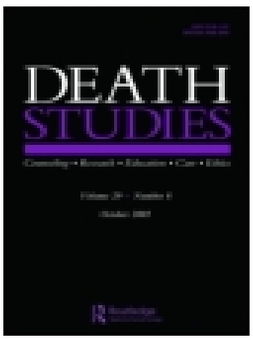

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Determinants of unbearable suffering in hospice patients who died due to Euthanasia: A retrospective cohort study

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ABSTRACT

In this retrospective study, determinants of unbearable suffering in hospice patients who died due to euthanasia were analyzed. The four dimensions of suffering (physical, psychological, social, and existential) were used as a framework. 28 patients (5% of all admitted patients in nine years) were included. Most patients indicated 3–5 determinants, predominantly a combination of physical (96% of patients) and existential determinants (89%). Fatigue, anorexia, and dry mouth were the most prevalent and severe symptoms. Psychological (21%) and social determinants (4%) were much less often described. The results of this study may be used to assess determinants playing a role in euthanasia requests.

Introduction

In the Netherlands, euthanasia is defined as the termination of life by a doctor at the request of a patient (de Haan, 2002; Deliens & Van Der Wal, 2003). The prevalence of euthanasia is increasing in the Netherlands from 2.8% in 2010 to 4.5% in 2015 and in the Dutch spoken part of Belgium from 1.9% to 4.6% between 2007 and 2013 (Chambaere, Vander Stichele, & Mortier, 2015; Dierickx, Deliens, Cohen, & Chambaere 2016; Onwuteaka-Philipsen 2017; Steck, Egger, Maessen, Reisch, & Zwahlen, 2013; Van Der Heide, Van Delden, & Onwuteaka-Philipsen, 2017). Euthanasia is a criminal offense unless six criteria are met. These criteria, also called the "requirements of due care," are specified in the Dutch Euthanasia Act (Textbox 1) (Deliens & Van Der Wal, 2003; Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, 2014).

One of these requirements is that the attending physician is convinced that the patient's suffering is unbearable and that there is no prospect improvement.

The latter part of this requirement "without prospect of improvement," refers to the professional domain of a physician. The patient's suffering is considered to be without prospect of improvement if the disease or disorder causing the suffering is incurable and there is no means of alleviating the symptoms so that the suffering is no longer unbearable. Medically speaking, the absence of any prospects of improvement can be determined with a reasonable degree of objectivity. The physician establishes this on the basis of the diagnosis and prognosis. Whether treatments are a realistic option depends on two things: the improvement that can be achieved and the burden such treatment would place on the patient (Regional Euthanasia Review Committees 2019).

In contrast, unbearable suffering is subjective and, therefore, much harder to assess (Dees, Vernooij-Dassen, Dekkers, & Van Weel, 2010; Rietjens, Van Der Maas, Onwuteaka-Philipsen, Van Delden, & Van Der Heide 2009; Van Tol, Rietjens, & Van Der Heide, 2012; Wijsbek, 2016). The views of the Royal Dutch Medical Association, the reports of the regional euthanasia review committees and case laws provide some indications. First, suffering must have an underlying medical dimension: a classified physical or psychiatric disease. Second, the patient's suffering must be recognizable by the physician as unbearable, based on the standards and values of this specific patient (Regional Euthanasia Review Committees, 2019; Royal

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Dutch Medical Association, 2013; Rietjens, Van Der Maas, Onwuteaka-Philipsen, Van Delden, & Van Der Heide, 2009; Van Wersch, 2016).In the international literature, there is no generally accepted definition of unbearable suffering in the context of a request for euthanasia (Dees et al., 2010; Ruijs, Kerkhof, Van Der Wal, & Onwuteaka-Philipsen 2013). The concept of "unbearable suffering" was found to contain physical, psychological, social and existential dimensions and to entail many different motivations (Dees et al., 2010; Ruijs, Kerkhof, Van Der Wal, & Onwuteaka-Philipsen, 2013). Based on a literature review, Dees et al. (2010) defined unbearable suffering in the context of a request for euthanasia 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." Unbearable suffering was defined by Ruijs et al. (2013) as "a subjective experience that is so serious and uncontrollable that it overwhelms ones bearing capacity."

