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Peer Reviewed

Euthanasia of Dutch Patients with Psychiatric Disorders between 2015 and 2017

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Abstract

Background: The Netherlands is one of the few countries in the world that allows euthanasia and assisted suicide (EAS) due to psychiatric suffering.

Methods: The Dutch regional euthanasia review committees published 43 case summaries online between 2015 and 2017, of which 35 were analyzed (22% of all psychiatric EAS cases) on patient characteristics and physician involvement.

Results: 77% of patients were women. 51% of patients were between 50 and 70. Major depression disorder and personality disorders were present in almost half of the patients. All patients were considered mentally competent.

Conclusions: The incidence of psychiatric EAS cases is rising, but we found no shift in patient characteristics. The division between psychiatric and somatic suffering may prove more complicated

than expected. Patients dying from suicide differ on several characteristics from patients dying through assisted suicide. The fact that all patients are considered competent suggest that they are unjustly seen as vulnerable or that the competence assessment lacks due diligence.

Key words: Euthanasia, assisted suicide, psychiatry, Dutch case summaries.

Introduction

The Netherlands is one of the few countries in the world that allows euthanasia or assisted suicide (EAS). The vast majority of Dutch patients who choose EAS are terminally ill cancer patients with a limited life expectancy. However, the number of psychiatric cases is rising (Onwuteaka-Philipsen et al., 2017).

Quantitative studies addressing this topic are scarce (Dierickx, Deliens, Cohen, & Chambaere, 2017; Doernberg, Peteet, & Kim, 2016; Groenewoud et al., 1997; Kim, De Vries, & Peteet, 2016; Schoevers, Asmus, & Van Tilburg, 1998; Thienpont et al., 2015; Tuffrey-Wijne, Curfs, Finlay, & Hollins, 2018). As a result, much is still unknown about the characteristics of Dutch psychiatric patients who die by means of EAS, the procedure that precedes this, and the reviewing process that follows. The fact that EAS for psychiatric patients is accepted in the Netherlands offers a rare opportunity to quantitatively study the effects of a liberal end-of-life policy. In 2016, Kim et al. (2016) analyzed the online reports of the regional euthanasia review committees (RTE) between 2011 and 2014. Their research showed that psychiatric patients receiving EAS in the Netherlands are mostly women suffering from complex and chronic psychiatric disorders. 76% of patients were above 50. They also found that physicians were thorough in their analysis and sometimes disagreed about meeting due diligence requirements. Finally, they concluded that the RTE almost always follow the medical opinion of the reporting physician.

More than three years have passed since the Kim et al. (2016) review period (2011-2014) and the RTE continue to share part of their anonymized reports online. We analyzed the reports that were published between 2015 and 2017, enabling us to study how the EAS practice is developing in the Netherlands. Our objective is to help inform the ethical debate on the subject of EAS among psychiatric patients.

Background

For several decades, the Netherlands has taken a liberal stance on end-of-life topics, which was formalized through the "Termination of Life on Request and Assisted Suicide Act" in 2002. This act does not exclude psychiatric patients, but for years only one or two psychiatric cases were reported each year (Onwuteaka-Philipsen et al., 2017). However, since 2012 this number has been rising, going from 2 reported cases in 2011 to 83 cases in 2017 (RTE, 2017). Although no correlation has been demonstrated, this increase does coincide with the opening of the End of Life clinic (EOL clinic). This private institution provides counseling and second opinions for patients who cannot go to their own physician with an EAS request. The EOL clinic now performs around 75% of all cases of EAS based on psychiatric suffering (Peters, 2016).

Law dictates transparency and independent review, and an independent physician, preferably a specialized euthanasia consultant (SCEN-doctor), must be consulted prior to the actual effectuation of EAS. All due diligence requirements of EAS have been described extensively before (Kim et al., 2016). They include that suffering must be unbearable and without prospect of improvement, there must be no reasonable way to relieve this suffering, and the request has to be voluntary and well-considered by a competent patient.

When it concerns psychiatric patients, according to the law, involvement of an independent consulting physician is enough. However, jurisprudence, formalized through the Code of Practice of the RTE (2015), states that an independent specialized psychiatrist has to be consulted when "the euthanasia request results (largely) from mental suffering". This requirement corresponds with the euthanasia guideline by the Dutch Association for Psychiatry (NVvP), which is currently under review (Berghmans, Widdershoven, & Widdershoven-Heerding, 2013). After EAS is performed, a coroner reports the case and the RTE assesses every case. Only when they conclude that due diligence requirements have not been met is the case then transferred to the public prosecutor for criminal investigation.

