

When unbearable suffering incites psychiatric patients to request euthanasia: qualitative study†

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Background

The concept of ‘unbearable suffering’ is central to legislation governing whether euthanasia requests may be granted, but remains insufficiently understood, especially in relation to psychiatric patients.

Aims

To provide insights into the suffering experiences of psychiatric patients who have made a request for euthanasia.

Method

Testimonials from 26 psychiatric patients who requested euthanasia were analysed using QualiCoder software.

Results

Five domains of suffering were identified: medical, intrapersonal, interpersonal, societal and existential. Hopelessness was confirmed to be an important contributor. The lengthy process of applying for euthanasia was a cause of suffering and added to experienced hopelessness, whereas encountering physicians who took requests seriously could offer new perspectives on treatment.

Conclusions

The development of measurement instruments to assess the

nature and extent of suffering as experienced by psychiatric patients could help both patients and physicians to better navigate the complicated and sensitive process of evaluating requests in a humane and competent way. Some correlates of suffering (such as low income) indicate the need for a broad medical, societal and political debate on how to reduce the burden of financial and socioeconomic difficulties and inequalities in order to reduce patients’ desire for euthanasia. Euthanasia should never be seen (or used) as a means of resolving societal failures.

Declaration of interest

During this study, L.T. worked as a psychiatrist at ULteam, a central institute in Belgium that manages end-of-life cases. Currently, L.T. is a psychiatrist at, and the co-founder of, LEIFpunt-Gent (Belgium), a newly founded institute addressing, managing and/or handling end-of-life questions. As an MSc student M.V. undertakes voluntary work for LEIFpunt-Gent.

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As of February 2016, euthanasia (i.e. deliberately ending a patient’s life by administering life-ending drugs at the patient’s explicit request)¹ and/or physician-assisted suicide (i.e. deliberately assisting a patient’s suicide attempt or providing the patient with the means to die by suicide)¹ can be legally practised in five states in the USA (Washington, Oregon, Montana, Vermont and California), four European countries (The Netherlands, Belgium, Luxembourg and Switzerland) and Colombia.^{1–4} Euthanasia legislation is mostly geared towards the unbearable suffering of people who are 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.² 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.^{5–9} However, although unbearable suffering is clearly a crucial factor in legally granting a patient’s 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.¹⁰ As a result of the vagueness of the term, the Belgian Federal Control and Evaluation Commission (FCEC) established to review whether 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.^{11,12} Our 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 in order 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 rates, the 3950 patients who died in the years 2014 and 2015 as a result of euthanasia constitute 1.8% of all deaths in Belgium.¹³ In one out of every seven of these (15%), the patient had 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.¹³ Belgian law on euthanasia allows requests for euthanasia from psychiatric patients to be granted, and this has already been the case for a small subgroup of individuals who have made such a request.^{14,15} However, specific Belgian guidelines for the management of euthanasia requests from individuals with a psychiatric disorder are still lacking,⁵ although, the specific guidelines of the Dutch Psychiatric Association (NVvP) and an as-yet-unpublished ‘4-track-approach’ are available as guidance alongside Belgian law.¹⁴ According to Belgian law, a physician

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†For commentaries on this paper see pp. 246–247 and 248–249.

has to come to 'a level of mutual understanding' with the patient about the extent of his or her unbearable suffering.⁶ 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 themselves, and may depend on their physical and mental strength and personality.¹⁶ 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.^{6,7,15} 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.¹⁷ Early research often failed to acknowledge the complexity of the suffering experience, and did not explore which aspects of an individual's suffering led them to consider their suffering unbearable.^{18,19} Currently, 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'.¹⁰ 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.²⁰ In addition, it was found that psychological, socioenvironmental, 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'.²⁰ 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* to be further refined, making distinctions in instances where the experiences of patient groups differ enough to necessitate acknowledging those differences.¹⁰ As 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 endeavours 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 requests made by this minority group is to analyse existing data. The current paper describes the qualitative analysis of a rich data-set of self-written or self-recorded 'testimonials' (about the underlying reasons for wanting to die and experiences of unbearable suffering) from 26 psychiatric patients who have made

a request for euthanasia (all seen by L.T.). 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 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.