Textbox 1. . Requirements of due care.

- Voluntary and well-considered request;
- Unbearable suffering without prospect of relief;
- The patient must be fully aware of his condition, prospects, and options;
- No reasonable alternative according to patient and doctor;
- Consultation of at least one independent physician;
- Termination of life in a medically appropriate manner.

Most euthanasia studies focus on euthanasia at home or in the general population (Dees, Vernooij-Dassen, Dekkers, Vissers, & Van Weel, 2011; Georges et al., 2007; Maessen et al., 2010; Ruijs, Van Der Wal, Kerkhof, & Onwuteaka-Philipsen, 2014). No data have been published on euthanasia in hospice patients. In the Netherlands, patients with a prognosis of less than three months have access to hospice care. Most patients are admitted for last resort care and stay until their death. Hospice care is focused on optimizing the quality of life of patients by diminishing their physical, psychological, social and existential suffering. In this setting of specialized palliative care, some patients request euthanasia.

The aim of this study is to analyze unbearable suffering in the context of euthanasia of patients admitted to a hospice. The main research question is: What are the documented determinants of unbearable suffering in patients admitted to a hospice who died due to euthanasia? Determinants are defined as physical and psychological symptoms and social and existential problems. We also investigated the symptom burden of patients at the time of the request.

Materials and methods

Study design

A retrospective mixed method cohort study was performed from 2016 until 2018. Data were collected from written medical records and from patients' symptom diaries. If available, data were collected from the report of the independent physician.

Setting

This study was performed in a professional driven hospice, located in the middle of the Netherlands, having a capacity of seven beds. Currently, there are approximately 100 admissions of new patients each year. Almost all patients stay until their death.

The multi-disciplinary core team consists of three hospice physicians (two general practitioners and a medical oncologist), a staff of registered nurses and nurse assistants and a chaplain. In addition, the core team is supported by a music therapist, a creative therapist, a physical therapist and other supportive care staff. Additional care and support are provided by trained volunteers.

Study population

All patients admitted to the hospice who died due to euthanasia between July 2007 (time of initiation of our hospice) and July 2016 were enrolled in the study.

Euthanasia procedure

When patients express thoughts or questions about euthanasia to the staff, the euthanasia procedure in the hospice is explained to the patient and his or significant others by the hospice physician. When the initial thoughts or questions develop over time to an actual request for euthanasia, implying that the patient wants to have his or her life ended by euthanasia in the short term, the request is discussed within the multi-disciplinary team. The rules set by Dutch law are strictly followed (Deliens & Van Der Wal, 2003; Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, 2014).

All requirements for due care are carefully checked and discussed with the patient and his or her significant others. In the end, it is the attending hospice physician who decides whether or not to comply with the request. Subsequently, the hospice physician is obliged to ask a second opinion of an independent physician to assess the first four criteria of due care. The independent physician speaks with the patient and makes a written report. The euthanasia is reported by the doctor to the municipal coroner. A regional review committee assesses whether a case of termination of life on request complies with the due care criteria and writes a report.

Outcomes

Determinants of unbearable suffering

The primary endpoints of the study were the physical, psychological, social, and existential determinants of unbearable suffering at the time of the actual request for euthanasia, as described in the medical records. If available, data were also retrieved from the reports of the consulted independent physician.