Methods

Case selection

All RTE reports of EAS between 2015 and 2017, labeled as psychiatric and published online before April 16, 2018, were screened (RTE, 2017). 43 reports were available: 24 from 2015, 10 from 2016 and 9 from 2017. 8 reports were excluded (case numbers: 2013-15, 2015-18, 2015-19, 2015-47, 2015-80, 2016-07, 2017-26, 2017-32 and one case from 2013). In six of the excluded reports, somatic suffering (sometimes terminal) was the main reason for EAS, and psychiatric complaints were either secondary or subsidiary in nature. One report was excluded because it was mistakenly duplicated online. One report was excluded because it was mislabeled and came from 2013. 35 reports were included for analysis.

It is important to note that in 2015 the RTE publication policy was adjusted to a lower publishing rate of cases labeled as psychiatric. The argument supporting this is that disproportionate attention was given to psychiatric reports while they constitute less than 1% of all EAS cases. Kim et al. (2016) describe an online publication percentage of 63% of all reported psychiatric euthanasia cases between 2011 and 2014. Between 2015 and 2017, the publication percentage lowered to 22%.

Categorization of patient characteristics

The 35 included reports were analyzed on the patient's age, sex, psychiatric classification, and somatic comorbidity. We used the Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition Text Revision (DSM-IV-TR) criteria to classify the psychiatric disorders because this was still the most frequently used version in the Netherlands between 2015 and early 2017. However, in anticipation of the DSM-5, we did not count obsessive-compulsive disorder (OCD) and post-traumatic stress disorder (PTSD) under the anxiety disorders because they are currently part of different chapters (American Psychiatric Association, 2000 and 2013). Although dementia is in the DSM, it lies beyond the scope of this study. On the RTE website, dementia is a separate domain, and in our results we categorize it as a comorbid somatic disorder.

The RTE reports are in essence non-medical documents, meaning that often psychiatric and

medical terms got translated. When terms like ‘complaints’ or ‘traits’ were used, we did factor them in, reasoning that only clinically relevant information will make it into these highly condensed summaries. We do, however, mention them separately in Table 2.

Categorization of physician involvement

We looked at the number of independently consulted physicians and psychiatrists, and the involvement of the EOL-clinic. We also screened the reports for disagreement among physicians about the prospect of improvement and mental competence. The reports were only categorized as containing disagreement if both screening authors agreed that this was clear from the text (SvV and FW).

Selection of case reports

We selected the highlighted cases by means of discussion between the authors. The first case was selected for being a ‘typical’ example, based on its patient and process characteristics. The second case was the only one not meeting due diligence requirements according to the RTE. The third case shows how complicated the EAS process can be and how this affects the RTE judgment. All reports can be found on the RTE website (RTE, 2017).

Results

Patient characteristics

77% of the patients were women. 74% were older than 50. 51% of all patients were between 50 and 70 years old and 17% were between 80 and 90 (Figure 1). Patients were most often diagnosed with mood disorders (66%) and personality disorders (54%). Also anxiety disorders (29%) and eating disorders (20%) were relatively common. As specific diagnoses, depressive disorder (46%) and PTSD (23%) were most common (Table 1). In 34% of the reports, a history of suicide attempts was mentioned. 71% of patients have more than one psychiatric disorder, meaning that a minority of 10 patients (29%) received EAS due to suffering caused by a single disorder. These

were, respectively, alcohol dependence, PTSD, anorexia nervosa, schizoaffective disorder, depression in extensive somatic disease, OCD with severe somatic comorbidity, and a depressive adjustment disorder due to tinnitus. Personality disorders only occurred together with other psychiatric disorders, meaning that based on these reports none of the euthanized patients suffered solely from a personality disorder. Although words such as 'severe' or 'grave' are often mentioned in the reports, no quantitative estimation about the severity of the suffering was deducible, for instance by GAF scores.

Somatic comorbidity occurred in 13 patients (37%), including cardiac arrhythmias; Alzheimer's dementia; heart failure; chronic obstructive pulmonary disease (COPD); arthrosis; hearing impairment; dizziness; Ehlers-Danlos syndrome; obesity; skin problems; migraine; chronic pain; tinnitus; diverticulitis; spastic quadriplegia; osteoporosis; anemia; and renal dysfunction.

