, irrespective of the (provisional or final) outcome of their euthanasia assessment procedure.

Ambivalence was present on three counts. First, whereas some participants longed for death, others struggled with death ideation resulting from not wanting to continue the life they were living or requested euthanasia in order to know their ineligibility for it. As seen in the literature regarding suicidology, death seeking behaviour can be seen as a cry *of* unbearable pain, a cry for extended help in life or a cry for help to exit life. Second, reported ambivalent feelings toward euthanasia and suicide suggest that patients view both as means to the same end, with euthanasia being more dignified and preferable than suicide but very difficult to obtain. Thirdly, this view of euthanasia being more dignified changes for some participants during the euthanasia procedure, once they realised that they were in control of neither the euthanasia procedure nor the outcome, which leads them to doubt whether euthanasia is a dignified way of dying for them and in some cases even to reconsider suicide.

As regards the impact on the clinical trajectory, the main finding is that the treating physician's rejection of the euthanasia request does not necessarily compromise therapeutic treatment, provided there is: 1) good physician-patient communication in which the reasons behind the rejection are well-motivated, 2) a meaningful referral, and 3) openness to discuss the (ambivalence toward the) death ideation and the euthanasia procedure in upcoming therapeutic sessions. In contrast, neglecting the euthanasia request seems to have only unfavourable consequences, e.g., the scenario of losing the patient to either another therapist or to death.

As regards the impact of the euthanasia trajectory on the participants' social relationships, divergent discourses emerge: from initially wanting and/or valuing some relatives being involved in the euthanasia assessment procedures to strongly opposing their involvement, and from the experienced rehabilitation of existing troubled social relationships or broken relationships to completely the opposite when experiencing a decreased sense of belonging or an increased feeling of being 'alienated'.

To conclude, the findings shed light on the enormous complexity of euthanasia. This is partially due to the diverse patient group. For instance, during the interviews and the coding procedures, the researchers observed noticeable differences between the subgroup of participants with and without neurodevelopmental disorders in e.g., how they presented and reflected on their

suffering. The complexity is also partially due to the euthanasia trajectory being perceived – even by those who had their request granted – as an emotional tug-of-war, due to the many self-disclosures and ‘pleas’, to (the difficulties to deal with) outcome uncertainty, and the suspicion of unequal assessment procedures. The latter may point to a tension between the physician’s autonomy to just stick to the legal framework without opting for stricter conditions and other physicians requiring additional criteria are fulfilled, and the burden of these (inconsistent) procedures on the patient.

3.3. PART THREE: THE PSYCHIATRIST’S PERSPECTIVE

3.3.1. Attitudes and preparedness to engage (Chapter 8)

The results revealed that three quarters of responding psychiatrists were in favour of keeping euthanasia as a legal end-of-life option for adult patients predominantly suffering from psychiatric conditions. Most of the participants were convinced that these patients can suffer unbearably (95%) and can find themselves in a medically futile situation (84%), and the absence of reasonable therapeutic perspectives (77%). Notwithstanding the large support for maintaining the option of euthanasia in the context of adult psychiatry, 7 out of 10 psychiatrists expressed concerns about today’s euthanasia practice in terms of due diligence and care in the assessment of a psychiatric patient’s euthanasia request. Half of the responding psychiatrists consider euthanasia assessment procedures compatible with a therapeutic relationship.

When confronted with euthanasia requests, the majority would refer the patient to a fellow physician for the further clarification of the request (e.g., to be enabled to focus on the patient’s treatment and thus life track) and approximately one third (especially the younger generation) would engage in the concrete assessment of euthanasia cases concerning psychiatric patients. Less than 10% would engage in the actual performance of euthanasia.

3.3.2. Concrete engagement (Chapter 9)

As regards concrete experiences, 80% indicated that they had been confronted at least once with an explicit euthanasia request from an adult psychiatric patient; 73% had even been engaged in the euthanasia trajectory, be it mainly

as referring physician. Half of the responding psychiatrists perceived themselves sufficiently competent to deal with euthanasia requests and procedures. Remarkably, only 5% indicated to have followed specific courses on medical end-of-life issues.

The main motives for engaging in these euthanasia assessment procedures were: 1) the patient's fundamental right to request euthanasia and the physician's duty to take these requests seriously; 2) the fundamental role of psychiatrists to engage in these procedures due to their specific expertise; 3) the opportunity that results from these euthanasia requests in terms of (further) actively exploring the (underlying) reasons behind the euthanasia request and (re-)evaluating the current treatment trajectory; and 4) the experience that some of these patients can be perceived as being and potentially remaining stuck in diverse life domains, which lowers their life perspectives to the extent that they can be perceived without any prospect for improvement.

Approximately 16% of the responding psychiatrists indicated that they were not willing to engage. The most important reasons for not referring a patient were: 1) the absolute belief that not all of the eligibility criteria had (yet) been met, and as a consequence, that there were still reasonable treatment options available; 2) fundamental ethical, moral or deontological reservations or even objections; 3) the patient's often complex medical, family and social situation; 4) psychiatrists feeling insufficiently competent to deal with such requests; and 5) previous experience with patients who had withdrawn their request for euthanasia themselves after spontaneous recovery, which resulted in the belief that the key criteria 'irremediableness' and 'constant and unbearable suffering' cannot be met in this patient group.

3.3.3. Case Reviews (Chapter 10)

The descriptive analysis on 46 completed euthanasia cases showed that in the majority of these cases, patients suffered from comorbid psychiatric and/or somatic disorders and has received different kinds of treatment over the course many years prior to them requesting euthanasia. Existential suffering, no prospect of improvement and loneliness were the main reasons surrounding their euthanasia request. Half of the reported euthanasia assessment procedures

culminated in the performance of euthanasia after at least two legally required advices were obtained, all positive bar one.

The whole procedure usually spanned double the amount of time when euthanasia was the outcome (13 instead of 6 months, except for some noticeable outliers). In all cases, the entire procedure entailed multidisciplinary consultations, including with family and friends.

Psychiatrists reported fewer difficulties in assessing due care criteria that could be ascribed directly to patients' characteristics, e.g., unbearable suffering or the voluntariness of the request, than when it could be ascribed to their medical condition, e.g., incurability by means of a lack of reasonable treatment perspectives.

In a few performed euthanasia cases, not all of the legal criteria had been sufficiently met in the responding psychiatrist's perception. Furthermore, both positive and negative experiences during the assessment procedure were reported, e.g., a reduced suicide risk vs. emotional burden and feeling pressured by the patient to approve euthanasia. Finally, our results revealed that in the majority of cases these complex euthanasia assessment procedures put a high emotional strain on participating psychiatrists.

3.4. PART FOUR: HEALTH CARE PROFESSIONALS AND VOLUNTEERS' CONCRETE (UN)FAVOURABLE EXPERIENCES AND SUPPORT NEEDS

The interview study among health care professionals and volunteers (Chapter 11) yielded insight into the many positive and negative experiences of a variety of health care workers in dealing with euthanasia requests in adult psychiatry. They reported several support needs across the extensive euthanasia trajectory, pertaining to concrete management of thorny issues that guidelines do not (yet) touch on or only superficially. Suggestions to enhance the euthanasia practice relate to tackling these existing issues, to enhancing education and training, to promoting incentives for psychiatric palliative and rehabilitation care approaches, and to paying sufficient attention to the impact of a euthanasia trajectory on all actors, including the patients and their social inner circle, involved.

One main finding is that the legalised option of euthanasia was experienced to work as a double-edged sword in the psychiatric practice: whereas it may encourage and empower some patients to also maintain the focus or to refocus on the *life track*, it may discourage or even further demoralise others, who feel less motivated to focus on the *life track* and are more swept into the *death track*. Experienced difficulties emerged on how this sword is to be handled. In this regard, the guidelines' recommendation for clinicians to make use of a 2-track approach (a parallel trajectory of seriously addressing and exploring the death request while also keeping the orientation towards rehabilitation) is reported to be of added value, but more practical guidance is deemed needed to walk the thin tightrope between both tracks in the most effective manner. In addition, most interviewees reported on the poor resources available to counterweight the death track as alternatives to death, as rehabilitation and palliative care approaches in psychiatry are still in their infancy.

Another main finding is that the position, role and needs of some paramedical personnel and other care workers seem to be overlooked. These care workers are often strongly involved in these patients' clinical trajectory and consequently, they can be strongly affected by the euthanasia trajectory. Even though these care workers all appreciated the close(r) and deep(ened) relationship with the patient and considered their challenging work as an act of meaningful care, they stress the need of specific protocols that are in tune with their specific needs. Moreover, and notably in psychiatric residential settings, the event of a euthanasia case being completely 'outsourced' is experienced as troublesome for these care workers, who feel side-lined and at the mercy of their intuition. In the event of the euthanasia case being carried out, they face disenfranchised grief, i.e. grief when incurring a loss that is or cannot be openly acknowledged, validated and mourned due to (perceived) social norms, e.g., the underlying assumption that only the closest social inner circle is allowed to experience and express actual grief or that mourning would discount to the professional image.

A third main finding is situated on a broader societal level and concerns the difficulty of working in the euthanasia practice during a time of increased media attention and debate surrounding carried out euthanasia cases standing the test of legal scrutiny. None of the participants reported these to be beneficial as they

complicated or even compromised the work atmosphere for those engaging or contributed to an atmosphere of reluctance to engage in euthanasia trajectories, and had a knock-on effect for patients with a euthanasia request under review. Finally, those who welcomed the practice being placed under more scrutiny, expressed being disappointed regarding the lack of ongoing, more nuanced, in-depth debate on euthanasia in the context of psychiatry, once the trial-induced heat had died down.

4. General Discussion of the Written Initiatives

4.1. COMPARING THE UNIVERSITY HOSPITALS' PROTOCOLS

Ghent University Hospital was not the only public hospital that developed a protocol regarding the management of euthanasia requests predominantly based on psychiatric reasons from people outside their walls of psychiatric wards.⁸⁹ The Louvain University Hospital also drafted their own protocol, with the inclusion of 3 additional due care requirements that are comparable to those of Ghent University Hospital. First, the protocol also includes the (non-binding) consultation of their Medical Ethics Committee at each step of the protocol. In addition, their protocol emphasises repeated multidisciplinary consultations and the involvement of not only the patient's treating psychiatrist, but also the patient's general practitioner who – in joint consultation – may decide where the actual euthanasia will be carried-out, by whom and by which means, as well as who will be present during the act of euthanasia.⁸⁹ In contrast, the University Hospital of Brussels did not include additional requirements, but collaborates closely with the interdisciplinary end-of-life consultation centre ULteam,⁸⁹ a neighbouring collaboration that is mirrored between the Ghent University Hospital and the end-of-life consultation centre in Vonkel. In the absence of perusal of these (neither publicly available, not in my possession) protocols, it is a matter of conjecture whether these protocols provide more than a practical step-by-step approach and to what extent they address the shortcomings identified in the Ghent University Hospital's protocol.

4.2. TOWARDS A MEDICAL CODE OF CONDUCT

The abovementioned shortcomings of the written initiatives (see 3.1.) are also not adequately addressed in the medical code of conduct of the Belgian Order of Physicians, first published in 2019.³¹¹ The medical code of conduct regarding euthanasia in the context of psychiatry is based on the written guideline of the Flemish Association for Psychiatry and the additional advice from its French-speaking counterpart, the Société Royale de Médecine Mentale de Belgique.

Compared to the previously published written initiatives that are discussed in Chapter 2, this code is also not legally binding, but – according to some of the interviewed physicians, deemed more authoritative, as the Belgian Order of Physicians has the power to e.g., investigate complaints regarding physicians' perceived malpractice and to undertake disciplinary sanctions. However, the aspect of authority should be interpreted with utmost caution, as the Belgian Order of Physicians is recognized as a 'legal entity' but their code of medical ethics has not been given 'legal authority'.³⁶⁷ The legal basis of their medical code of conduct is limited to the observance of "the honour and dignity of the medical profession".³⁶⁷

The medical code of conduct also stresses that great caution should be applied in euthanasia assessment procedures concerning this patient group. The code included the following additional due care criteria and reflections²⁴:

(1) As regards the physicians involved: at least two of the advising physicians must be psychiatrists and at least three of the physicians involved must meet and discuss the case *in-person*. In addition, it is also recommended to invite *all the care workers* in close contact with the patient, e.g., the nursing team, the psychologist, to this consultation. To promote compliance with this recommendation, the Belgian Order of Physicians even suggests a financial reimbursement for this 'multidisciplinary euthanasia consultation'.

²⁴ The medical code of conduct is mentioned to be a work in continuous progress and that is to be taken literally. The text has been amended over time, the latest amended version is published in February 2022.

(2) As regards the irremediability of psychiatric disorders, the Belgian Order of Physicians follows the recommendations of the advisory texts, with the explicit addition of an illness trajectory of (an unspecified number of) 'years'.

(3) As regards the patient's next of kin, the Belgian Order of Physicians follows the reasoning and suggestions made by the advisory texts, when stating that physicians must encourage the patient to allow their social inner circle to be involved during the euthanasia trajectory, unless there are good reasons not to do so. In addition, the code – vaguely – appeals to the physician's duty to society in general:

However, the physician's duty is not only restricted to the patient, but also to third parties who may be seriously harmed by the patient's request. Supporting these third parties and protecting society is inextricably linked to the issue of practicing euthanasia in psychiatric patients.

(4) As regards the interpretation of some of the legal criteria, distinction was made between the criteria 'mental capacity' versus 'mental competence', as both terms are often used interchangeably, though distinct in their essence.²⁵

(5) As regards conscientious objection, the code recommends the physician who refuses to perform euthanasia due to conscientious objection to refer the patient to another physician. In doing so, they must ensure that they do not give the patient the impression that the physician to whom the patient is referred will grant the euthanasia request, and refrain from any judgment on the appropriateness of the request.

To conclude, also this initiative has the same major shortcomings due to the lack of recommendations on 1) how to handle mixed advices, 2) on the (after)care for

²⁵ The terms are even used interchangeably in research articles on the euthanasia topic. Whereas 'mental capacity' refers to a legal concept, 'Mental competence' refers to a medical concept. As regards mental capacity, it is usually the 'Justice of the Peace' who – upon the physician's advice – determines if a person can be considered no longer capable of performing legal acts. For instance, a person may be no longer able to take care of their own property or, by extension, for themselves, and therefore may be in need to gain support from a material or personal guardianship respectively.

'Mental competence' points to the degree to which a person can e.g., make well-considered decisions and act in well-reasoned ways. In the clinical euthanasia practice, it refers to the degree to which a patient may express a well-considered, voluntary, and sustained euthanasia request. It's not up to a judge, but to the physician involved, to assess the degree of mental competence.

patients facing rejection of their euthanasia request, and 3) on the insufficiently worked out recommendations concerning the patient's relatives (see 4.4.)