Symptom burden

Symptom burden was defined as the prevalence of clinically relevant symptoms. Symptom burden was assessed by means of the Utrecht Symptom Diary (USD) (De Nijs, Echteld, & Vrehen, 2010). The USD is a Dutch adapted translation of the Edmonton Symptom Assessment System (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). The USD is a self-assessment tool, assessing the severity of pain, insomnia, dry mouth, dysphagia, anorexia, constipation, nausea, dyspnea, fatigue, anxiety, and depressed mood. All symptoms are scored on an eleven-point numerical scale (0 = not at all present to 10 = very severe, could not be worse). A symptom is considered to be clinically relevant if the USD-score is >3. Systematic use of the USD is part of the standard hospice care. All patients able and willing to self-assess their symptom severity are asked to fill out the USD twice a week or more often if indicated. Only the USD scores completed within one week before or after the request for euthanasia were used.

Patient characteristics

Patient characteristics include age, sex, marital status, diagnosis, setting before transfer to the hospice and the use of medication. Physical functioning at admission and at the time of the actual request for euthanasia was assessed by a nurse or physician using the Karnofsky Performance Scale (KPS) (Karnofsky & Burchenal, 1949). The Karnofsky Performance Scale Index classifies patients with regard to their physical function and symptoms. It ranges from 100 (normal functioning, no symptoms) to 0 (death).

Data on a potential euthanasia wish at admission were collected. This refers to the presence of an advance directive addressing euthanasia and/or documentation of euthanasia having been discussed before with other physicians or with the physician at admission.

Analysis

The determinants of unbearable suffering were analyzed by means of content analysis. The four dimensions of suffering (physical, psychological, social, and existential) were used as a framework to categorize the data. First, the descriptions from the medical records and (if available) the report of the consulted independent physician were literally written down by the first author (DB) and subsequently categorized, resulting in a list of determinants. When the first author was in doubt about the determinant or category, it was discussed in the research team (EdG and ST), until consensus was reached.

Ethical considerations and consent

This study was conducted according to the Declaration of Helsinki, the guidelines for Good Clinical Practice and the Dutch law (World Medical Association Declaration of Helsinki, 2013; International Council for Harmonisation of Technical Requirements for Pharmaceuticals for Human Use, 2016). At admission, all patients agreed that their data could be used for scientific research.

Results

In total, 28 (5.1%) of the 544 patients who died in the hospice between July 2007 and July 2016, died due to euthanasia (Table 1). Patients were predominantly women (82%) and had a mean age of 70 years (range 42-93). 93% of the patients had cancer and 7% heart failure. Half of the patients was referred to the hospice from a hospital. At admission, 57% of the patients had a KPS ≤40, increasing to 89% at the time of the euthanasia request.

Benzodiazepines (mostly used for insomnia), opioids (mostly used for pain), corticosteroids (used

Table 1. Patient characteristics.

Number of patients	28
Age in years: mean (range)	70 (42–93)
Female sex	23 (82%)
Diagnosis	
Cancer	26 (93%)
Gynaecological cancer	*8 (29%)*
Pulmonary cancer	*5 (18%)*
Gastro-intestinal cancer	*4 (14%)*
Haematological cancer	*4 (14%)*
Brain tumor	*3 (11%)*
Other types of cancer	*2 (7%)*
Heart failure	2 (7%)
KPS at admission*	
10–20	4 (14%)
30–40	12 (43%)
50–60	8 (29%)
70–80	2 (7%)
Unavailable	2 (7%)
Marital status	
Married	12 (43%)
Widow(er)	9 (32%)
Divorced	5 (18%)
Single	2 (7%)
Referral from	
Hospital	14 (50%)
Home	12 (43%)
Nursing home or rehabilitation house	2 (7%)
Potential euthanasia wish known at admission	
No	6 (21%)
Yes	22 (79%)
Actual request for euthanasia at admission	2 (7%)
Duration of admission: mean in days (range)	41 (8–134)

*KPS: Karnofsky performance status.

for fatigue, nausea or neurological problems), and anti-emetics were used during admission by 24, 22, 19, and 18 patients, respectively. Only one patient used an antidepressant, which was prescribed before admission to the hospice.

For 22 patients (79%) a potential wish for euthanasia in the future was documented at admission. Thirteen patients (46%) were in the possession of an advance directive before admission, 12 patients (43%) discussed euthanasia before with another physician and fourteen patients (50%) discussed a potential wish for euthanasia at the day of admission to the hospice. The median period from the admission to the actual euthanasia request was 32 days (range 0–125).