Role of the physician

In 31 cases (89%), at least one independent psychiatrist was consulted for a second opinion, and in all cases an independent SCEN-doctor was involved. In 4 cases, there were disagreements between the involved physicians about the prospect of improvement (Case-numbers: 2016-11, 2016-78, 2017-8, 2017-9). In all cases, the consulted physicians agreed that the patient was competent to choose for EAS. In 4 cases (11%), no independent psychiatrist was involved. As a result, the RTE judged one euthanasia procedure in 2017 as not meeting due diligence requirements (Case 2017-24). This case is described in further detail below. In 19 of the 35 online published cases (54%), involvement of the End-of-Life Clinic was described.

Highlighted reports

Case 2016-5: a woman with a personality disorder and therapy resistant depressive symptoms

A woman, between 60-70 years old, diagnosed with bipolar II and unspecified personality disorder, suffered from recurrent depressive episodes for fifteen years. On several occasions during this period, she attempted suicide. Treatment had not improved her mood and functioning. When

she requested euthanasia, her attending psychiatrist and general practitioner would not support this request after which the patient consulted the EOL-clinic. A psychiatrist of the EOL-clinic took her request under consideration and consulted another independent psychiatrist who concluded that the patient was competent in her request and that all meaningful treatment options had been exhausted. Finally, a SCEN-doctor concluded that the due care requirements had been met, after which euthanasia was performed. The RTE judged the process as diligent.

Case 2017-24: failure to adequately consult an independent psychiatrist

Between 2015 and 2017, one case did not meet the due diligence requirements according to the RTE. It concerns a man, between 40-50 years old, with a long-term treatment history of various psychiatric disorders. His final diagnosis was a schizoid personality disorder. Seven months before euthanasia took place, an independent specialized psychiatrist was consulted to assess whether autism was a more suitable diagnosis, which was not the case in the expert's opinion. Six months before euthanasia, a new psychiatrist took over treatment. The patient requested euthanasia but the psychiatrist would not support this request. At this point, the patient consulted the EOL-clinic and the case was assigned to one of their general practitioners, who consulted a SCEN-doctor who was not a psychiatrist. In summary, three psychiatrists, a general practitioner, and a specialized euthanasia consultant were involved during the process leading up to this patient's euthanasia. Afterwards, the RTE judged that it was made sufficiently clear that the patient suffered unbearably and that there was no prospect of improvement. What made them judge the case as insufficiently diligent was the lack of consultation by a specialized psychiatrist in the context of an EAS request and the absence of an independent mental competency assessment.

Case 2016-78: disagreement about the prospect of improvement between consulted psychiatrists

The patient was a man between 30 and 40 years old with a schizoaffective disorder and unspecified personality problems, suffering mostly from depressive complaints and frequently requesting euthanasia. Three psychiatrists were involved in the euthanasia procedure. First, the patient asked his attending psychiatrist, who consulted a second psychiatrist. A third independent

psychiatrist was consulted, who advised additional medicinal and psychotherapeutic treatment. The second psychiatrist, in concurrence with the attending psychiatrist, chose to disregard this advice, arguing that these were not reasonable options due to patient's lack of motivation for further treatment, and performed euthanasia. According to the RTE, the performing psychiatrist had sufficient reasons for why he or she saw no benefit in the proposed treatment options and the process was judged as diligent.

Discussion

Similar patients with increased access

Compared to the research by Kim et al. (2016), our study shows that the percentage of female patients is fairly consistent (70% between 2011 and 2014 versus 77% between 2015 and 2017). The age distribution is also similar and the majority of patients were above 50 years old (76% vs. 74%). Depression was found in both studies to be a relatively common disorder within patients that die by EAS (55% vs. 46%). Patients suffering from (comorbid) personality disorders also continue to represent a large group within this population (52% vs. 53%).

Although the changed publication policy by the RTE makes comparison between these numbers difficult, our findings suggest that *more* people, of *similar age* and with *similar problems* have access to EAS. We found no trend towards EAS among younger or 'different' psychiatric patients, which is often feared when using the slippery slope argument. Further research is needed to be able to elaborate on this finding, for instance by including severity scores such as a GAF-index.