Method

Patients

We analysed a data-set consisting of self-written or self-recorded 'testimonials' from 26 psychiatric patients. These testimonials provided a means for the patients to express both the reasons for their request and their experiences of unbearable suffering. General descriptive information regarding a group of 100 patients – of which these 26 patients were members – is available elsewhere.¹⁴ All patients were seen by L.T. at an out-patient psychiatric clinical setting in the Dutch-speaking region of Belgium, with intake beginning at the end of 2007 and ending in December 2011 (when L.T. joined a newly founded central institute in Belgium to manage end-of-life cases, therefore ceasing case management at her private practice). The sample consisted of 20 women and 6 men, ranging in age from 22 to 80 years old (mean 50.46, s.d. = 14.93). At presentation, 24 patients were professionally inactive (of these, 3 patients were in retirement and 2 were students with disabilities). 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 lived on a psychiatric ward. In total, 22 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. In total, 12 patients were still alive (i.e. had cancelled or put their euthanasia on hold) and 12 patients had died: 9 as a result of euthanasia, 2 by suicide and 1 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 5 years ago, and we wished to avoid the chance of doing harm when bringing back painful memories). Patient characteristics are described in Table 1 and Table 2 at <http://osf.io/pe25n>.

Procedures

Between October 2007 and December 2011, 100 psychiatric patients presented themselves with a request for euthanasia at an out-patient psychiatric clinical setting in East Flanders. During or after their consultation (for example, for clarification of their euthanasia request), 26 of these patients spontaneously handed in a self-written or self-recorded testimonial to L.T., in which they expressed the reasons for their request and their experience of unbearable suffering. A total of 6 testimonials were sent by email, 19 were written on paper and 1 was video recorded. These testimonials were kept in the patients' medical files. In 2013, L.T. 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

software (version 0.5 beta, <http://qualicoder.com>) and given a unique identifier. Attributes were then added to facilitate identification of patterns related to demography.

L.T. and M.V. 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 L.T. and M.V. 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, G.-J.Y.P. (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 L.T. and M.V., 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 the code. Third, G.-J.Y.P. was asked to read all data and check all coded fragments. Fourth, all fragments were re-read by L.T. and M.V. and their codes were sorted into more abstract subcategories (in English), and then generally classified into overarching main categories (in English), as suggested by M.V. and discussed with L.T. and G.-J.Y.P. The hierarchical coding structure is available in Fig. 1 at <https://osf.io/pe25n>. 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 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 study¹⁴ that has already been approved, an amendment for the continuation of this study was submitted to the Ethics Committee of the Antwerp Hospital Network. Ethical approval (EC Approval No. 4183) was obtained on 22 December 2015 (also available at <http://osf.io/pe25n>).

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 providing 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 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 gastrointestinal damage or complaints (or even organ dysfunction) to visual and auditory impairments, as well as more general physical symptoms such as pain (in various parts of the

body), nerve damage, general malaise, headaches and fatigue. Psychosomatic complaints included fibromyalgia, chronic fatigue, nausea and attacks of fever, but also lack of sexual desire and physical symptoms that 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 dysfunction.

The burden of medical suffering was also described as being beyond patients' capacity to cope with for a number of treatment-related reasons. First, some patients reported suffering greatly from the deleterious effects or ineffectiveness of medication, treatment or surgery procedures (for example, iatrogenic trauma can result from a physician administering unnecessarily radical surgical procedures). Even during stays in psychiatric wards, sometimes the symptoms being treated got worse rather than better. Similarly, sometimes former (in)voluntary residential stays on 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 (because of the severity and continuity of their disorder(s)), or from any prescription for medication (because of earlier suicide attempts) – 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 resulting erroneous treatment experiences. Third, difficulties in the communication patterns between patients and their physicians were mentioned, including 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 suggest that applying for the procedure of euthanasia might contribute to additional suffering. First, patients reported an unwillingness on the part of physicians to discuss a request for euthanasia. Second, patients experienced a lack of transparency in the application procedure. Sometimes they were left ignorant about the legal requirements (for example, how many physicians should be consulted, how much time the procedure could take, and whether alternative options would still be available if the request was refused). 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’ (misled) 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 application 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)

Although, on the one hand, the testimonials illustrate that a lack of transparency or unwillingness to discuss a request may have further aggravated the suffering experiences of patients, on the other hand, encountering physicians who took a 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 the family context). Furthermore, traumatic 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 misuse or addiction and self-injury (for example 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 (such as shame) and the fear of surviving another attempt were taken into account by patients when a request was made. 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, 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 request for euthanasia would not be granted.

Alongside considerations relating to themselves, patients considered the feelings of others when choosing euthanasia over suicide attempts. Despite the urgency of their wish to die and perceived psychasthenia (psychogenic weakness), a reluctance to harm important others was also reported. This led, in some instances, to conflicting feelings, such as an urgent wish for 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 (such as 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 troubles in the patient’s life was reported. For example, friends, family and/or physicians neglecting or underestimating these struggles and suffering, or ‘sweeping aside’ (ignoring) 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 stigmatised (‘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 because of feelings of inferiority, problems with small talk or an inability to deal with the 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 (consequences) of a patient’s mental disorder(s) could also lead to the patient wanting to relieve their loved ones and believing that their loved ones would be better off without them.