4.3. THE PRESENCE OF MULTIPLE GUIDELINES SUBVERTS UNIFORMITY

In contrast to the situation in the Netherlands, no guideline was published in Belgium that aimed to assist physicians with the handling of euthanasia requests and procedures in the context of psychiatry, until long after legislation. Whereas the Royal Dutch Psychiatry Association recently updated their guideline for the 3rd time since legislation, the Flemish Psychiatry Association published their first version only in 2017. Moreover, whereas the Dutch Psychiatry Association's guideline provides one sole framework that may serve all clinical settings, multiple guidelines are circulating in Flanders (Belgium) to serve in various institutions and organisations.

The common ground is that neither the Dutch nor the Belgian guidelines explicitly appeal to be considered 'a standard' in the sense that they entail mandatory rules from which physicians should not deviate. Guidelines have no legal status and thus are not mandatory. They are generally supposed to be applicable to close to all euthanasia cases and in close to all circumstances, and thus allow for some deviation in individual cases if there are well-reasoned arguments for doing so. In short: guidelines are intended to support rational clinical decision-making and due care action.

However, the circulation of multiple guidelines in Belgium may impede uniformity in the handling of euthanasia requests. This can be deemed problematic as our qualitative studies with euthanasia requestors (Chapters 4 to 7) revealed that the whole trajectory may add additional suffering to the suffering already experienced as unbearable, due to e.g., the perceived inequality in euthanasia assessment and procedures. (It also makes one wonder why the Netherlands did, and Belgium did not succeed in the publication of one guideline.)

Implications for psychiatric practice

The euthanasia practice in the context of psychiatry may benefit from one single, clear, and inclusive guideline, which applies to all psychiatric facilities. That guideline can make use of a single set of operationalisations and

recommendations to remove all existing redundancies, to synchronise formulation, and to harmonise the current set of recommendations through; 1) consensus with all relevant actors in the field, 2) tailored to the specific needs of each psychiatric facility (e.g., the care for the bereaved fellow patients in residential settings), and 3) a review of built-up empirical evidence to establish a common, transparent, and uniform best-practice policy.

In that respect, our qualitative in-depth research with health care professionals and volunteers (Chapter 11) showed mixed findings on the practical value of the current guidelines. Whereas it was perceived as helpful for some, it was considered unhelpful (in terms of being redundant, impractical, vague, and lacking in different areas) and even flawed, biased or discouraging to others. The study also yielded insight into concrete needs, e.g., for protocols differentiating between diverse sub-populations (e.g., age differentiation), with a sharpened focus on both care/aftercare for patients with euthanasia requests rejected and withdrawn, as well as on the do's and don'ts concerning these patients' social inner circle.

Implications for future research

More than 15 years after the MELC-study (2007), a follow-up study on the presence and content of ethical policies on euthanasia in all psychiatric hospital settings is recommended. It is of course possible that psychiatric hospitals have formulated their own directives on how to handle euthanasia requests from APC within their institution.

4.4. FILLING IN THE BLANKS VERSUS FURTHER COMPLICATING OR EVEN ERODING THE LEGAL FRAMEWORK

Some recommendations of the guidelines did attempt to fill in some remaining blanks left by the legislator. As the intro of section 3 of the Law on Euthanasia states that the physician can – *without prejudice – impose any additional conditions to his/her own action*,²³¹ a set of additional conditions of due care can be deemed lawful. However, a new question arises, namely, whether some of the recommendations in the guidelines can be considered to run against the spirit of

the Law on Euthanasia or even a potential violation of the Law on Patients' Rights. The most sensitive and potentially thorny issues are discussed below.

In-person consultation among physicians

For instance, the guidelines of e.g., the Flemish Psychiatry Association and the Medical Code of Conduct recommend that the physicians – and preferably also the health care team surrounding the patient – would meet for an in-person discussion on the euthanasia case. Further analysis of the interview study among health care professionals and volunteers (Chapter 11) indicated that whereas some interviewees consider the recommendation an important additional safeguard for all actors involved, others consider it a means to erode the spirit and the letter of the Law.

An identical dissension occurred between some of the (co-)authors of Chapter 11 based on the following interpretation of the legislative text. According to some, the legal criterion that the advising physicians should formulate their legal advice in complete independence expressly rules out an in-person dialogue between all physicians. According to others, due to the above-mentioned clause in the Law on Euthanasia's Section 3, one can also assume that this in-person meeting may be seen as a lawful additional condition, if (and only if) the advising physicians have had the opportunity to formulate their advice independently, and upon the patient's consent (if that consent is not obtained, it would be a violation of the Law on Patient's Rights), a reading that was confirmed by an expert in Medical Health Law.

The patient's health care team

Another recommendation that may compromise the legislative text is the involvement of (past and present) health care team members surrounding the patient.

In her PhD-dissertation on the Belgian Laws concerning medical end-of-life decisions, lawyer Evelien Delbeke (2012) also highlighted the added value of the involvement of the patient's general physician. In most cases, the latter has built up a relationship of trust with the patient, spread over many years, and often has a good notion of the patient's past and current family context. Therefore, general physicians may be in a better position to assess the motives behind the

euthanasia request than the physician who is entrusted with the clarification of the euthanasia request, who may know the patient for only a few weeks or months.⁵⁹ Delbeke also believes that there should be a mandatory consultation²⁶ between this general practitioner and the attending (and potentially performing) physician given the importance of verifying the voluntary and well-considered nature of the euthanasia request, on the same conditions that the legislator has imposed on the nursing team. The involvement of the patient's general physician can be deemed lawful as physicians are bound to medical secrecy.

But what if non-physicians are involved? The legislator stipulates that the euthanasia request must be discussed only with (some members of) a nursing team, but only if this nursing team has regular contact with the patient. This concerns purely a consultation between the physician and (members of) the nursing team, under the duty of 'shared professional secrecy'²⁷.

Even though the nursing team has a rather informal role and any advice given by this nursing team is not legally binding, it goes without saying that their advice or even their individual opinion may affect the outcome of the euthanasia procedure. To prevent the nursing team from giving positive or negative advice because of financial interests, the Legislator refers in section 15, second paragraph, to section 909 of the Civil Code. This section stipulates that the nurse may not receive a gift or inheritance during the course of the life of a patient and/or after the death of a patient they (have) treat(ed). In 2003, this article was further extended to all professionals working in the medical health sector, with the inclusion of pharmacists.³⁶⁸ The consultation of former and present (non-) professionals during euthanasia trajectories may pose a problem if (some of) these people are not bound to section 909 of the Civil Code and not bound to professional secrecy.

²⁶ According to Delbeke, this consultation may, but must not take place during an in real life meeting. A telephone consultation may suffice.^{59(p167)}

²⁷ According to this duty, following 4 conditions must be guaranteed during a physician-nursing team conversations: 1) all nurses are bound by professional secrecy (like physicians are bound to medical secrecy), 2) the consultation must be deemed necessary to establish the continued treatment of the patient (hence, it does not apply if the patient is only sporadically in contact with a nurse or nursing team), 3) the consultation is done in the patient's best interests, and 4) the patient is entitled to oppose this consultation, although this may have repercussions for the decision-making procedures.

The conceptual confusion on 'relatives' and 'family', their role and involvement

In my opinion, one of the guidelines' main shortcomings that must be urgently addressed concerns the conceptualisation, the position, and the extent of involvement of the patient's 'family and relatives'. This is highly needed, as recent media articles revealed that physicians feel increasingly intimidated by the patient's relatives (mostly family) doing everything within their power, with the inclusion of calling in a lawyer, to prevent euthanasia from being carried-out.^{363,369,370}

One major problem is that the guidelines offer no clear definition or delineation of the concept of 'family' (e.g., the nuclear or broader family, friends as self-chosen family?) and 'relatives' (by blood ties and/or by true affective bonds?). Most guidelines use the concept of 'family' and 'relatives' every now and then as separate entities and then again as interchangeable. For example, the vision text of the Brothers of Charity seems to clarify the concept in the introduction by mentioning the term 'naastbetrokkenen' (closely involved), but further on in the guideline, the double-term is again used when stating that "*the consultation with family and most-involved relatives is an important due care criterion. After all, they are directly involved in the patient's life. For physicians and care workers, it is essential to consult them.*" In addition, the guideline of the Brothers of Charity does take into account the specific needs of fellow patients, living within the same residential context and therefore also considered 'closely involved' in the patient's current life. After all, the death of a fellow patient by means of euthanasia can have a traumatic impact on the other patients within this psychiatric '*living and residential community*'.^{225(p7)}

Most guidelines go a step further and entrust the patient's family and relatives with an important, albeit still informal, role during the clarification of a euthanasia request. By means of hetero-anamnesis and the observation of the social interactions between the patient and their relatives during consultation(s), the physician may achieve a more complete picture of the patient's life history and current situation, and not only from a purely medical perspective. By doing so, the physician may attain a more objective perspective on the legal criteria,

e.g., 'the voluntary, deliberate and sustained request for euthanasia,' and the (un)bearability and (non-)alleviability of the patients' suffering experience.

Nevertheless, the guidelines clearly state that consultation with family and relatives is essential but can only take place upon the patient's consent. Some guidelines also acknowledge that the patient can have well-founded reasons for deciding not to inform, let alone to involve them. Our qualitative studies with patients (Chapters 4 - 7), health care professionals and volunteers (Chapter 11) showed that there can be mention of severe neglect and abuse in the patient's family history, which may be considered sufficient ground for them not being involved and not informed. However, a forthcoming paper on our interview study among physicians and caregivers will reveal that some of the physicians consider the involvement of at least the patient's nuclear family (i.e., parents, life partner and/or children) during consultations essential, also in the event of broken and severely damaged family relationships. Some are even of the opinion that the euthanasia can only be carried-out upon their approval.

The in-depth interviews with patients (Chapter 7) also revealed other critical concerns as regards the involvement of their 'relatives' from an ethical and/or from a practical perspective. As regards the ethical perspective, some patients pointed to e.g., the potential violation of their legally binding patient's right on medical confidentiality and privacy, and the risk that a stronger involvement may undermine their autonomy. As regards practical modalities, they pointed to e.g., the lack of tools and support to decide on when and to what extent to engage whom, and how to cope with emotional reactions (be it absent, negative, mixed, or with disagreements). Some questioned the desirability of involving 'relatives', especially in the case of a tentative euthanasia request. Finally, they pointed to the emotional burden and responsibility it places on their closest inner circle as well as the possible conflicts it provokes between those who were or were not informed or more deeply involved.

Recommendations for policy

It seems that the recommendation to strengthen the role of the patient's relatives was adopted from the Dutch guideline, that in turn based their recommendation on the results of a focus group study among bereaved parents,

more specifically parents who lost their adult child by means of euthanasia or suicide.^{328(p359)} During an initial focus group, they were questioned about their specific concrete experiences and needs, that were then discussed during a focus group with the bereaved parents, physicians and other caregivers (such as psychiatric nurses). Based on this dialogue, the recommendation for the involvement of 'family and relatives' was drawn up, although it lacked the voice of other bereaved relatives (e.g., life partners, children, friends). A recent Dutch interview study with 14 'relatives' (parents, life partners, siblings, friends and/or fellow-patients) of euthanasia requestors revealed the emotional impact the trajectory has on each of them, but showed mixed findings on 1) the desirability of being involved to a greater extent in the euthanasia assessment procedure and 2) the need for (after)care.³⁶⁵

More importantly, the conceptualisation of 'relatives' and 'family' needs to be concretised (and changed into 'closest inner circle?'). Can some people be considered part of the patient's social inner circle and therefore directly and much involved in the patient's life and concerned on the patient's well-being per definition, just because they have the legal status of family and are bonded by blood ties? Moreover, it is known that poor quality relationships (family neglect, family abuse or family violence) can cause or contribute to these patients' mental struggles.^{371,372} If that is the case, can it be deemed ethical to force the patient to inform or even involve them? Can euthanasia then still be considered a way of dignified dying?

Recommendations for psychiatric practice

By pointing out the importance of good (after)care for the patient's closest inner circle, the guidelines acknowledge their difficult, emotionally straining position, and rightly so, in my opinion. This provision of (after)care should be more concretised.

Our survey results on the 46 completed euthanasia cases (Chapter 10) revealed that their involvement frequently occurs in the euthanasia practice but also showed that physicians can feel pressured by the patient's relatives (family and/or friends) to disapprove the patient's euthanasia request, although the reverse scenario (pressured to approve) was also reported. The interviews among euthanasia requestors (Chapter 8) and among health care professionals

and volunteers (Chapter 11) provide essential factors, e.g., practical modalities to be considered in this respect. In addition, the end-of-life consultation centre Vonkel has recently established a partnership with Similes, a Flemish organisation caring for relatives affected by their loved one's mental illness (or also struggling with their own mental illness). In Louvain, the recovery-oriented organisation REAKIRO is established to care for both patients and their closest social inner circle affected by euthanasia ideation and euthanasia trajectories. Such networks and initiatives can be further developed and expanded, which is an additional policy recommendation. Finally, a forthcoming study will reveal that the mandate for the provision of (after)care for the close inner circle can be given to or is already undertaken by some health care team members (e.g., mobile team members) who are involved in both the patient's care and euthanasia trajectory.

Recommendations for future research

Scientific evidence can enrich the normative debate on medical-ethical and juridical principles. As mentioned above, the focus group studies on which the Dutch recommendations for the involvement of 'family and relatives' were based, did only include the voices of bereaved parents. To date, only one recent Dutch study addressed the concrete experiences and needs of these patients' social inner circle by means of in-depth interviews.³⁶⁵ To date, such informative research endeavours are lacking in Belgium.

Moreover, the focus group studies excluded the voices of a heterogeneous sample of patients' social inner circle but also the patients' voices are missing. Future focus group studies could bring the voices of all actors involved together for mutual learning purposes on each other's needs, expectations, and limits.

5. General Discussion of the empirical research findings

5.1. A HIGHLY CONTENTIOUS BUT BY NO MEANS A PERIPHERAL PHENOMENON

In contrast to the situation in the Netherlands, there were no survey studies conducted among psychiatrists working in Belgium. That changed in 2017, when

one survey study was conducted among psychiatrists and their trainees from one University Psychiatric Centre in the city of Louvain¹⁷³ and in 2018-2019, when our survey was launched among psychiatrists affiliated to the Flemish Association for Psychiatry (Chapters 8 to 10).