Data from the report of the independent physician were available for 12 patients.

Determinants of unbearable suffering

The determinants of unbearable suffering are shown in Table 2. Most patients indicated three to five determinants (median 4, range 2–6). Physical determinants were mentioned predominantly (96% of patients), followed by existential, psychological and social determinants, mentioned in 89%, 21%, and 4% of patients, respectively (Table 2). Unbearable suffering was described by a combination of physical and existential determinants in 19 patients (68%) (Table 3). For another four patients (14%) psychological determinants were added to this combination. There were no patients mentioning determinants in all four different dimensions. For two patients, unbearable suffering was described in only one dimension (physical and existential, respectively).

Fatigue ($N = 14$), pain ($N = 10$), and physical decline ($N = 8$) were the physical determinants most frequently noted. In only one patient, no physical symptom was mentioned at all. Fear (for fecal vomiting, choking or unbearable pain) was mentioned four times. Depressed mood was never mentioned as a motive for euthanasia. The inability to fulfill social roles, being the only symptom mentioned in the social

Table 2. Determinants of unbearable suffering.

Dimension	Determinant	*N* (%)
Physical		27 (96%)
	Fatigue	14 (50%)
	Pain	10 (36%)
	Physical decline	8 (29%)
	Vomiting	4 (14%)
	Nausea	3 (11%)
	Dyspnea	3 (11%)
	Inability to move	2 (7%)
	Difficulty swallowing	2 (7%)
	Difficulty speaking	1 (4%)
	Inability to eat due to ileus	1 (4%)
	Diarrhoea	1 (4%)
	Dizziness	1 (4%)
	Diplopia	1 (4%)
	Frequent need for paracentesis of ascites	1 (4%)
	Urinary incontinence	1 (4%)
	Fecal incontinence	1 (4%)
	Inability to undertake activities	1 (4%)
	Hemiparesis	1 (4%)
	Inability to use one arm	1 (4%)
	Aphasia	1 (4%)
	Word-finding problems	1 (4%)
Psychological		6 (21%)
	Fear for a specific symptom*	4 (14%)
	Psychological decline	2 (7%)
Social		1 (4%)
	Not being able to life as a parent/partner	1 (4%)
Existential		25 (89%)
	Hopelessness	14 (50%)
	Physical dependency	13 (46%)
	Loss of autonomy	11 (39%)
	Futility	8 (29%)
	Loss of dignity	8 (29%)
	Not able to do things you consider important	1 (4%)
	Waiting for dying	1 (4%)

*The determinants mentioned in 'fear for a specific symptom' are fear for fecal vomiting, choking and unbearable pain (2 times).

Table 3. Combinations of dimensions of determinants.

Dimensions				
Physical	Psychological	Social	Existential	Number of patients (%)
+			+	19 (68%)
+	+		+	4 (14%)
+	+			2 (7%)
+		+	+	1 (4%)
+				1 (4%)
			+	1 (4%)

Table 4. Symptom burden at the time of the euthanasia request.

Symptom	Mean score	Prevalence (score >0) *N* (%)	Clinically relevant (score >3) *N* (%)
Fatigue	7.1	14 (93%)	14 (93%)
Anorexia	5.7	11 (73%)	10 (67%)
Dry mouth	4.8	11 (73%)	8 (53%)
Pain	4.1	10 (67%)	7 (47%)
Constipation	3.4	9 (60%)	6 (40%)
Dyspnea	2.7	6 (40%)	5 (33%)
Insomnia	2.4	7 (47%)	4 (27%)
Nausea	2.1	8 (53%)	5 (33%)
Depressed mood	1.8	5 (33%)	3 (20%)
Dysphagia	0.8	3 (20%)	2 (13%)
Anxiety	0.6	3 (20%)	1 (7%)

dimension, contributed to unbearable suffering for one patient. With regard to existential problems hopelessness ($N = 14$), physical dependency ($N = 13$), loss of autonomy ($N = 11$), futility ($N = 8$), and loss of dignity ($N = 8$) were most frequently mentioned.