Differentiation between psychiatric and somatic cases

The labeling of reports as psychiatric by the RTE shows that it can be challenging to differentiate between somatic and psychiatric grounds for EAS. Several reports, where in our opinion the suffering was mainly caused by somatic disease, were labeled under 'psychiatric cases'. This included psychiatric patients with severe somatic morbidity or patients with serious somatic illness and secondary psychiatric complaints such as depression or anxiety. The guideline by the Dutch

Psychiatric association on EAS does mention the following on somatically ill patients with psychiatric comorbidity: “If the psychiatric disorder is an important reason why the patient chooses death, the psychiatrist should in principle follow the same procedure as in [psychiatric] cases where there is no somatic-psychiatric comorbidity” (Tholen et al., 2009). The complex division between *soma* and *psyche* does not get much attention in the debate about psychiatric EAS. It is however relevant when different or stricter rules are implemented for ‘psychiatric’ EAS cases, like in the RTE Code of Practice. Ambiguity about this division might lead to insufficient diligence or unjustified restraint in individual EAS cases. Further discussion about what makes a case primarily ‘psychiatric’ could prevent this.

EAS and suicide

Several findings suggest that patients who commit suicide are different than those that die through EAS. First, we found that two third of the EAS-patients seem to have no history of suicide attempts. Kim et al. (2016) found that half of the patients they studied attempted suicide. Secondly, these groups also seem to differ epidemiologically. For instance, while Dutch men are two times more likely to die by suicide than women, they are only a minority among Dutch EAS patients where women outnumber men three to one (Statistics Netherlands, 2017). This finding is important because suicidal patients and patients seeking EAS are often displayed as a similar group (Boer, 2017). The difference might be explained by the fact that patients who die by suicide cannot request EAS because they are dead. It is also possible that the difference is explained by male-female differences, such as impulsivity. Or it might mean that the argument that EAS prevents ‘inhumane’ suicides is unsubstantiated. Further research should elaborate on this finding.

Mental competence

Although most of the reports describe patients suffering from severe and complex psychiatric disorders, all of them were found mentally competent to decide about their own death. A possible explanation is that physicians only report and cooperate in cases of euthanasia that meet due care criteria. This could mean that concerns about the vulnerability of psychiatric patients receiving EAS are unsubstantiated. Another explanation is that the assessment lacks due diligence. Further

research should focus on how competence is assessed and the process that allows the RTE to pass this as sufficiently diligent.

Strengths and weaknesses

The strength of the study is that the online RTE-reports are one of few accessible sources to quantitatively study psychiatric EAS in the world. The fact that a substantial amount of reports have been published over the years now allows us to study trends by comparing our research to the earlier study by Kim et al. (2016).

The main weakness of this study is the nature of the online RTE-reports. The goals of publishing RTE reports are to educate and to further societal debate. The studied reports are highly condensed and adjusted for a broader audience, leading to dilution of the subtle and complicated description of complex psychiatric problems. This often led to unclear statements like ‘depressive symptoms’, and the description of personality disorders remained especially unclear. The reports are not primarily meant for scientific research. This also introduces a selection bias where only the ‘remarkable’ cases get published. Furthermore, between the research conducted by Kim et al. in 2016 and our current analysis, the publication practice has changed and, as a result, a substantially smaller proportion of psychiatric cases were published (63% vs. 22%). This has to be taken into account in the comparisons made between the studies.

Conclusions

This study aims to provide an overview of EAS among Dutch psychiatric patients between 2015 and 2017 and put it in a longitudinal perspective. To achieve this objective, we analyzed reports that were published online by the Regional Euthanasia Review Committees in this period. They show that relatively many women of diverse ages and with complex and chronic psychiatric problems die through EAS.

This research adds to the scarce quantitative empirical research available on the topic of psychiatric EAS. Future research should focus on a more complete and undiluted overview of the patients and process leading up to euthanasia. A method could be to directly study the medical

records underlying the online published RTE reports; these are currently not accessible for research. Also, much is unknown about the patients who get denied euthanasia. Finally, qualitative research among patients and families that go through a euthanasia procedure is not yet available.