In that period of time, the calls to repeal or amend the Law on euthanasia in terms of excluding adults with psychiatric conditions from euthanasia sounded loud and clear in the media. These calls are not supported by the majority of surveyed psychiatrists in Belgium¹⁷³ (nor by the majority of surveyed psychiatrists in The Netherlands^{131,169}). These survey studies also point to the fact that euthanasia cannot be minimised as a peripheral phenomenon in adult psychiatry, as the majority of psychiatrists has been confronted with these euthanasia requests.^{131,169,173}

A minority of psychiatrists had been already actively engaged or is willing to actively engage in these euthanasia trajectories, other than as referring physician.^{131,169,173} Additional qualitative evidence revealed the reasons behind this hesitancy to engage: euthanasia assessment and performance is by no means a matter of simply ticking off a checkbox, but is professionally and emotionally extremely demanding and challenging.¹⁶⁹⁻¹⁷¹ In that regard, it seems striking that only a minority of surveyed psychiatrists in Belgium (and The Netherlands)¹³¹ has followed specific training concerning medical end-of-life decisions (Chapters 8 to 10).

In addition, Chapter 8 revealed that psychiatrists who perceive themselves sufficiently competent to deal with these euthanasia requests are (significantly) more likely to be actively involved in such assessments as preliminary, formal advising physician or attending physician. However, the potential link between education and concrete engagement, and the (moderating) role of perceived competence therein, can only be assumed, as the low number of psychiatrists who followed specific education impeded statistical hypothesis testing.

Finally, the expressed concerns about whether these euthanasia requests are always assessed and monitored adequately and rigorously is worrying (Chapters 8, 10 and 11). Both overly permissive, e.g., insufficiency of due diligence and care, as well as overly restrictive approaches, e.g., refusal of referral, were reported in this respect.

Recommendations for policy and practice

As regards the concerns on inadequate assessment, this points to the question of whether these requests are always monitored adequately and rigorously, and consequently, to the discussion of how they should be monitored, by means of the establishment of an a-priori committee (without unnecessarily complicating the procedure) or by making a selection of anonymised cases available for in-depth research purposes, modelled on the anonymised cases that the Dutch review committee had made available in the past.^{132,133,373,374}

Taking into account (1) the increased number of euthanasia requests based on psychiatric reasons^{127,308}, (2) the reported difficulties with finding physicians willing to discuss, let alone to engage in, these euthanasia trajectories (Chapters 4 to 7), (3) the evidence of growing intake waiting lists at the Dutch Centre of Expertise in Euthanasia³⁶⁶ (anecdotally confirmed in Vonkel, be it to a lesser extent), it seems likely that a proportion of these patients does not receive proper care and attention within a reasonable period of time. Notwithstanding the many (plausible) reasons for not engaging in these trajectories, leaving some of these patients in the cold for months (Belgium) or even years (The Netherlands) cannot be considered proper mental health care. The findings of Chapter 8 and 10 revealed that integrating all medical end-of-life options in the academic curriculum of all medical professionals can be helpful in this regard, as increased knowledge may strengthen the perceived competence to adequately deal with these euthanasia requests and procedures.

Recommendations for future research

Concerns were expressed about euthanasia requests being managed and monitored in an insufficiently rigorous manner. In this respect, a thorough and independent evaluation of the euthanasia practice in the context of adult psychiatry is recommended (as done in The Netherlands by means of their quinquennial reports for governmental debate purposes¹⁶⁹ and scientific reviews of carried-out cases that the Dutch regional euthanasia review committee post online^{292,375}). In Belgium, empirical research into a larger proportion of cases of euthanasia for psychiatric reasons remains scarce and is complicated due to limited registration.¹¹⁷ To date, only carried-out cases reported to the Federal Control and Evaluation Commission for Euthanasia^{96,117} and one retrospective

study on 100 cases from one mental healthcare centre¹²⁶ have been analysed, be it in insufficient detail. These and Chapter 11's findings vaguely reveal that the consultation process spans several months (even years), takes multiple consultation sessions with multiple actors (e.g. patient, clinicians, family and friends), and that a minority of euthanasia requests are carried-out^{28, 126, 322}. More research is needed in order to provide the (inter)national community with fundamental and detailed insights on how thoroughly the majority of these requests are dealt with. The much-consulted end-of-life consultation Vonkel is in any case at the forefront of providing these needed insights by making the anonymized data from their electronic medical record registration accessible for research purposes.

5.2. LEGAL CRITERIA NOT PUT ON PSYCHIATRIC FOOTING

When browsing through the electronic databases of the Belgian parliaments' debates preceding euthanasia legislation^{376, 377}, it was clear that the legislator did not have adults predominantly suffering from psychiatric disorders in mind. In line with the systematic review on why euthanasia should (or should not) be legally allowed in this specific patient group (2020),¹³⁵ the main concern of our surveyed psychiatrists (Chapter 8 and 10) as well as of the surveyed psychiatrists in The Netherlands¹³¹ is that certain legal criteria are difficult to interpret, difficult to reliably assess and/or difficult to be met in the psychiatric practice, due to the higher levels of 'epistemological uncertainty'³⁷⁸ regarding the aetiology, diagnosis and prognosis of mental illnesses.¹³⁵

5.2.1. Irremediableness

In agreement with recent Dutch research findings, the criterion of irremediableness appeared to be the most challenging legal criterion to be assessed, due to e.g., the abovementioned higher level of uncertainty in psychiatry³¹⁹, the wide range of treatment options (e.g., pharmaceuticals, psychotherapy, psychosocial interventions and brain stimulation), and the occurrence of spontaneous recovery in psychiatry.^{319, 320} The efforts made to

²⁸ It's difficult to assign a number to it, as only the end-of-life consultation team in Vonkel post their annual report online, with the inclusion of some facts and figures concerning the patients consulting them regarding the euthanasia request. According to Vonkel's most recent annual report, approximately 12% (62/507) of the total number of euthanasia cases based on psychiatric reasons culminated in the act of euthanasia in the years 2015-2020.¹²⁷

operationalise this legal criterion so it would suit the psychiatric practice better, did not seem to make the assessment of this criterion any easier. The case review (Chapter 11) revealed that responding psychiatrists experienced similar levels of difficulty during the assessment of 'medical futility', 'incurability of the disorder' or the operationalised 'lack of a reasonable therapeutic perspective'.

Also, the operationalisation of the criterion 'irremediableness' barely takes note of what some psychiatrists reported as a critical therapeutic tool, namely the aspect of 'hope'. According to some, seriously contemplating the potential lack of reasonable therapeutic perspectives may induce feelings of hopelessness and demoralisation in this vulnerable patient group.^{150,166,379} A proportion of the interviewed healthcare professionals and volunteers shared this opinion (Chapter 11). In addition, whereas Chapters 4 to 6, and 10 revealed that feelings of hopelessness and pointlessness are indeed key elements underlying these euthanasia requests, Chapter 6 showed that some people request euthanasia to hear their ineligibility for it, to learn that there are still treatment options available that could make their struggles in life more bearable. Hence, by requesting euthanasia, they try to have their ailing hope restored.

Although hope is often portrayed as a critical factor in medicine in general, and even more so in recovery-oriented approaches in psychiatry, its conceptual framework remains unclear and its empirically assessed predictive abilities remain inconclusive.³⁸⁰ Generally speaking, 'hope' consists of two main components: (1) a 'desire' for altering, getting or achieving something, and (2) a cognitive belief about the probability of its fulfilment. In the context of psychotherapy, the probability of the desire to e.g., get the symptoms in remission, to achieve a better quality of life, is up to the physician's expertise to make realistic assessments about. If the patient would have unrealistically high expectations, then these should be tempered, and vice versa, if the patient would have unrealistically low expectations, then these should be uplifted.

In the context of euthanasia, the fear exists that exploring the death track would result in patients losing their belief in possibly effective treatment options. However, one should not confuse disappointment (the loss of a particular desire or a particular hope) with hopelessness (the loss of the ability to hope) as the first does not automatically result in the latter.³⁸¹ One can be disappointed that

the proposed treatment did not turn out as effectively as desirably believed and still desirably believe that another treatment option can turn out (more) satisfactorily.

Moreover, inducing false hope in patients by means of e.g., not properly informing them on diagnosis and treatment outcomes, offering false premises, gold-plating positive and omitting negative probabilities, or ignoring treatment fatigue, can also result in an acquired loss of the ability to hope as well as in the ability to trust the physician's judgement.³⁸² On the other hand, when realistic perspectives can be sketched by the physician and accepted by the patient, a continued ability to hope can be achieved.³⁸² Hence, a distinction should be made between justified (realistic, true) hope or delusional (false) hope that points to the ability of hope versus the outcome that can turn out true or false, that refers to the fulfilment or loss of one particular hope.

A related core question in this regard is: who is more clinging to hope and thus more fearful of losing the ability to hope, the patient or the physician? In addition, and also in line with Dutch findings, the influence of transference and countertransference was reported (Chapter 8), i.e. the jointly established phenomena where the patient and the therapist (subconsciously) perceive and interact with one another.¹⁷¹ In the context of euthanasia, the issue of negative countertransference is much-debated^{284,383,384} and concerns inter alia: (1) feelings of inadequacy, powerlessness and failure in physicians^{49,50}, (2) moral distress between the physician's duty to preserve life and to heal suffering²⁸⁴, (3) 'compassion fatigue' or the traumatic distresses and burnout reported in mental health care workers^{360,385}, (4) frustration due to a therapeutic climate that gives patients a free pass to consult other physicians in function of their euthanasia request²⁸⁴. The potential interplay between 'hope' and 'countertransference' is understudied and thus poorly understood.

5.2.2. Mental Competence

The legal criterion of 'mental competence' is also much-debated in the scientific literature, as it is questioned whether it can be sufficiently present in the mentally ill and whether it is adequately assessed in euthanasia practice.¹³⁵ Our findings showed that the vast majority of the surveyed psychiatrists (90%) are of the opinion that these patients can make a well-considered euthanasia request

(Chapter 8) and that relatively few psychiatrists (9%) experienced difficulties regarding the assessment of mental competence (Chapter 10).

A marked finding is that some psychiatrists referred to specific diagnoses as contraindications for these people to be considered mentally competent, and therefore eligible for euthanasia, which has caused much ink to flow.^{138,145,158,343} Ruling out patients for euthanasia on the basis of a diagnostic label can be problematic, as diagnostic classification is often contested due to low reliability and validity.³⁵²⁻³⁵⁴ For example, in our survey and (forthcoming) interview study, people with bipolar and borderline personality disorders were most often (spontaneously) said to have impaired mental competence. In the literature, however, it appeared that these two mental illnesses are often misdiagnosed and consequently ineffectively or even adversely treated to a great extent.^{386,387} In my opinion, despite the fluctuating decision-making competence that can indeed be considered inherent in the respective disorders, these patients can find themselves in periods of remission, in which they can take stock of their past and present life and – together with their physicians – can draw realistic pictures of what the future may (not) hold in store for them.

5.2.3. Unbearable suffering

As FCECE reports mentioned some dissension among its members concerning the question of how to comprehend and evaluate unbearable mental suffering,^{193,210} Chapters 4 and 5 focused exclusively (and Chapter 6 partially) on the indices that may render these adult patients' suffering unbearable. The findings are confirmed in a recent Dutch interview study with 21 adult patients with psychiatric conditions and a euthanasia request¹⁷², namely that the suffering of these adults often transcends the medical (hi)story. In addition to the medical aspects, that often concerned the intertwined relationship between mental and physical factors, a variety of intrapersonal, interpersonal, and societal elements were reported.¹⁷² The accumulation of misfortunes and setbacks resulted in feelings of hopelessness and pointlessness, that ultimately render the suffering unbearable. These multi-layered aspects of suffering, however, with hopelessness as a key criterion are not exclusive for to specific patient group, as

they were also reported in people predominantly suffering merely from somatic conditions as well.^{183,388} One Dutch interview study (2011) among euthanasia requestors with somatic conditions and some with psychiatric comorbid conditions revealed that most people did not suffer continuously, unless they were diagnosed with a (comorbid) depression.¹⁸³

That study also suggests that in all cases, the unbearableness of suffering must be understood on the continuum of the factors in the patient's past, present as well in the future (lack of) perspectives.¹⁸³ Our study partially confirmed this idea, as most interviewed patients did report to be suffering since childhood onwards. However, this was not always the case, as we have interviewed people that started to struggle in later life. The unbearableness of their suffering was ascribed solely to their deteriorating psychiatric condition and related consequences, e.g., unemployment, as they looked back on their past life with gratitude and satisfaction.

In their review of 35 carried-out euthanasia cases based on psychiatric reasons, Van Veen et al. (2019) concluded that a clear division between somatic and psychiatric suffering may prove more complicated than expected.³⁷⁴ Some interviewed people in our sample raised this conclusion up a notch, as they reported that their struggle in life was mainly due to contextual factors rather than to genuine psychiatric symptoms (Chapter 6). These people put emphasis on their life history, that was characterised by serious adversity, often rooted in seriously adverse upbringing and an accumulation of other traumas in later life that were deemed not feasible to overcome with the help of psychiatric medicine (alone).

In that respect, the reported determinants that could have prevented these adults from considering a hastened death point to the many societal factors (e.g., socio-economic inequalities, public stigma surrounding mental illness, and failed youth services) that are beyond the scope of the field of medicine in general and psychiatry specifically. Moreover, these factors can be considered key in preventing some of these people from developing a mental illness in the first place. But this does not discharge the field of psychiatry from critical reflection and related action. The many reported traumatic experiences in – often residential – psychiatric settings represent the thorny issue that is pinpointed by

critical psychiatry movements, namely the inappropriate response with 'power approaches' to the so-called 'psychiatric identities' in psychiatry.^{296,299,389,390}

Finally, whereas Chapter 8 revealed that close to all surveyed psychiatrists (and thus also those not being in favour of euthanasia legislation) are of the opinion that these patients can suffer unbearably, Chapter 10 showed that this criterion is less difficult to reliably assess.

Recommendations for practice and future research

Both the key criterion 'irremediableness' as its operationalisation 'no reasonable therapeutic options available' seem to be equally difficult to interpret, determine and assess in the context of psychiatry. This is partially due to the high level of uncertainty in psychiatry but seems also due to the difficulties to reconcile this criterion within the therapeutic alliance. The mechanisms of and interplay between hope as clinical tool, and transference and countertransference are understudied in the context of euthanasia. This must be seen as an impulse to stimulate future research, of which the findings can be taken into account during the preparations of a future update of the guidelines (preferably merged into a single one that is universally accepted).