Symptom burden

In 15 patients out of the 28 patients included, information on symptom burden at the time of the actual request was available (Table 4). Fatigue, anorexia, dry mouth, pain, and constipation occurred in more than half of the patients. The three most severe symptoms were fatigue (mean score 7.1; clinically relevant, a score >3 in 93%), anorexia (5.7; 67%), and a dry mouth (4.8; 53%). The three least severe symptoms were depressed mood (1.8; 20%), dysphagia (0.8; 13%), and anxiety (0.6; 7%).

The patients mentioning fatigue ($N = 14/15$ evaluable patients) and pain ($N = 10/15$) as determinant of unbearable suffering had higher scores for these symptoms than patients who did not, mean scores for fatigue 8.4 versus 5.7 and mean scores for pain 8.0 versus 1.8.

Discussion

The records of 28 patients were studied to obtain more insight into the determinants of unbearable suffering of patients who requested and died due to euthanasia in a hospice. The percentage of patients in the hospice who died due to euthanasia (5.1%) reflects the national number in the Netherlands (4.5%) (Onwuteaka-Philipsen, 2017).

Worldwide, there is an ongoing debate about euthanasia and its relation to palliative care. The EAPC White paper on euthanasia and physician-assisted suicide clearly stated that euthanasia is not a part of palliative care and highlighted the importance of palliative care to ensure that people do not ask for euthanasia through lack of optimal symptom control (Radbruch et al., 2016). While the latter statement is undisputed in The Netherlands, proponents of euthanasia state that unbearable suffering may occur despite optimal palliative care and that euthanasia may be regarded as an ultimate form of palliative care in situations where unbearable suffering cannot be relieved otherwise and euthanasia is requested by the patient.

In the great majority of patients, the experience of unbearable suffering consisted of a combination of physical determinants, in particular, fatigue, pain and physical decline, and existential determinants, in particular hopelessness, physical dependency, loss of autonomy, futility, and loss of dignity. The psychological dimension played a minor role and the social dimension hardly contributed to unbearable suffering.

Unbearable suffering cannot be measured. It should be regarded as a result of the sum of physical symptoms and existential problems. While the components may not all be unbearable in themselves, the resulting suffering may be unbearable for the patient.

These findings are in accordance with the literature about euthanasia in the general Dutch population (Dees et al., 2011; Georges et al., 2007; Ruijs et al., 2014).

Two Dutch papers have been published about unbearable suffering and euthanasia. Dees et al. (2011) performed a qualitative study in 31 Dutch patients at home who explicitly requested euthanasia, using in-depth interviews exploring what made their suffering unbearable. Themes and subcategories occurring in >20% were:

- Medical (94%): fatigue (32%), physical decline (42%), and cognitive decline (32%);
- Psycho-emotional (94%): loss of autonomy (58%), loss of self (55%), negative emotions (55%), being worn out (52%), and dependency (39%);
- Socio-environmental (65%): being a burden (42%); loneliness (26%);
- Existential (100%): hopelessness (97%), limitation of activities (74%), pointlessness (55%), and being tired of life (55%).

Georges et al. (2007) reported a retrospective interview study on the perspectives of 87 Dutch relatives of terminally ill patients, who died due to euthanasia or physician-assisted suicide at home, in a hospital, in a nursing home or in a hospice. The most frequently mentioned reasons for euthanasia were hopeless suffering (74%), loss of dignity (56%), no prospect of recovery (43%), meaningless suffering (36%), ADL-dependency (35%), general weakness (33%), pain (32%), and being a burden to others (22%).