‘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 socioeconomic problems were reported: the pressure to make a living when there was no financial support from others, additional (financial) insurance problems because of 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 7 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 because of a lack of social support from 'society in general', were 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 because of the (symptoms of their) illness, or because 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, feeling like a puppet of 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 were living, but not really or fully participating in. When these experiences of suffering progressed, perspectives on life itself could be 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, because of gradually losing their role 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 the battle could never be won, led to some patients reporting that they were tired of 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. First, 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. Second, several temporal variables contributed to the extent of suffering reported (for example, 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 history of suffering, with problems starting at an early age and therefore contributing to the experience of long-term suffering. Third, a pessimistic view of the future was outlined: (f) a progressive and deteriorating evolution of the 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 research, as well as acknowledging the need to fully disclose research outcomes,²¹ the results of this study have been made publicly available at the Open Science Framework at <http://osf.io/pe25n>. In addition to other resources from this study (such as the final coding structure and the letter of ethical approval), we compiled two lists. The first contains the different aspects of patients' suffering and the second contains the eight (a–h) descriptors patients used to describe the extent of their suffering.

Discussion

Main findings

The aim of this qualitative study was to take the first steps to better understand the unbearable suffering experience(s) of psychiatric patients who had made a request for euthanasia. We hope that a better understanding of these issues will help practitioners, patients and policy makers 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 has 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 findings from the FCEC data on the 3950 patients who died as a result of euthanasia in the years 2014 and 2015.¹³ These data show that, despite the fact that most patients were terminally ill and only a minority suffered from a non-terminal mental disorder, in 3752 individuals (60.6%) unbearable physical suffering and in 2437 individuals (39.4%) unbearable psychological suffering were reported as a reason for making the euthanasia request.¹³ This also suggests an interaction between mental and physical health processes in both patient groups. These results also confirm earlier findings that psychiatric patients may suffer 'continuously',²⁰ 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 although unbearable suffering experiences often find their origin in the medical symptoms of patients' disorders, they are also highly affected by psychological, socioenvironmental, existential and biographical factors, with hopelessness being a critical element.²⁰ The data presented here support these findings, and extend them, by suggesting that, in psychiatric patients, these symptoms may start at an early age and may further progress because of 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 directly criticise) 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 the euthanasia decision-making processes should be applied, as a request for euthanasia can be a symptom of a patient's mental disorder.⁵ 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 (for example, cancer patients). As Grassi *et al* 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'.²² 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 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 NVvP are then followed in order to qualify untreatable suffering. For example, any therapeutic option for a particular condition must meet the following three requirements. There must be: (a) a real prospect of improvement, (b) the possibility to administer adequate treatment within a reasonable period of time, and (c) a reasonable balance between the expected treatment results and the burden of treatment consequences for the patient must be reached.²³ 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 factors, 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 compared with 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.

At the level of societal suffering, our results highlight a distinction between external social difficulties (socioeconomic 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. As a result of 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 conditions,²⁴ 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.²⁰

Exacerbation caused by the complexities of the euthanasia application process

It is noteworthy to mention the additional suffering 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 between patients and physicians dealing with these requests.

Also of note is 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 or euthanasia being seen as a final resort. From this perspective, physicians need to respond with a formal 'No, unless . . .' to a patient's request for euthanasia, which in cases of emergency can be transformed into a 'Yes, unless . . .'²³ It seems worthwhile to study the impact of physicians' communication approaches (a reticent *v.* 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 to 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.

Identifying key aspects of 'unbearable suffering' in this patient group

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'.¹⁰ 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 because of an accumulation of traumatic misfortunes, intrapersonal, interpersonal, societal and/or bad (or suboptimal) 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, undertook suicide attempts and made euthanasia requests.

Strengths and limitations

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 compared with (open-ended and funnel) questions provided in in-depth interviewing. Furthermore, as the patients were depending on the approval of physicians, including L.T., in order to get their euthanasia request granted, they may have felt a need to convince the physicians about the underlying reasons for their request involving suffering beyond their capacity to cope, while hiding some other information.

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 population that is defined by unbearable suffering. None of these spontaneously written or recorded and presented testimonials was censored or left out of the analyses. 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. The fact that patients were not given direction on how to write their testimonials, but 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 because of L.T.'s (as a clinical professional) and M.V.'s (as a researcher) familiarity with the topic of euthanasia, available scientific studies were not re-read, 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 a third person (G.-J.Y.P.), who was unfamiliar with the topic of euthanasia, scrutinising the process.

Future directions for research

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 <http://osf.io/pe25n>. 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 making a request for euthanasia 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.²⁵ 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 the suffering experiences of psychiatric patients who underwent euthanasia with those of the patients who decided to continue their life, and making comparisons 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 for 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.

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