Second, the perceived absence of mental competence in a few surveyed cases (Chapter 11) suggests the need for a more standardised capacity evaluation. To our knowledge, only one Dutch and one Belgian evidence-based study on this topic have shown that the assessment of this criterion differs between individual physicians (i.e., to some extent due to their personal values and belief system)³⁵⁵, and, in some cases, seems even flawed, which has led to dissension among physicians on the evaluation outcome.¹³²

Third, the unbearableness of suffering seems to partially transcend the discipline of psychiatry and also partially due to experienced adversity in psychiatry (iatrogenic suffering). Although recourse to paternalism and coercion can be accepted (and spontaneously agreed upon by a proportion of interviewed patients) as necessary and unavoidable in certain circumstances, critical analysis and reflection are deemed essential regarding when, why and how more authoritarian approaches can be used under which circumstances and to what

extent. This debate should also include the voices of these patients, if only because of their status as psychiatric service users.²⁹⁶ In addition, those interviewed expressed the need for a more human-centred, holistic clinical environment, characterised by: 1) continuity of care (non-abandonment) and more tailor-made care; 2) a shift from medical paternalism to shared decision-making, based on values such as respect, connectedness and openness; and 3) congruence with a multidisciplinary recovery approach (i.e., taking into consideration mental, social and existential factors, rather than just the symptoms of the patient's psychopathology). After all, our and Dutch findings showed that the interviewed patients clearly needed and benefitted from being recognised in their suffering and seen as a whole person.

Finally, our research only looked at whether these legal criteria were deemed present and at the perceived difficulties in assessing them, but not at *how* these criteria are assessed. To date, scarce research focused on how mental competence and irremediableness are assessed^{132,133,319,355,374}, or how the unbearableness of suffering is assessed. Consequently, it remains unknown if and to what extent the factors transcending the field of psychiatry have been taken into account. More knowledge in this regard is deemed needed, as the Belgian Law on Euthanasia clearly stipulates that the suffering must result from the medical condition or from an accident. Would the latter leave the door open to interpret experienced adversity in childhood and later life as an accident and a valid basis to consider the victims of adversity eligible for euthanasia if their suffering cannot be sufficiently alleviated with the use of psychotherapeutic and psychosocial interventions?

Recommendations for policy

As regards policy, our findings urge a serious ethical debate on society's responsibility to tackle the reported societal inequalities and failures, instead of passing the buck to the – underfunded – field of psychiatry. Ensuring accessible, high-quality, and better equipped (youth) mental health services, and more societal support regarding people with mental struggles should be priorities. Health care professionals cannot be asked to foresee, treat, and alleviate all types of suffering, and surely cannot be asked to resolve society's failures.

5.3. THE TWO-TRACK APPROACH: TWO ARE NEEDED FOR RIDING AND BALANCING A SEESAW

The guidelines (Chapter 2 and 3) did not only focus on the interpretation and operationalisation of the legal criteria, but also recommended a two-track approach. This approach offers the patient: 1) a *life track* by means of ensured continuity (and potential re-evaluation) of clinical treatment, and the (further) exploration of rehabilitation perspectives, and 2) a death track, by means of taking the euthanasia request seriously and thus, to explore e.g., the patient's eligibility for euthanasia. Following both tracks is of utmost importance, as our interview studies (Chapters 4, 6-7 and 11) revealed that there is mention of patients with euthanasia requests falling on deaf ears, and patients being dismissed from or denied access to treatment, simply because they had requested euthanasia or had it in review. As discussed earlier, these cannot be considered actions of good clinical care.

The interview study among health care professionals and volunteers (Chapter 11) confirmed the value of and appreciation for the two-track approach as it may avoid a narrowed focus on one single track. However, the life track comes off rather poorly as recovery-oriented and palliative care approaches are insufficiently developed and implemented in psychiatry.

Due to the lack of a clear definition of 'recovery', this concept is interpreted and implemented in the practice in various (often culture-insensitive) ways.^{391,392} Generally speaking, it can be defined as a journey of change through which people learn how to strive to achieve their functional potentials in order to live a more self-directed, satisfying life *despite* the illness and *despite* the negative consequences resulting from the illness.³⁹²⁻³⁹⁵ As mentioned in the Introduction (Chapter 1) recovery-oriented approaches have made their entry in the field of psychiatry, due to the evidence of partial or even complete recovery in a proportion of patients, provided the provision of e.g. peer-run services, social support, community life, and employment.^{353,391-395}

Despite the promising effects, the existing literature points to a majority of people with psychiatric conditions experiencing the many barriers for recovery^{392,395}, many of which are also reported by our interviewed patients (Chapters 4 to 6). These concerned e.g., not being able to find a suitable job

(not even as a volunteer), being disproportionately vulnerable to stigma, traumatic events, and victimization, and experiencing adverse effects of therapies and barriers to accessing (good quality) mental health services.^{392,395}

The recovery-model may not provide a suitable answer to all patients, as a proportion may not sufficiently recover and may further deteriorate. In that respect, palliative care approaches are suggested to be used. Palliative care is rooted in somatic medicine and generally described as a multidimensional care approach addressing the multilevel needs of people (and their social inner circle) facing incurable life-threatening disorders, with the aim to reduce the problems associated with illness and to increase their quality of life.

As mental illnesses can be perceived as life-threatening, impacting on quality of life, and severely affecting the social inner circle, palliative approaches in psychiatry may seem necessary. Trachsel et al. (2016) suggested the following definition for palliative psychiatry (i.e., a paraphrase of the World Health Organisation's definition of palliative care that is commonly used in somatic medicine):

Palliative psychiatry is an approach that improves the quality of life of patients and their families in facing the problems associated with life-threatening severe persistent mental illness through the prevention and relief of suffering by means of a timely assessment and treatment of associated physical, mental, social, and spiritual needs. Palliative psychiatry focuses on harm reduction and on avoidance of burdensome psychiatric interventions with questionable impact.^{396(p3)}

Nonetheless, palliative psychiatry is still in its infancy as there is neither a definition²⁹ that is uniformly agreed upon nor clear guidelines on how these palliative approaches should be best implemented in psychiatry.³⁹⁷

In Belgium, a model of 'Oyster Care' is being developed that offers flexible, tailor-made care for patients with severe and persistent mental illness who are in danger of being neglected or overly burdened by psychiatric services (under- versus overtreatment).²⁴ Oyster Care refers to the aim of providing a safe

²⁹ On a personal note, the use of family in Trachsel's definition is ill-chosen as it cannot be assumed that 'family' is much involved in the patient's life and well-being, and it cannot be assumed that they do not contribute to the suffering.

'exoskeleton' or 'shell' for these patients, rather than appealing to their 'internal abilities' as recovery, reintegration and resocialisation is not within their reach.²⁴ The Oyster Care model is based on the following 4 pillars of holistic, patient-centred care: (1) the provision of adequate care for their somatic comorbidities; (2) the provision of mental care with the emphasis on mental comfort, safety and increased wellbeing; (3) the provision of social care with the emphasis of daily activities and contacts; and (4) existential care with the emphasis on the search for what may render life meaningful.²⁴ However, this model of care is relatively new and insufficiently integrated in today's psychiatric practice.^{23,24}

Recommendations for policy

In my opinion, offering patients a two-track approach is one of the most valuable contributions of the guidelines, and deserves to be considered in an eventual law revision. Now, in the revised Law, it is stated that:

"the physician who refuses to examine/explore a euthanasia request, must provide the patient (or the person in confidence) the contact details of a centre or association, specialized in euthanasia legislation, as well as provide the patient's medical record to the physician, who is designated by the patient or the person taken in confidence, within 4 days of the explicit request."⁶³

This seems to be a good attempt to avoid patients being left in the lurch, especially those patients who are expected to die within a short period of time and should not be kept in the dark unreasonably long. The question is whether this time constraint suits the field of psychiatry, due to (1) the reported countertransference, e.g., the low threshold for patients to consult end-of-life consultation centres on their own initiative seems to frustrate a proportion of psychiatrists,²⁸⁴ and (2) the amended paragraph seems to provide physicians an easy way to opt out and 'pass the buck' to the already-overburdened end-of-life consultation centres.

Finally, full-scale implementation of recovery-oriented and palliative approaches in psychiatry is deemed highly needed, especially in countries whose euthanasia legislation does not exclude adults with psychiatric conditions. The euthanasia

request should be based on suffering that cannot be sufficiently alleviated despite a variety of proper care options and not by a lack thereof.

Recommendations for practice

It is recommended that psychiatrists embrace the two-track approach, as our (and Dutch) findings confirm that these patients need to experience being listened to, being taken seriously, and being recognized in their suffering. In addition, it should not be ruled out that the euthanasia request is not a cry for help in dying, but rather a cry for additional help in life. It is highly recommended that treating physicians who would not actively engage in the death track but rather keep their emphasis on the life track do engage in meaningful referral (which is legally enforceable).

Recommendations for future research

I'd like to underline the recommendations of van Weeghel et al. (2019)³⁹² that more research is needed into the working mechanisms of individual recovery processes and the complementarity between the recovery-oriented and problem-oriented approaches, with the addition that more research is needed into how the recovery-approaches can be best implemented in the context of euthanasia. The same applies to the palliative and oyster care approaches.

5.4. TOWARDS A BETTER PAVED 'DEATH TRACK'

As mentioned earlier and in line with a recent Dutch interview study, our findings (Chapter 7) point to the beneficial effect of patients' euthanasia requests being taken seriously and for them being heard and recognised.¹⁷² Being able to discuss their death ideation in a serene manner could empower patients to (further) explore alternatives to death. Our study added that (some of) these patients are sensitive to the physicians' challenging task of assessing their request and can show their understanding and empathy for their physician's decision to undertake more stringent due care criteria or even to refuse the euthanasia request. Moreover, our findings show that a rejection of the euthanasia request does not necessarily jeopardise their current therapeutic treatment, provided (1) the reasons behind the rejection are well-motivated, (2)

the (ambivalence toward the) death ideation and the euthanasia procedure can be discussed in upcoming therapeutic sessions, and (3) a meaningful referral to a colleague-physician is guaranteed. In contrast, neglecting the euthanasia request seems to have only unfavourable consequences, e.g., patients quitting the therapy. This finding suggests that both physicians and patients may benefit from open and serene discussions about death and euthanasia.

Nonetheless, our study (Chapter 11) found a need for more guidance on the proper implementation of the two-track approach. For instance, issues emerged on how to handle the tension between both tracks in the most effective manner, given the experience that exploring the euthanasia request may empower some patients but may discourage others from giving alternatives to death a fair chance of success.

Chapter 11 also revealed that this issue does not only concern the medical professionals but a wide range of health care professionals and volunteers. As non-physicians spend more time with the patient (often also with the patient's most involved social inner circle) than physicians normally do, they can be considerably affected by these euthanasia trajectories. Even though all these mental health care workers appreciated the close(r) and deep(ened) relationship with the patient and considered their challenging work an act of meaningful care, most of them reported a lack of education and skills on this matter. For instance, the people working in residential psychiatric settings reported that they could only rely on institutional suicide policies as there were no euthanasia policies available for them. These and other people revealed the need for e.g., more guidance regarding how to balance secrecy towards physicians in the event of expressed suicidality or how to position themselves towards the patient (can one become friends?).

One of the most notable encounters during the interview study was with non-physicians that felt completely side-lined. In (residential) settings that 'outsourced' euthanasia requests, these healthcare professionals faced distress that exceeded their own coping capacity and caused some to question their professional competence. In the event of these euthanasia cases being carried-out, these healthcare professionals faced 'disenfranchised grief', i.e., grief when incurring a loss that is or cannot be openly acknowledged, validated, and mourned due to (perceived) social norms. Disenfranchised grief is not specific to

the euthanasia practice in the context of adult psychiatry, as it is seen in health care workers, after being faced with patient deaths in a palliative care, suicide or in the well-known Covid-19 mitigating context.²¹⁻²⁶

Moreover, the question is also whether this outsourcing scenario can be deemed in accordance with the Law on Euthanasia. Some of these healthcare professionals were psychiatric nurses who – in the event of being in regular contact with the patient – should be at least consulted by the attending physician during the euthanasia trajectory.

Recommendations for policy

The briefly sketched event of psychiatric nurses being side-lined may be due to a suboptimal sequence in the euthanasia trajectory. According to the Law's suggested sequence, the euthanasia trajectory starts with the patient requesting euthanasia and the physician who may or may not actively engage in it. The suggested sequence implies that the attending physician is entrusted with e.g., the task to clarify the euthanasia request, to ensure that at least two formal advices from two independent advising physicians (of whom at least one is a psychiatrist) is obtained, and to ensure that the nurses who are in regular contact with the patient are at least informed on the euthanasia request and procedure. As the Law does not stipulate how and by whom the euthanasia should be performed, the attending physician may perform the euthanasia herself, with or without the assistance of another physician, or entrust another physician with the performance. In practice, however, the sequence of euthanasia trajectories may differ from each another. It is reported that in some cases, the formal advices on the euthanasia request have been obtained and the attending/performing physician ought to be sought. Hence, a plausible explanation for these psychiatric nurses being side-lined could be due to the stage of the course of the euthanasia procedure in which the attending/performing physician was assigned. As these trajectories can span many months to even years, it could be plausible that the patient was no longer in regular contact with the psychiatric nursing team. Poor communication between the physicians and the nursing team involved or a violation of this legal procedural criterion is also plausible. In case of the latter, this may be seen as a breeding ground to ask questions on how these euthanasia cases are monitored.

In case of the first, an eventual revision of the Law could take the recommendation of the guideline of the Flemish Association for Psychiatry²⁰³ into account and make the implied sequence mandatory.

Finally, the findings of Chapter 8, 10 and 11 revealed the need for all medical end-of-life options to be integrated in the academic curriculum of all medical care workers, and for both education and training initiatives for all care workers who may be confronted with euthanasia trajectories in a psychiatric context.

Recommendations for practice

The interviewed non-physicians reported the need for an organisational policy on improving, assisting, and supporting them and fellow colleagues in more effective ways. In contrast to the existing protocols on how to deal with suicidality, there is no such protocol available regarding euthanasia. Guidance is deemed much needed because these personnel spend more time with the patient, and usually are the ones taking care of the patient before, during and after each step in the euthanasia trajectory, which is reported to be extremely difficult in the event of a patient being stressed before each consultation, being upset in the absence of a formal advice and especially if the formal advice turns out to be negative. Also, they often function as a trust person to the patient and as an intermediary between the patients and their fellow patients, their closest social inner circle, and their treating physicians. Hence, their needs must be considered.

In addition, euthanasia policies should also address the need to recognise, validate and address grief in the work context, to properly prevent and manage disenfranchised grief and related consequences, e.g., fatigue, burnout, and low-perceived work ability. This also concern medics, as Chapter 8 brought an underexposed issue to light: namely, the high emotional strain on almost three quarters of the surveyed psychiatrists.

As regards the medics, more guidance seems needed on how to better pave the death track. At first, clear communication management is of utmost importance, as our interview study (Chapter 7) found that the treating physician's neglect of the euthanasia request seems to have only unfavourable consequences on the patient's mental state (e.g., increased feelings of despair) and the therapeutic

trajectory (e.g., treatment abandonment). In contrast, the rejection of the euthanasia request does not necessarily complicate the therapeutic trajectory. Hence, the worst-case scenario of losing a patient to either another therapist or to death seems more likely to happen if the physician reacts e.g., in a deaf-mute or aggressive manner, or expresses other forms of poor communication skills.