Trying to compare the results of our study with these studies is difficult, as determinants are described and categorized in different ways and different populations are studied. Clearly, physical and existential determinants predominate in their contribution to unbearable suffering. With regard to physical determinants, fatigue, physical decline and pain are most frequently mentioned. With regard to the existential domain, the determinants are more diverse. Frequently emerging existential issues are hopelessness, lack of perspective, physical dependency, loss of autonomy, futility, and loss of dignity. In our study and that of Georges, not many determinants in the psychological dimension have been found, whereas Dees found negative emotions (not specified) in 56% of patients.

There do not seem to be big differences in physical and existential determinants of unbearable suffering between patients dying of euthanasia in a hospice or at home. In contrast, there is a big difference with regard to the social dimension. Dees found social determinants in 65% of patients, while we found determinants in only 4% of patients. Especially being a burden (42%) and loneliness (26%) were mentioned frequently. This difference is probably explained by the different populations under study: Dees studied a general population (most patients living at home) while our population consists of hospice patients only. The relatives of patients living at home might have to do more caretaking, while all palliative care in the hospice setting is carried out by professionals and volunteers. Also, since the hospice is an environment with other patients, volunteers, and medical staff, it is plausible that loneliness is a less significant factor in hospice patients and is more prevalent in patients living at home. The study of Georges is not comparable for this item because of the population (patients living at home, in a hospital, nursing home or hospice) and the design (interviews with the relatives of patients that could have led to underreporting these specific determinants).

Another relevant study on unbearable suffering in terminal patients is a prospective study of Ruijs et al. (2014). He followed 64 Dutch primary care cancer patients estimated to die within 6 months. 27% ($n = 17$) explicitly requested euthanasia, which was performed in 8% of patients ($n = 5$). Unbearable symptoms were present in 94% of patients with an explicit request (note: not in all of these patients euthanasia was performed) and in 87% of patients without an explicit request. Overall unbearable suffering was noted in 33% and 28%, respectively. These differences were not statistically significant.

Based on these results, unbearable suffering does not seem to be the discriminating factor whether euthanasia is requested or not. Other factors may play a role in this respect, such as life history, social and cultural circumstances and personality characteristics (standards, values and existential motivations such as the will to live or not) (Dees et al., 2011, Ruijs et al., 2014). Further research is needed to address these issues.

Some limitations of our study need to be addressed.

First, we performed a retrospective study using data from the medical records and the reports of the independent physician. We did not directly interview patients themselves. Documentation in the medical records and the reports of the independent physician may not fully reflect the patients' motives for euthanasia.

Second, in the study of Ruijs et al. (2014), there was no difference in the presence of unbearable symptoms between patients with and patients without a euthanasia request (Ruijs et al., 2014). In our study, we did not include patient in whom euthanasia was not performed, so we do not have any information about symptom burden in these patients. Therefore, we cannot be sure that the symptoms we found were the key determinants leading to the request. Moreover, we only analyzed patients who died due to euthanasia. We do not have data on ungranted requests or procedures that were not completed, for example, because of rapid decline resulting in a natural death before the euthanasia could be performed.

Third, we cannot exclude the possibility that there has been overreporting of physical symptoms by patients in order to facilitate their request being granted. The best way to prevent this bias would have been to perform a prospective study interviewing patients with a euthanasia request with blinding of the results for the attending physician.

Fourth, a relatively small number of patients was included, in particular in the part about symptom

burden at the time of the request. Whether a study on this topic on a much larger sample of patients is feasible is questionable.

Finally, 82% of the patients of our study was female, whereas in 2015 of all patients receiving euthanasia in The Netherlands 46% was female. In the hospice of study, the percentage of women is higher than men (58% vs 42%). Whether determinants of unbearable suffering and/or the experience of unbearable suffering differ between men and women is not known.

Taking these limitations into account, the results of our study should be regarded as exploratory.

The results of this study may guide physicians and multidisciplinary teams to assess determinants that can play a role in euthanasia requests, in particular with regard to existential issues. Since the law does not provide any guidance on unbearable suffering, our study may support attending physicians in this emotionally difficult procedure.

Disclosure statement

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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