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Supplements:

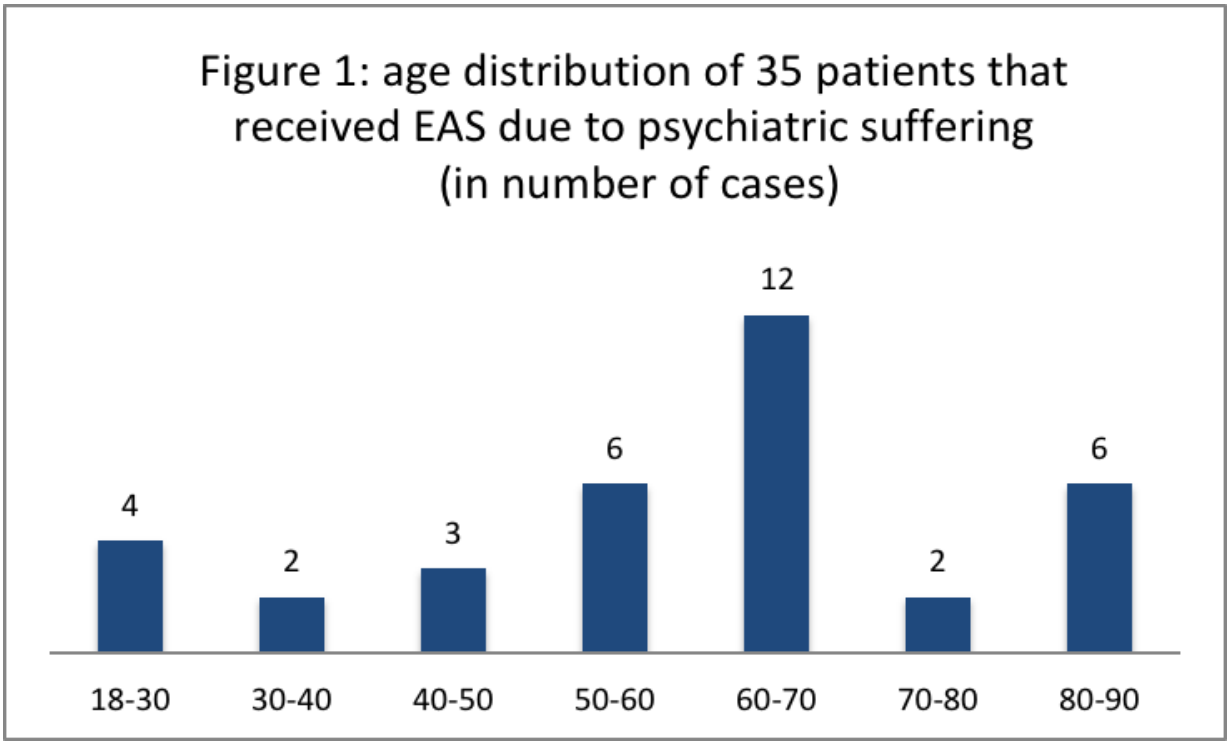

Table 2: Psychiatric conditions of 35 patients receiving EAS	N	% [A]
Mood disorders	**23**	65.7
Depressive disorder	16	45.7
Bipolar disorder (I and II)	2	5.7
Dysthymia	2	5.7
Symptoms of depression	3	8.6
Anxiety disorders	**10**	28.6
Panic disorder	3	8.6
Social phobia	1	2.9
Anxiety disorder NOS	1	2.9
Symptoms of anxiety or panic	5	14.3

Post-traumatic stress disorder	**8**	22.9
Obsessive compulsive disorder	**4**	11.4
Psychotic disorders	**6**	17.1
Schizophrenia	1	2.9
Schizoaffective disorder	2	5.7
Psychosis NOS	1	2.9
Symptoms of psychosis	2	5.7
Somatoform disorders	**5**	14.3
Pain disorder	1	2.9
Hypochondria	1	2.9
Somatoform disorder NOS	3	8.6
Autism spectrum disorders	**1**	2.9
Pervasive developmental disorder NOS	1	2.9
Substance use disorders	**3**	8.6
Alcohol dependence	1	2.9
Alcohol and drug dependence	2	5.7
Eating disorders	**7**	20.0
Anorexia Nervosa	6	17.1
Eating disorder NOS	1	2.9
Personality disorders	**19**	54.3
Borderline personality disorder	2	5.7
Schizoid personality disorder	1	2.9
Personality disorder NOS	13	37.1
Personality problems	3	8.6

A. The percentages describe the number of patients suffering from the complaint, disorder, or group of disorders. Because most patients are diagnosed with several disorders, the combined percentages exceed 100%.

Acknowledgements: none

Competing Interests: none

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Publication Date: October 5, 2018