But even if a psychiatrist is willing to actively engage in these euthanasia procedures, proper communication skills and expectation management seem to be of utmost importance. This seems appropriate in addressing the many feelings of ambivalence inherent in some of these patients during the whole euthanasia trajectory, irrespective of any temporary or final outcomes. It also seems highly needed as most of the interviewed patients openly questioned whether the euthanasia trajectory could in fact be considered a way towards a dignified, good death. During the interviews, it was noticed that many of them (re)considered suicide, and they were well aware of alternative ways of non-medically assisted dying through e.g., the Dutch *Coöperatie Laatste Wil* (Cooperative Last Will) or through the tips and tricks learned from e.g., peers.

It struck me how some of the patients' expectations seem to have changed during the euthanasia trajectory. This was in my view due to three factors. One, the turbulent situation preceding, during and following the recent court case trial, resulting in e.g., physicians considering additional changes to the euthanasia procedure or pulling out of it entirely. Two, the implementation of (some of the) guidelines' recommendations of additional and/or stricter due care criteria than legally required. And three, due to a lack of knowledge on what euthanasia legislation and the euthanasia practice is all about, e.g., not a patient's right but something that should be assessed, through a joint dialogue between the patient and a handful of physicians, spread over multiple consultations.

Hence, it should be clearly and carefully explained to the patient that euthanasia is not an enforceable right. A proactive approach, in which the whole procedure is explained, and all potential outcomes discussed before the assessment procedure is initiated, is highly necessary to prevent severe distress that compromises the treatment trajectory. In addition, it is of utmost importance to explore and deal with the emotions of disappointment, anger, despair, and suicidal ideation (preferably during parallel consultation sessions on the life and on the death track).

Attention to the impact of the euthanasia procedure on a patient's mental state, treatment trajectory and their most-involved social inner circle is paramount in clinical practice. This need of a proactive approach has been already addressed in a Dutch qualitative article of Dees et al. (2013) among patients, their relatives, and physicians but as mentioned earlier, neither sufficiently in the guidelines nor in the medical code of conduct.

Future focus group studies among all actors involved, e.g., patients, their most involved social inner circle, and the health care professionals and volunteers, can shed light on mutual expectations and needs, and how they can be best addressed.

5.5. THE TENSION BETWEEN ALLOWING EUTHANASIA AND PREVENTING SUICIDE

Chapter 6 reported on the main motives for requesting euthanasia and how it relates to unregulated suicide. Our results match with a recent Dutch interview study (2021), indicating that most of the interviewees request euthanasia when feeling emotionally worn-out and after having drawn up a balance sheet on whether life is or can become worth living, which has turned out negative.¹⁷² Also in line with the Dutch findings, ambivalence towards death and dying was key, as some interviewees longed more for help in life than help in dying.¹⁷²

Our results partially match with the Dutch finding that interviewees phrased a 'clear distinction between euthanasia and unregulated suicide', that was attributed to the level of 'rationality' and irrationality, respectively.¹⁷² Our interviewees also echoed that the recourse to euthanasia was based on a well-reasoned decision that may not always but sometimes had been there in the event of suicide. In line with the Dutch findings, the 'clear distinction' between both acts was attributed to (1) the more effective way of dying in the event of euthanasia, as even carefully planned suicide attempts do not always result in death and lead to new deteriorating consequences, (2) the legalised way of dying in the event of euthanasia, and thus without legal prosecution for relatives, and (3) a more dignified way of dying than suicide (for both the interviewees and their beloveds), with autonomy, self-determination and the need for recognition, as underpinning motives.¹⁷²

However, some new findings emerged. First, recourse to the euthanasia procedure is also taken to hear the physician involved say that one is not (yet) in a medically futile position. Second, and as regards the highly appreciated value of patient autonomy, self-determination, and dignity in dying in our society, our findings (Chapter 7) revealed that some adults are alternately switching their minds from suicide to euthanasia and vice versa. This is due to the growing realization that they are in control of neither the euthanasia procedure itself nor the outcome, as the euthanasia procedure is based on joint consultation with all physicians and usually also – although not legally required – with the relatives involved. In addition, almost all interviewees, even those who had their request granted, had not felt that their assessment procedure had been ‘dignified’ and hence in that sense doubted whether euthanasia can be regarded as a means for ‘dignified dying’. Most interviewees experienced the whole euthanasia trajectory as an emotional tug-of-war, due to the many self-disclosures and so-called ‘pleas’ for recognition and approval, the presumption of unequal assessment procedures etcetera, putting their perspective of dignified dying at stake.

In addition, the finding of the so-called ‘therapeutic effect’ of physicians taking euthanasia requests seriously as it may calm the patient’s mind resulting in suppressed suicidal ideation and behaviour and increased empowerment to give alternatives to death a fair chance of success^{126,172} was expressed by some, but not all interviewees. If so, this effect seems to have only an ephemeral instead of long-lasting nature. This ambivalence seems to be partially rooted in the different motives for requesting euthanasia (be it in a more tentative, exploratory, prospective, or urgent way) and partially due to the euthanasia trajectory being perceived as burdensome. The mixed findings regarding ‘the therapeutic effect’ may also be partially ascribed to the individual patient characteristics, as the interview study among health care professionals and volunteers (Chapter 11) revealed that the two-track approach may function as a double-edged sword. It also seems due to the existing barriers to accessible, affordable, and qualitative mental health care, as previously discussed.

A recently published and interesting position paper of Nicolini et al. (2021)³⁰⁹ pointed to the preponderance of female euthanasia deaths in this patient group and tried to explain it using the ideation-to-action theory of suicide. Multiple models of ideation-to-action theories of suicide exist, and they all come down to

what factors may lead a person from suicide ideation to suicide attempts, with access to lethal means and perceived capability to make use of them are amongst the factors. Also, it is well known in the literature of suicidology that women have an increased risk of non-fatal suicidal behaviour compared to men, who are more likely to die from suicide (= gender gap) due to the latter capability of making use of more effective means to kill themselves, e.g., firearms. Nicolini et al. (2021)³⁰⁹ formulated the hypothesis that euthanasia requests could be considered as one of many more ways to prematurely end their life that would be preferred by women due to its non-violent and effective character, as they are less likely to complete suicide themselves.

However, one should not shy away from the core question of the motivation behind the question of *why* these women (and fewer men) want to have their lives ended in the first place and if this could be attributed to other socio-cultural factors as well?

To date, scarce evidence from Dutch and Belgian quantitative studies only addressed the presence (thus, not the potential influence and role) of the following determinants: (1) gender, with the abovementioned preponderance of female euthanasia requestors and deaths, (2) age, with a growing proportion of the younger generation (< 30 years) requesting (and being disproportionately denied) euthanasia, and (3) clinical determinants, with a majority suffering from at least one psychiatric condition, with mood, personality and autism spectrum disorders as the most common ones.¹²⁴ The data collected did not allow for other determinants to be captured. In addition, the scarce evidence is mostly based on the relatively small numbers of euthanasia deaths, which is striking, as the majority of these requests end up rejected or withdrawn.^{88,169,308}

Recommendations for future research

In an increasingly diverse society, rapidly evolving in terms of fluidity (e.g., gender fluidity) and multi-ethnicity, more research is needed to address individual and socio-cultural determinants and mechanisms underlying these euthanasia requests. This may allow us to develop a socio-ecological model of euthanasia and to understand how it relates to already existing ones (cf. socio-ecological models of suicide).^{307,398,399} The gathered findings can serve not only

the euthanasia practice but can improve the current (culture-sensitive) state of the psychiatric practice as a whole (i.e., the problem-, recovery-, as well as palliative-oriented psychiatry).

6. Concluding thoughts

This PhD-trajectory was meant to lead to much-needed insights into the understudied euthanasia practice in the context of adult psychiatry, from both a patient and healthcare worker perspective. In what follows I will offer my overarching conclusions.

From our findings I conclude that the legal option for euthanasia in APC can be preserved. A substantial proportion of psychiatrists as a group – actors with intimate knowledge on the issue – seem to be in favour of this legal option: 3 out of 4 responding psychiatrists indicated as much in our survey. Even if all the other psychiatrists working with APC would think otherwise – which is highly unlikely – one out of 5 would be in favour, agree that APC can be deemed mentally competent, experience unbearable suffering without any prospect of improvement and be in a medically incurable condition. This means as much as saying that some APC can meet the core legal requirements in the original euthanasia law. Also, it is important not to discriminate or stigmatize APC (as is so often the case with this group) by excluding them from the option of euthanasia, which is available to so many other people with serious incurable illness. As seen in Canada, excluding this option for APC may not stand up to legal tests.

However, the many rich data did point to the many challenging aspects surrounding these euthanasia trajectories and how some of these can be tackled. Below I will formulate some main suggestions, running like a thread from concrete measures that may prevent a proportion of APC from requesting euthanasia, to suggestions aiming to achieve the highly needed level of 'best clinical euthanasia practice', and even to proposed issues to be (re)considered if the Law on Euthanasia would be subject of parliamentary debate and amendment, which is, of course, a political decision.

First and as regards preventive measures, the time is now (not to say years ago) to take societal responsibility instead of passing the buck to the underfunded field of psychiatry. I was particularly taken aback when APC testified on adversity in their early life, when being e.g., abused in their family of origin, admitted to 'foster care' where they could not be protected from continuous maltreatment and abuse. There is definitely a need for enhanced services to meet the needs of youth, if we want these vulnerable people to stand a chance in later life. But even then, there will always be people in need of mental healthcare. If we would strive for more APC to stand a chance in life, the difficult-to-treat may no longer fall off the psychiatric wagon. This care must at least be lifted to the level of easy-to-treat patients, and arguably even beyond that. The amount of euthanasia requests voiced by APC could be seen by policymakers as the 'canary in the mine' of sorts, of how well our healthcare system is performing for people with longstanding and complex psychiatric problems, an extremely vulnerable group in society. Knowing that in Belgium, barely 6% of the total healthcare budget is invested in mental health, a figure below the minimum OECD standard of 10%, is hard to grasp. Especially in a country that records one of the highest suicide rates in the European region and that allows euthanasia for APC. In that respect, it is striking to notice that rehabilitation, palliative care, and oyster care approaches, and even promising therapeutic approaches with (to date) illegal drugs are still in their infancy. Euthanasia must only be an option to hasten death if and only if all reasonable psychiatric resources are exhausted. But even the more traditional, regular psychiatric care has her own responsibility to take in preventing APC from additional 'iatrogenic trauma', i.e., trauma caused by experiences with and within the healthcare system. In this respect, a critical analysis and reflection are essential regarding when, why and how more paternalistic approaches and coercion can be used under which circumstances and to what extent.

Second, the time is now to achieve a best-clinical assessment practice for euthanasia because it cannot be ruled out that the abovementioned measures will not suffice, and that some APC will always request euthanasia and enter a euthanasia trajectory under the current Law. Our survey revealed that only a minority of psychiatrists – even those in favour of euthanasia in APC – are willing to engage in euthanasia trajectories other than as referring physician, mainly

because the legal criteria do not translate easily to the field of psychiatry and because the euthanasia trajectory is difficult to reconcile within the therapeutic alliance. But just because something is difficult does not mean it should be avoided or banned. If one accepts the potential for eligibility of APC for euthanasia under the current legal requirements, then the challenge should be met by professionals. This reluctance, while it may have detrimental effects if discussion is blocked entirely, is also a healthy basic attitude so as not to agree with or approve the request too easily (and hence corroborating the contra-argument that euthanasia constitutes an 'easy way out' for society for this patient group instead of focusing more on care and recovery). There is great distance between entering into conversation about death and uncritically granting the request.

Of course, the more challenging a task, the more welcome practice guidelines are. This PhD project took place just when guidelines of all kinds were being issued. Their implementation may take some time and their effect may only become apparent later. Follow-up research should determine to what extent they meet the needs of all practitioners involved and where they can be further refined. In any case, our research has already revealed some gaps, e.g., how to position the role of 'relatives' (a concept that itself should be concretised). In addition, these written guidelines were designed with a strict emphasis on practical policy-implementation, e.g., on how the legal requirements can be adequately embedded in the field of psychiatric medicine and which additional safeguards are deemed recommended. Notwithstanding the best intentions underlying the guidelines, the field of practice must strive to go one step further than a tick-box exercise and develop a best-clinical euthanasia policy, preferably one single and inclusive one (as every patient is entitled to an equal consideration of her best interests) though tailored to the specific needs of each psychiatric facility and patient group (not a contradiction, as clinical and background profiles do differ). I posit here that overly crystallizing criteria and practice requirements (i.e., translation of criteria) is not the province of politicians, but rather of the profession itself.

It is my hope that more psychiatrists would dare to engage, as this PhD study clearly shows that euthanasia requests are often more a cry for additional help than a cry for help in dying. In that sense, euthanasia assessment can in the first

place be regarded as a starting point for reviewing APC's entire life context and recalibrating guidance and treatment if possible. The most important thing here is not to dismiss them with their question, but to look at what can still be done for them through conversations about their death wish – in all the areas they are struggling with. This should in any case be part and parcel of the euthanasia assessment procedure. In certain cases, as suggested by our research, the beneficial effect of open discussions on the death wish can be considerable. Feeling heard and being recognized in their suffering can already do a lot for APC. Even with approval for euthanasia, some APC conjure up the courage to continue living, safer in the knowledge that there is an 'emergency brake' in case they don't succeed in obtaining a certain level of quality of life. Of course, this does not imply that all APC will rescind their request; some may in the end qualify for euthanasia according to the legal criteria, after thorough clinical assessment.

In this respect, it is abundantly clear from our research that APC's unbearable suffering stems from more than just the medical component of their situation. That is why the assessment of a euthanasia request must not be entrusted solely to the psychiatrist. There is a clear need for a multidisciplinary approach in assessment, involving e.g., general physicians, geriatricians and clinical psychologists (a profession also experienced in testing and assessment). In this way, decision making can automatically become more robust: with more (already involved) people come more, different perspectives and more diverse insights into the entire situation of the APC. Involvement of one or more members of the social circle can also be desirable or recommended, as long as the APC agrees with their involvement – though as we have seen this can also constitute an extensive additional stressor for APC. In any case, further research is needed to explore in-depth to what extent and how non-medical factors play a role in euthanasia applications by APC, what the source(s) of suffering is and how they are connected to the APC's medical condition, of which its incurability and irremediability is still the core prerequisite for eligibility for euthanasia.

As to which concrete measures are to be taken to bring more consistency in euthanasia assessment and practice, I offer a few thoughts.

- First, practice will always benefit from more objectification in assessment. The use of a standardized instrument on 'mental competence' is recommended.

Instruments such as the NEOSI are welcome tools, in this case for determining the nature and extent of APC's suffering, to base assessment, follow-up and consultations on. Here too, I see another task for research, i.e., to develop, test and prepare relevant and valid instruments for implementation in assessment practice.

- Second, we could consider formulating additional (procedural) criteria for the non-terminally ill, albeit not solely for APC to not produce a discriminatory effect for APC. Measures such as an a priori assessment (e.g., via consultation of an ethics committee) entail risks. Given the perceived arduous trajectory of recurrent consultations with different physicians and the many uncertainties, APC already have the strong idea of having to jump through a large number of hoops, so adding any extra hoops must be considered with extreme caution. Organs such as an ethics committee might be populated by people with a priori restrictive normative standpoints on the issue, leading to blockage of any euthanasia requests based on ideology, and regardless of APC's eligibility. This would need to be avoided at all costs, to ensure a reliable and trustworthy process.
- Third, abandoning the 'colloque singulier' for this group and requiring agreement of more than one physician (instead of colleagues merely being consulted) can be an interesting consideration to include in practice guidelines. Striving for consensus and putting the final decision in the hands of more than one physician – and ideally physicians with complementary expertise, e.g., also general physicians and psychologists who may have a more holistic view of the APC they follow in their practice – will provide better guarantees for adequate decision making and will also instil physicians themselves with more confidence that their end decision is sound. Actually, consensus-seeking is already occurring standardly in euthanasia practice today.
- Fourth, APC are now (too) quickly referred to end-of-life consultation centres. These centres seem to work like magnets for APC, allowing treating physicians to 'pass the buck'. Our findings reveal that these centres are both praised and criticised. As regards the first, they are considered, e.g., a highly needed and much consulted 3rd line partner for the 'individual professional' and as low thresholds for serene talks about death for patients with complex clinical features. However, this 'low threshold' is threatened by waiting lists

and understaffing. In addition, poor professional collaboration and even APC being victim of internal rivalries between centres were mentioned in interviews. A debate is needed on what should be the 'position' or role of these centres. Nonetheless, given the amount of APC they have already encountered, they have arguably built-up considerable expertise in the consultation and accompaniment of APC with a euthanasia request. In the future, such centres could shift their mission to a more advisory role for psychiatrists and a more supporting role for APC. In this way, these centres can serve and support euthanasia assessment procedures as much as possible, without being expected to take over from attending psychiatrists. In case there were any need among attending physicians regarding how to handle and assess euthanasia requests, training and instruction can be offered by these centres.

As a final note and as regards potential future Law amendment: for treating physicians who – for whatever reasons – are not willing or ready to engage, a more realistic timeframe should be offered for (meaningful) referral. As many APC must wait several months to even find regular psychotherapeutic help, a referral within one week in the context of a euthanasia request seems unrealistic. Personally, I do understand that this frustrates many physicians. As death is not foreseeable in the majority of these cases and a proportion of these euthanasia requests are not a cry for help in dying but a cry for extended aid in life, a month reflection time, for both the physician and the APC, seems more realistic. Also, a posteriori monitoring is a thorn in many physicians' sides, and it clearly does not suffice to rely on the FCECE's biennial reports (no individual case level monitoring). If the need for this robust monitoring has not yet become clear with this research, then it will never be. To Government and policymakers, I would urge you to develop a program for an adequate and independent monitoring of the euthanasia practice, as in The Netherlands by means of their quinquennial reports for governmental debate purposes and scientific reviews of carried-out cases that the Dutch regional euthanasia review committee post online.

In addition, I believe that there must be a way to find a middle course between the provision of measures to tackle the concerns on the lack of an a priori evaluation on the one hand and unnecessarily overburdening the euthanasia practice on the other hand. On a personal note and taking into account the many

private and group practices that do not have ethical committees to discuss euthanasia cases with as well as the abovementioned caveats surrounding local ethical committees, the establishment of small provincial a priori evaluation commissions (cf. The Netherlands) can be considered to split the workload on euthanasia cases concerning the non-terminally ill. In order to cut the administrative tape, the attending (and preferably also the advising) physician may fill in the already existing FCECE documents. To not overly extend the euthanasia trajectory, the provincial committee's feedback should be hand-in within a specified timeframe (cf. Spain), e.g., within 1 month. When the case culminates in euthanasia, the attending physician may then send the document, completed with the details on the act itself and the provincial's committee feedback to the FCECE for a posteriori evaluation.

To conclude, although euthanasia requests from APC are rather rare and seldom granted, they cannot fall off the radar on grounds of a low prevalence rate. Any debate about ways forward or backward regarding the euthanasia practice in psychiatric patients will inevitably remain heated, but as a pioneering country with one of the most progressive laws on euthanasia, Belgium must be on the forefront to undertake these much-needed actions. This PhD study must be seen as a nudge into this direction.

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SUMMARY

This dissertation is based on the papers submitted to, or published in, scientific journals during the course of my PhD (October 2017-December 2021).

Chapter 1 provides a general overview of the current state of adult psychiatry in Belgium. Then, the historical background of the euthanasia debate is portrayed, as well as the road towards euthanasia legislation in Belgium and its implementation in the Belgian clinical practice, and compared with the legal frameworks in other countries. Chapter 1 concludes with an overview of past research studies on euthanasia in general and in the context of adult psychiatry, before zooming in on the research purpose and questions.

The overarching research aim is to set a firm research agenda in order to establish a more thorough understanding of the euthanasia practice in the context of adult psychiatry in Belgium. In doing so, the following 3 main objectives are distinguished, each consisting of several research questions to be answered.

Objective 1: to describe the first written guidelines on how to deal with euthanasia requests in the context of adult psychiatry

1. What are the added value and potential shortcomings of the Flemish written guidelines on how to adequately deal with euthanasia requests and procedures in the context of adult psychiatry?
2. What are the added value and potential shortcomings of Ghent University Hospital's step-by-step protocol on how to deal with euthanasia requests from external facilities?

Objective 2: to provide the first insights into why adults, predominantly suffering from psychiatric conditions, request euthanasia in Belgium.

3. How do these people phrase the nature and extent of their suffering experiences, and what renders their suffering unbearable?

4. What are their motives for requesting euthanasia, how does it relate to suicide, and what would have prevented them from considering a hastened death?
5. How do they phrase the impact of the euthanasia procedure on their mental state, their clinical trajectory, and their social relationships?

Objective 3: to provide the first insights into psychiatrists' attitudes and engagement regarding euthanasia in the context of psychiatry, as well as the first insights into their, and other health care workers', concrete experiences and support needs regarding these euthanasia trajectories.

The following research questions were set:

6. What are psychiatrists' attitudes towards, and readiness to engage in, euthanasia assessment procedures and/or performance concerning these adults with psychiatric conditions?
7. To what extent have these psychiatrists been confronted with, and engaged in, psychiatric euthanasia practice?
8. What can be learned from their latest experience with a completed euthanasia case (irrespective of its outcome)?
9. How do physicians and other care workers phrase their concrete experiences and support needs regarding the euthanasia trajectory concerning this patient group?

In **Chapter 2**, the 5 written guidelines were described and discussed by means of a point-by-point critical reflection on: 1) the measures proposed to operationalise the legal requirements; 2) suggestions for additional safeguards going beyond the legal requirements; and 3) the areas for improvement. The analysis showed that all initiatives advocate for stricter care criteria, such as the mandatory consultation of not one, but at least two psychiatrists, and the establishment of a two-track policy where the focus is put both on life (a continued and further exploration of alternatives to death) and on the possible end of life (the clarification of the euthanasia request). The guidelines' recommendations differ from one another. Some of the differences between the guidelines reflect different ethical stances towards euthanasia, while others reflect differences in views regarding the practical implementation of the legal due care criteria. The most notable differences relate to the suggestion to (not)

establish an a priori evaluation system and to (not) ensure an extended reflection period between the euthanasia request and the actual performance of euthanasia.

Notwithstanding the initiatives resulted in some useful advice for adequate decision-making, some shortcomings were identified. These shortcomings include little attention for the aftercare of patients, especially those whose euthanasia request ends up rejected, and how the involvement of important relatives can be concretised. Insufficient attention was also paid to the manner in which serious or manipulative suicide threats and/or negative or contradictory advices from fellow advising physicians should be dealt with.

Chapter 3 provided a detailed description and discussion of the step-by-step protocol of Ghent University Hospital on the management of euthanasia requests coming from patients from outside their psychiatric walls. The protocol stipulates several due care criteria that go beyond the requirements of the Belgian Euthanasia Law. For instance, the legally required first and second consulted physicians should all be psychiatrists and be affiliated with a psychiatry department of a Flemish university hospital. Moreover, euthanasia for psychological suffering can only be performed if the advices of these consulted physicians are positive. Importantly, preliminary reflection by the multidisciplinary Hospital Ethics Committee was introduced to discuss every request for euthanasia for psychological suffering coming from outside the hospital.

In this way, the protocol supports psychiatrists faced with the complexities of assessing such requests, improves the quality of euthanasia practice by ensuring transparency and uniformity, and offers patients specialised support and guidance during their euthanasia procedure. Nevertheless, some concerns still remain (e.g. relating to possible unrealistic patient expectations and to the absence of aftercare for the bereaved or for patients whose requests have been rejected).

Chapter 4 zooms in on the legal criterion of 'persistent and unbearable suffering'. The physician is expected to be reliably assess this criterion, even though assessment tools to objectify the criterion are unavailable. As yet, there is not even a generally accepted, but only a cautiously suggested definition of

"unbearable suffering", which is mainly based on scientific studies concerning patients predominantly suffering from somatic conditions. Therefore, the research agenda was set for the first study focusing on the analysis of the spontaneous testimonies of 26 people with both a psychiatric illness and a request for euthanasia, who described the unbearableness of their experienced suffering. Five domains of suffering were distinguished: 1) medical, 2) intrapersonal, 3) interpersonal, 4) social and 5) existential forms of suffering. The 26 people also indicated the extent of their suffering. Results revealed that these people were confronted with a variety of difficulties in life that often started at early age, accumulated and worsened over time, and became chronic, therapy-resistant and pointless. The suffering of these patients was therefore not only expressed in the medical symptoms, but also in the social and societal consequences of the progressively degenerating course of mental illness.

This demonstrates the importance of personal and civic commitment, and relational connectedness, all essential prerequisites for these people to transcend their suffering towards a meaningful, dignified life despite their illness. Where these people pinpoint the limits of psychiatry, it should be noted that it's also up to the society as a whole, to tackle societal and economic inequalities and other injustices. After all, it must never be the physicians' task to solve society's failure by means of euthanasia, only because no suitable job, no sufficient qualitative social contact and no appropriate care can be offered.

Chapter 5 concerned a research study that aimed to develop a new assessment instrument that maps the nature and extent of unbearable suffering indices (NEOSi) in adults with psychiatric conditions, and to establish its cognitive validity. During a first round of cognitive interviews a variety of issues regarding content, form and language were reported, relevant aspects of suffering were deemed missing and the answering options were perceived as imprecise. These findings underline the relevance of cognitive validation studies in order to detect and resolve problems in the early stage of instrument development. All participants made suggestions for improvement, expressed their appreciation for this research topic and method, and were willing to participate in a follow-up study.

The assessment instrument was adjusted according to the participants' feedback and its cognitive validity was optimised by means of a second round of cognitive

interviews. The results indicated that participants perceived the items of the adjusted instrument sufficiently comprehensible, sensitive to delicate nuances, and all-inclusive. The answer options were perceived as easy and more precisely to answer. In addition, a commonly shared preference on clustered items, item sequence and logical structure was distinguished. All participants voiced their appreciation of the research topic and method. This research resulted in a cognitive valid assessment tool to evaluate unbearable suffering in a more concrete, objective and measurable way.

Chapter 6 concerned an in-depth interview study with 16 patients who had their euthanasia request under assessment in the period 2016-2020. The study aimed to deepen our understanding of why these patients request euthanasia, how this relates to the option of suicide, and what could have prevented these-patients from considering death and requesting euthanasia.

The findings revealed that most patients were in a state of feeling emotionally worn-out as a result of the many accumulated misfortunes and setbacks, leading to the all-pervasive sense that life is no longer worth living. Whereas some patients reported lifelong adversity, others struggled predominantly in later life. Whereas some patients longed for death strongly, others expressed ambivalence towards death ideation, and some even requested euthanasia to hear of their ineligibility for it, to restore hope and to (re)find meaning in life. Patients valued euthanasia over suicide as being more dignified and acceptable, both for themselves and for their inner circle. With regard to preventive factors, patients posited the need for improved accessibility and quality of mental healthcare, as well as a profound change in society's perception of, and support for, these patients.

Chapter 7 reports on the impact of the euthanasia assessment procedure as experienced by these 16 patients on 3 counts: 1) their mental state, including death ideation; 2) their treatment trajectory; 3) their social relationships.

The findings of this in-depth qualitative interview study revealed that the euthanasia assessment procedures brought out a plethora of experiences, both favourable and unfavourable. Whereas thoughts of suicide remain present to a certain extent, being in the assessment procedure prompts some patients to reconsider alternatives towards life, and also to attempt new treatment options.

However, many patients experience ambivalence about the supposedly inherent desirability and dignity in euthanasia. Worries also surfaced about the rationale behind, and the effects of, involvement of the patient's social circle, and about the impact it could have on them.

Chapters 8 to 10 present the results from one recent survey study among psychiatrists affiliated with the Flemish Association of Psychiatry. **Chapter 8** focuses on the responding psychiatrists' attitudes regarding euthanasia in general and euthanasia in the context of psychiatry in particular. Results showed that close to three quarters of responding psychiatrists agree that euthanasia should remain permissible for this patient group. However, almost 7 out of 10 question some of the approaches taken by other physicians during the euthanasia assessment and only half consider euthanasia assessment procedures compatible with the psychiatric care relationship. Where active engagement is concerned, an informal referral (68%) or preliminary advisory role (43.8%) is preferred to a formal role as a legally required advising physician (30.3%), let alone as performing physician (< 10%).

Chapter 9 reveals their concrete experiences in psychiatric euthanasia practice. During their careers, 80% of those responding have been confronted with at least one euthanasia request predominantly based on psychiatric conditions, and 73% have become involved in the assessment procedure. Their engagement was limited to the roles of: referring physician (in 44% of the psychiatrists), attending physician (30%), legally required 'advising physician' (22%), and physician participating in the actual administration of the lethal drugs (5%). Within the most recent 12 months of practice, 61% of the respondents have been actively engaged in a euthanasia assessment procedure and 9% have refused at least once to be actively engaged due to their own conscientious objections and/or the complexity of the assessment. The main motive for psychiatrists to engage in euthanasia is the patient's fundamental right in Belgian law to ask for euthanasia and the psychiatrist's duty to respect that. The perception that they were sufficiently competent to engage in a euthanasia procedure was greater in psychiatrists who have already had concrete experience in the procedure.

Chapter 10 provides more detailed information on 46 unique cases, based on the psychiatrists' latest experience with a completed euthanasia assessment

procedure, irrespective of its outcome (i.e., whether euthanasia was performed or not). Findings revealed that most patients suffered from comorbid psychiatric and/or somatic disorders, and had received different kinds of treatment for many years prior to their euthanasia request. Existential suffering was the main reason for the request. The entire procedure spanned an average of 14 months, and an average of 13.5 months in the 23 cases that culminated in the performance of euthanasia. In all cases, the entire procedure entailed multidisciplinary consultations, including with family and friends.

Psychiatrists reported fewer difficulties in assessing due care criteria related to the patient's self-contemplation – e.g., unbearable suffering on top of the due care criteria related to their medical condition; incurability due to lack of reasonable treatment perspectives. In a few cases in which euthanasia was the outcome, not all legal criteria were fulfilled in the reporting physicians' opinions. Both positive and negative experiences of the assessment procedure were reported: e.g., reduced suicide risk for the patient; an emotional burden and a feeling of being pressured for the psychiatrist.

Chapter 11 is based on the results of an in-depth interview study with 16 physicians and 14 other mental healthcare professionals or volunteers (other than the patients' relatives acting as family caregivers). Their concrete experiences concerned the following 8 domains: (1) the impact of euthanasia on the clinical trajectory and (2) on the therapeutic relationship, (3) internal and (4) external collaborative partnerships, (5) patients' social inner circle (non-)involvement, (6) the use of recently published guidelines and, (7) the first criminal trials on this topic, and (8) the act of euthanasia. Their concrete support needs concerned; (1) protocols addressing specific sub-populations and pathologies, (2) protocols specifically drawn up for non-medics, (3) guidance on how to adequately implement the two-track approach, (4) (after)care for patients, (5) (after)care for the health care team, (6) guidance on the patient's social inner circle involvement, (7) enhanced education measures, and (8) enhanced financial measures, including incentives for holistic, palliative care approaches.

Chapter 12 represents the final part of the PhD-dissertation and consists of: 1) a recap of the research objective and questions, 2) a discussion of the methodology used per research study, including its main strengths and

limitations, 3) an overview of the main findings, 4) a discussion of a few important matters deserving the fullest attention, including recommendations for policy, practice and future research, and 5) concluding thoughts, written from my individual perspective.

As regards the latter, the emphasis is put on how complex the euthanasia practice is, due to e.g., the differences in patient's clinical and background profiles, in the variety of motives for requesting euthanasia, in the multi-layered aspects of suffering that often transcend the resources of the (underfunded) field of psychiatry, and how challenging the translation of the legal criteria in psychiatry is. When browsing through the electronic databases of the Belgian parliament's debates preceding euthanasia legislation, it was clear that the legislator did not have the adult person, predominantly suffering from psychiatric disorders, in mind. In the event of future amendments, it seems highly necessary to take the specific features of this sub-discipline and sub-group into account. In my opinion, it would be unjust and discriminatory to exclude the option of euthanasia for this particular patient group, but it would be fair to consider different wordings and procedural criteria that would suit the context of adult psychiatry better. But above all, I would recommend and wish psychiatry to be better funded and better equipped with recovery- and palliative-oriented approaches in the mental healthcare professionals' toolbox. Euthanasia must never be used as a tool to solve society's failures as this would lead the profession away from medicine towards re-entering its darkest pages in history.

SAMENVATTING

Dit proefschrift is gebaseerd op alle papers die in de loop van mijn doctoraatstraject (oktober 2017-december 2021) gepubliceerd (of formeel ingediend) werden in enkele wetenschappelijke tijdschriften.

Hoofdstuk 1 schetst een algemeen overzicht van de huidige status van de volwassenenpsychiatrie in België. Vervolgens werd de historische achtergrond van het euthanasiedebat weergegeven, evenals de weg naar de uiteindelijke euthanasiewetgeving in België en de implementatie ervan in de Belgische klinische praktijk. De Belgische euthanasiewetgeving wordt ook kort vergeleken met de wettelijke kaders in andere landen. Hoofdstuk 1 sluit af met een overzicht van de huidige stand van wetenschappelijk onderzoek naar euthanasie in het algemeen en in de context van de volwassenenpsychiatrie in het bijzonder, alvorens in te zoomen op de onderzoeksdoelen en de bijhorende onderzoeksvragen.

Het overkoepelende doel was het aanscherpen van de onderzoeksagenda inzake euthanasie om (eindelijk) de euthanasiepraktijk in de context van de volwassenenpsychiatrie in België onder de onderzoeksloep te nemen. Daarbij worden de volgende 3 hoofddoelstellingen onderscheiden, elk bestaande uit meerdere onderzoeksvragen die om antwoorden schreeuwden.

Doelstelling 1: het kritisch beschrijven van de eerste schriftelijke initiatieven inzake het adequaat omgaan met euthanasieverzoeken in de context van de volwassenenpsychiatrie.

De daarbij horende onderzoeksvragen luiden als volgt:

1. Wat zijn de pluspunten en mogelijke tekortkomingen van de Vlaamse richtlijnen over hoe adequaat om te gaan met euthanasieverzoeken en -procedures in de context van de volwassenenpsychiatrie?
2. Wat zijn de pluspunten en mogelijke tekortkomingen van het stapsgewijze protocol van het UZ Gent over hoe om te gaan met euthanasieverzoeken van patiënten die in externe instellingen behandeld worden voor hun psychopathologie?

Doelstelling 2: het verschaffen van de eerste noodzakelijke inzichten in waarom volwassenen die overwegend lijdend aan psychiatrische aandoeningen euthanasie aanvragen in België.

De daar bijhorende onderzoeksvragen luiden als volgt:

3. Hoe verwoorden deze mensen de aard en de omvang van hun lijdenservaringen, en wat maakt hun lijden zo ondraaglijk?
4. Wat zijn hun (onderliggende) motieven om euthanasie te vragen, hoe verhoudt de euthanasievraag zich tot zelfmoord, en wat hadden ze nodig om niet met deze euthanasie- en of suïcidegedachten te worstelen?
5. Hoe verwoorden zij de impact van de euthanasieprocedure op hun mentaal welzijn, op hun klinisch traject, en hun sociale relaties?

Doelstelling 3: het verschaffen van de eerste noodzakelijke inzichten in de attitudes en het engagement van psychiaters ten aanzien van euthanasie in de context van de volwassenpsychiatrie, alsook de eerste inzichten in de concrete ervaringen en ondersteuningsnoden van henzelf, en van andere hulpverleners, met betrekking tot deze euthanasietrajecten.

De volgende onderzoeksvragen werden gesteld:

6. Wat zijn de attitudes van psychiaters ten aanzien van, euthanasie en (in welke mate) zijn ze bereid om zich te engageren voor de uitklaring, het adviseren of uitvoeren van deze euthanasieverzoeken?
7. In hoeverre zijn deze psychiaters reeds geconfronteerd met, en betrokken geweest bij, deze euthanasietrajecten?
8. Wat kunnen we leren uit hun laatste ervaring met een afgeronde euthanasiezaak (ongeacht de uitkomst)?
9. Hoe verwoorden artsen en andere hulpverleners hun concrete ervaringen en ondersteuningsnoden met betrekking tot deze euthanasietrajecten?

In **hoofdstuk 2** werden 5 adviesteksten beschreven en bediscussieerd door middel van een puntsgewijze kritische reflectie over: 1) de voorgestelde operationalisering van de wettelijke zorgvuldigheidscriteria; 2) de gesuggereerde aanvullende zorgvuldigheidscriteria; en 3) de mogelijke verbeterpunten. Uit de

analyse bleek dat alle initiatieven pleiten voor striktere zorgvuldigheidscriteria, zoals het verplicht consulteren van niet één, maar ten minste twee psychiaters, en het instellen van een tweesporenbeleid waarbij de focus zowel op het leven (de verdere behandeling van de psychopathologie) als op het mogelijke levenseinde (de uitklaring van het euthanasieverzoek) wordt gericht. Ondanks deze overlap werden er ook verschillen in de aanbevelingen bespeurd. Deze aanbevelingen werden toegeschreven aan verschillen in waarden-gestuurde standpunten en aan een verschil in focus (klinische beoordeling dan wel overkoepelende ethische reflectie). De meest opvallende verschillen tussen de onderzochte initiatieven hebben betrekking op de voorstellen om al dan niet een a priori evaluatiesysteem in te stellen en om een al dan niet langere verplichte reflectieperiode te waarborgen tussen het euthanasieverzoek en de uitvoering.

Alle initiatieven resulteerden in enkele zinvolle adviezen voor een adequate besluitvorming, maar ook enkele tekortkomingen. Het gaat daarbij onder meer om het gebrek aan aandacht voor de nazorg van patiënten, vooral voor diegenen wiens euthanasieverzoek werd afgewezen, en hoe de betrokkenheid van belangrijke naasten vorm dient te krijgen. Ook werd onvoldoende aandacht besteed aan hoe er adequaat kan omgegaan worden met een ernstige dan wel manipulatieve suïcidedreiging of/en negatieve of tegenstrijdige adviezen van collega-artsen inzake het euthanasieverzoek.

Hoofdstuk 3 gaf een gedetailleerde beschrijving en bespreking van het stapsgewijze protocol van het Universitair Ziekenhuis Gent over het omgaan met euthanasieverzoeken van patiënten die niet binnen, maar buiten de eigen psychiatrische muren worden behandeld. Het protocol bepaalt verschillende zorgvuldigheidseisen die verder gaan dan hetgeen de Belgische euthanasiewet voorschrijft. Zo moeten beide (wettelijk vereiste) geraadpleegde artsen psychiater zijn, en de tweede geraadpleegde psychiater moet aan een psychiatrische afdeling van een Vlaams universitair ziekenhuis verbonden zijn. Bovendien kan de euthanasie uitsluitend worden uitgevoerd als alle ingewonnen adviezen positief zijn. Belangrijk is ook dat de multidisciplinair samengestelde ethische commissie van het Universitair Ziekenhuis Gent als a priori commissie functioneert in de zin dat elke stap van het euthanasietraject besproken wordt tijdens een samenkomst met deze ethische commissie.

Op die manier ondersteunt het protocol de eigen psychiaters die geconfronteerd worden met de complexiteit rond de evaluatie van zulke euthanasieverzoeken, verbetert het de kwaliteit van de euthanasiepraktijk door te zorgen voor een transparante en uniforme behandeling van al deze euthanasieverzoeken, en biedt het patiënten een gespecialiseerde ondersteuning en begeleiding tijdens hun euthanasietraject. Toch werden er enkele kritiekpunten geïdentificeerd, bijvoorbeeld rond het adequaat omgaan met mogelijke onrealistische verwachtingen van de patiënten en het ontbreken van nazorg voor de nabestaanden of voor patiënten wier verzoek is afgewezen.

Hoofdstuk 4 zoomde in op het wettelijk criterium 'aanhoudend en ondraaglijk lijden'. Van de arts wordt verwacht het aanhoudend ondraaglijk lijden te kunnen inschatten of invoelen, ook al zijn er geen objectiveerbare tools voorhanden. Vooralsnog bestaat er zelfs geen algemeen aanvaarde, maar slechts een voorzichtig gesuggereerde definitie van 'ondraaglijk lijden', die voornamelijk gebaseerd is op wetenschappelijke studies naar ondraaglijk lijdende patiënten met een overwegend somatische aandoening. Daarom werd het voortouw genomen om een eerste wetenschappelijke studie te lanceren die zich focust op de analyse van 26 spontane getuigenissen van mensen met zowel een psychiatrische aandoening als een euthanasieverzoek over de ondraaglijkheid van hun lijden. Vijf domeinen van lijden werden daarbij onderscheiden: 1) medische, 2) intra-persoonlijke, 3) interpersoonlijke, 4) sociaal-maatschappelijke en 5) existentiële vormen van lijden. Daarnaast gaven de patiënten ook de omvang van hun lijden aan dat aan de basis van hun euthanasieverzoek lag. Vaak werden patiënten reeds op zeer jonge leeftijd geconfronteerd met tal van problemen die na verloop van tijd accumuleerden, verergerden en vaak een chronisch, therapieresistent en uitzichtloos karakter kregen. De lijdensdruk van deze patiënten uitte zich dus niet alleen in de medische symptomen, maar ook in de sociale en maatschappelijke gevolgen van een vaak chronisch en progressief degenererend ziekteproces.

Hieruit blijkt het belang van persoonlijke engagementen, relationele verbondenheid, gelijke kansen en productieve bijdragen aan de maatschappij als essentiële randvoorwaarden om mensen met een gehavende geestelijke gezondheid op weg te zetten naar een zinvol, menswaardig bestaan. Waar de patiënt de medische praktijk wijst op de grenzen en drempels van medische

mogelijkheden om de symptomen van de aandoening te verlichten, ook tijdens de uitklaring van een euthanasieverzoek, dient opgemerkt te worden dat de samenleving in haar geheel gebaat is bij een grondig en diepgaand debat om deze sociale, maatschappelijke en economische ongelijkheden en drempels weg te werken. Het mag en kan immers nooit de taak van de arts zijn om het falen van de maatschappij via euthanasie op te lossen, omdat geen geschikt werk, voldoende kwalitatieve sociale contacten of gepaste zorg kunnen aangeboden worden.

Hoofdstuk 5 spitste zich toe de ontwikkeling van een cognitief valide screeninginstrument (NEOSi genaamd) dat de aard en omvang van ondraaglijk lijden in kaart kan brengen. Tijdens een eerste ronde cognitieve interviews werden er zowel inhoudelijke, vormelijke als taalkundige problemen bij het merendeel van de items vastgesteld, en de antwoordcategorieën 'frequentie' en 'intensiteit' werden onvoldoende genuanceerd bevonden en relevante lijdensaspecten waren nog niet in het instrument opgenomen. Dit benadrukt het belang van cognitief valideringsonderzoek om problemen al in het beginstadium van de ontwikkeling van een vragenlijst te detecteren en weg te werken. Alle deelnemers gaven zelf suggesties voor verbetering en aanvulling, spraken hun waardering uit over onderzoek en meetmethode, en wensten betrokken te worden bij vervolgonderzoek.

Het assessment instrument werd aangepast in overeenstemming met de feedback van de deelnemers en tijdens een tweede cognitieve interviewronde getest. Uit deze resultaten bleek dat alle deelnemers het aangepaste instrument voldoende begrijpelijk, genuanceerd, exhaustief, en makkelijk en trefzeker te beantwoorden vonden. Deelnemers spraken een overwegend gedeelde voorkeur uit over de bundeling, volgorde en antwoordopties van de items. Ten slotte drukten deelnemers opnieuw hun waardering uit over onderzoeksthema en meetmethode. Dit onderzoek resulteerde in een cognitief valide beoordelingsinstrument dat de aard en omvang van het lijden binnen diverse levensdomeinen in kaart brengt zodat artsen het op een meer concrete en objectiveerbare manier kunnen evalueren.

Hoofdstuk 6 betreft een diepte-interviewstudie met 16 patiënten die in de periode 2016-2020 hun euthanasieverzoek in review hadden.

Uit de resultaten bleek dat de meeste patiënten zich op emotioneel gebied volledig uitgeput voelden ten gevolge van de vele opeengestapelde tegenslagen tijdens hun levensloop, wat leidde tot het alomtegenwoordige gevoel dat het leven voor hen niet langer de moeite waard is. Terwijl sommige patiënten reeds van kindsbeen af tegenspoed hadden gekend, kregen anderen het vooral op latere leeftijd hard te verduren. Terwijl sommige patiënten sterk naar de dood verlangden, uitten anderen een sterke ambivalentie ten opzichte van hun doodsidesaties. Sommigen verzochten hun arts(en) zelfs om euthanasie om te horen dat zij daarvoor *niet* in aanmerking kwamen, in de hoop om weer een zinvolle betekenis in het leven te kunnen vinden. Initieel hadden deze patiënten een sterke voorkeur voor euthanasie in plaats van suïcide omdat ze euthanasie associeerden met een meer waardig en aanvaardbaar levenseinde, zowel voor henzelf als voor hun naaste omgeving. Wat de preventieve factoren betreft, stelden de patiënten met klem vast dat de povere toegankelijkheid en de povere kwaliteit van de geestelijke gezondheidszorg, alsook de negatieve perceptie van en de verminderde steun voor mensen met een psychiatrische problematiek in de samenleving dringend en grondig hersteld moet worden.

In **Hoofdstuk 7** werd bij diezelfde 16 patiënten gepolst naar de impact van hun euthanasieprocedure op: 1) hun mentale gezondheid, inclusief op hun doodsidesaties; 2) hun behandelingstraject; 3) hun sociale relaties.

De bevindingen toonden aan dat de euthanasieprocedure tal van gunstige alsook ongunstige ervaringen met zich mee kan brengen. Zelfmoordgedachten bleven bij de meeste geïnterviewden tot op zekere hoogte aanwezig, al heeft de euthanasieprocedure er bij sommigen toe geleid dat ze zich voldoende gesterkt voelden om nieuwe behandelingsopties en andere levensgerichte zorg alsnog een kans te geven. Veel patiënten kampten in de loop van de euthanasieprocedure met ambivalente gevoelens ten aanzien van de (vooraf nog veronderstelde) inherente wenselijkheid en waardigheid van euthanasie. Er is ook bezorgdheid gerezen over de beweegredenen om de sociale kring van de patiënt te betrekken bij de euthanasieprocedure, en gewezen op de mogelijke positieve dan wel negatieve impact die dit op de patiënt alsook op sommige leden van de sociale kring zou kunnen hebben.

In hoofdstukken 8 tot en met 10 worden de resultaten gepresenteerd van een recent survey-onderzoek onder psychiaters die aangesloten zijn bij de Vlaamse Vereniging voor Psychiatrie. **Hoofdstuk 8** focust op de attitudes van de bevraagde psychiaters ten opzichte van euthanasie in het algemeen en euthanasie in de context van de volwassenenpsychiatrie in het bijzonder. Uit de resultaten blijkt dat bijna driekwart van de bevraagde psychiaters het ermee eens is dat euthanasie als levenseindeoptie voor deze patiëntengroep mogelijk moet blijven. Bijna 7 van de 10 bevraagde psychiaters plaatsen echter vraagtekens bij de aanpak die collega-artsen tijdens de euthanasieprocedure hanteren en de helft van de bevraagde psychiaters acht euthanasietrajecten verenigbaar met de psychiatrische zorgrelatie. Wat de mate van toekomstig engagement in deze euthanasietrajecten betreft, bereken de meesten hun engagement liefst tot een informele doorverwijzing (68%) of een rol als preliminair adviserend arts (43,8%), en in beduidend mindere mate een formele rol als formeel adviserend arts (30,3%) of uitvoerend arts (< 10%).

In **Hoofdstuk 9** worden hun concrete ervaringen in de psychiatrische euthanasiepraktijk onthuld. Tijdens hun loopbaan werd 80% van de bevraagde psychiaters reeds geconfronteerd met ten minste één euthanasieverzoek dat hoofdzakelijk gebaseerd was op psychiatrische aandoeningen, en 73% is betrokken geweest bij de beoordelingsprocedure. De betrokkenheid was veelal beperkt tot de rol van: doorverwijzend arts (bij 44% van de psychiaters), uitklarend arts (30%), formeel adviserend arts (22%), en uitvoerend arts (5%). In de 12 maanden die vooraf gingen aan de survey bleek dat 61% van de bevraagde psychiaters actief betrokken geweest was bij een euthanasietraject. Minstens 9% heeft ten minste eenmaal geweigerd actief betrokken te worden omwille van de eigen gewetensbezwaren en/of de verhoogde complexiteit van de beoordeling. Het belangrijkste motief voor psychiaters om met deze euthanasieverzoeken aan de slag te gaan, is het fundamentele recht van de patiënt om de vraag naar euthanasie te stellen en de plicht van de psychiater om dit binnen de huidige euthanasiewet te respecteren.

Hoofdstuk 10 verschaft meer gedetailleerde informatie over 46 unieke euthanasiecasussen, waarvan de evaluatieprocedure volledig beëindigd werd, ongeacht de uitkomst ervan (d.w.z. of de euthanasie werd uitgevoerd of niet). Uit de resultaten bleek dat de meeste patiënten leden aan comorbide

psychiatrische en/of somatische stoornissen, en voorafgaand aan hun euthanasieverzoek verschillende soorten therapieën hadden gevolgd en dit gedurende vele jaren. Existentieel lijden lag aan de basis van de meeste euthanasieverzoeken. De gehele euthanasieprocedure nam gemiddeld 14 maanden in beslag, en gemiddeld 13,5 maanden in de 23 gevallen die zijn uitmond in de uitvoering van euthanasie. In alle gevallen ging de hele procedure gepaard met multidisciplinair overleg, inclusief met familie en vrienden van de patiënt.

Psychiaters rapporteerden minder moeilijkheden bij het beoordelen van de zorgvuldigheidseisen die verband hielden met de zorgvuldigheidscriteria die aan de patiënt zelf kunnen toegeschreven worden, bv. ondraaglijk lijden, dan met de zorgvuldigheidseisen die verband hielden met hun medische aspecten, bv. de ongeneeslijkheid van de aandoening of het gebrek aan redelijke behandelingsperspectieven. In een paar casussen met euthanasie als eindresultaat, was volgende de rapporterende artsen *niet* aan alle wettelijke criteria voldaan. Ten slotte werden allerhande positieve en negatieve ervaringen gerapporteerd die tijdens de euthanasieprocedure kunnen plaatsvinden: gaande van een verminderd zelfmoordrisico bij de patiënt tot een grote emotionele belasting en gevoelens van onder druk te worden gezet bij de rapporterende de psychiater.

Hoofdstuk 11 is gebaseerd op de resultaten van een diepte-interview met 16 artsen en 14 andere professionals of vrijwilligers uit de geestelijke gezondheidszorg (anders dan mantelzorgers binnen de eigen sociale kring van de patiënt). Hun concrete ervaringen hadden betrekking op de volgende 8 domeinen: (1) de impact van het euthanasietraject op het klinisch traject en (2) op de therapeutische relatie, (3) interne en (4) externe samenwerkingsverbanden, (5) de (niet-)betrokkenheid van de sociale kring van de patiënt, (6) de recent gepubliceerde richtlijnen, (7) de eerste juridische rechtszaken, en (8) de uitvoering van de euthanasie. Acht concrete ondersteuningsnoden werden onderscheiden; (1) aandacht voor specifieke subpopulaties en sub-pathologieën in de bestaande protocollen, (2) specifieke protocollen voor niet-artsen, (3) meer houvast inzake het zo adequaat mogelijk implementeren van het tweesporenbeleid, (4) de (na)zorg voor patiënten, (5) de (na)zorg voor het zorgteam, (6) meer houvast inzake het betrekken van de

intieme kring van de patiënt, (7) meer doelgerichte opleidingen, en (8) meer financiële injecties, inclusief om meer holistische, palliatieve zorgbenaderingen te kunnen uitbouwen.

Hoofdstuk 12 vormt het laatste deel van het doctoraal proefschrift en bestaat uit: 1) een recapitulatie van de onderzoeksdoelstellingen en -vragen, 2) een bespreking van de gehanteerde onderzoeksmethoden, inclusief de voornaamste sterke punten en beperkingen per methode, 3) een overzicht van de voornaamste bevindingen, 4) een bespreking van enkele (heikele) punten die onze volledige aandacht (dringend) vereisen, inclusief enkele aanbevelingen voor beleid, praktijk en toekomstig onderzoek, en 5) slotbeschouwingen, voornamelijk geschreven vanuit mijn individueel perspectief.

Wat dit laatste betreft, leg ik de nadruk op de complexiteit van de euthanasiepraktijk, die kan toegeschreven worden aan de verschillende patiëntenprofielen, in de variëteit aan motieven die aan de basis liggen van het euthanasieverzoek, in de meerledige aspecten van het lijden die vaak de middelen en doelen van het (ondergefinancierde) veld van de psychiatrie overstijgen, en aan hoe uitdagend de vertaling, interpretatie en evaluatie van de wettelijke criteria is in de context van de volwassenpsychiatrie. Tijdens het grasduinen in de elektronische databanken van het Belgisch parlement, op zoek naar allerhande parlementaire stukken die de euthanasiewetgeving voorafgingen, werd me duidelijk dat de wetgever de individuen die overwegend lijden aan psychiatrische stoornissen niet in gedachten had. Een toekomstige revisie van de wet kan mijns inziens veel baat hebben bij enige reflectie over de specifieke kenmerken van de psychiatrie als medische discipline en de mensen met een psychiatrische problematiek als doelgroep. Naar mijn mening zou het onrechtvaardig en discriminerend zijn om de mogelijkheid van euthanasie voor deze specifieke patiëntengroep uit te sluiten, maar het lijkt me billijk om een vertaalslag van de huidige criteria of zelfs additionele procedurele criteria te overwegen die beter matchen met de specifieke context van de volwassenpsychiatrie. Maar bovenal zou ik het de psychiatrie toewensen om beter gefinancierd te worden en bijgevolg beter uitgerust te worden met de broodnodige holistische, herstel- en palliatief georiënteerde zorgbenaderingen. Een euthanasiewet kan en mag in geen geval dienen als oplossing van maatschappelijk falen, waarbij deze patiënten het kind van de vermijdbare

rekening worden. Anders zou de wetgever de beroepsgroep van psychiaters opnieuw ertoe kunnen leiden om nog extra bladzijden aan haar donkerste bladzijden in de geschiedenis toe te voegen.

CURRICULUM VITAE

Monica Verhofstadt (°1980) is a clinical psychologist. Since October 2017, she joined the Belgian End-of-Life Care Research Group as a doctoral researcher. In the preceding years she did volunteer work at Vonkel, a Belgian non-profit organisation dedicated to supporting patients and their relatives with end-of-life issues such as grief, bereavement, end of life decisions, etc. There, she conducted intake interviews with patients requesting for euthanasia and joined the first Belgian research projects on euthanasia requests from and the euthanasia practice regarding psychiatric patients.

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THANK-YOUS

“There must be some other possibility than death or lifelong penance ... some meeting, some intersection of lines ; and some cowardly, hopeful geometer in my brain tells me it is the angle at which two lines prop each other up, the leaning-together from the vertical which produces the false arch. For lack of a keystone, the false arch may be as much as one can expect in this life. Only the very lucky discover the keystone.”

Wallace Stegner (Angle of Repose)

Over the years, I've met many people who struggled with mental illness and its consequences. It remains striking to notice that, in so many cases, mental illness is accompanied with loneliness and many more struggles in so many more life domains. I experienced myself how it may feel if you lose the ability to live a 'normal life' and the ability to carry out normal day-to-day work and social activities. The difference is that *Luck* was in so many occasions on my side, as I always seem to encounter and remain to be surrounded by the most compassionate, supportive, and inspiring people.

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The director of the end-of-life care research group, Professor Luc Deliens, was willing to take up a role as co-promotor at the Vrije Universiteit Brussels. At first,

I could not believe my ears that a man who co-authored 457 (!?) research articles in the past decade would still find some time for it. Luc, this has been a leap in the dark for you, because you were worried more than once about me potentially damaging the image of your research group if e.g., my personal medical history would come out. I hope I can prove you wrong. If not, I am sure that the research group will survive!

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I also had the opportunity to interview a variety of mental healthcare professionals and volunteers. Initially, I hoped to gain a more crystal-clear view on the topic. Thanks to all of you, I ended up with an even more blurred view and I could not have been any happier with it;-). You almost literally blow my mind in the utmost positive way. Thanks also to the many psychiatrists taking the time to fill in the survey: no sinecure to participate in research when free time is such a scarce resource. And last, but not least, thank you to the members of the Examination Board for the many constructive comments, and helpful suggestions to further improve the doctoral thesis. The time and energy spent on this 'bulged at the seams'-dissertation is much appreciated.

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At the very end of this research trajectory, some hustle and bustle occurred that left us with the decision to switch from main host institution. I am extremely grateful for the understanding and support my promotor and I have received from the Joint PhD and legal services from both universities, and the Doctoral Schools and the Ombuds Person at the Vrije Universiteit Brussels.

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As written in the preface, the research agenda on euthanasia in the context of adult psychiatry in Belgium actually started in Vonkel, and more specifically with psychiatrist dr. Lieve Thienpont. Lieve, you gave me the pressure-less opportunity to engage in volunteering work in Vonkel and to take a break from it whenever needed. You were, however, more 'directive' as to whether or not considering a PhD-trajectory, which I considered to be far from my (in those days, disabled) reach. I am forever grateful to you for welcoming me in the

Vonkel family and for continuously pushing me (well, not always;-)). I've met so many incredibly empathetic and supportive people there, not in the least my buddy Rahis (whom I have sorely neglected during the writing of this dissertation, but I will make up for that), Rita (oh, I would give my life for some more '*bo'trammekes met choco*' as one say in the juicy dialect of Ghent, at your 70s place), Louissette, Ida, Mayke, Tony, Marc, Ann, Koen and Jona.

But far and foremost, I fell with my ass in the butter (as we tend to say in Antwerp for something unexpectedly and extremely delightful to happen) to be surrounded by the best friends one could wish for.

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Should I Kill Myself, or have a Cup of Coffee?

Albert Camus (A Happy Death)