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The Impact of the Dutch Euthanasia Act on the Number of Requests for Euthanasia and Physician Assisted Suicide - A Cohort Study in General Practice Between 1977 and 2007

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1. Introduction

In 2002 Euthanasia (E) and Physician assisted suicide (PAS) were legalised by passing of the Euthanasia Act in the Netherlands. In this law E was defined as the administration of drugs with death of the patient as the ultimate result, at the explicit request of a patient. PAS was defined as the prescription of drugs by a physician for the purpose of self-administration by the patient. Recent studies showed that the number of deaths in the Netherlands due to E/PAS has decreased after the implementation of the Euthanasia Act in 2002. E decreased from 2.6% of all deaths reported in 2001 to 1.7% in 2005.[1,2] PAS decreased from 0.2% of all deaths in 2001 to 0.1% in 2005.[1] Improved palliative care, including the use of deep continuous sedation at the end of life, and an increase of the average life expectancy are some of the possible explanations for this decrease.[1,2] In addition, the general misperception that morphine shortens life is more and more condemned.[1] This could also explain a decrease, as fewer palliative treatments are registered as E. Our main research question is, whether the number of requests for E or PAS has changed after the implementation of the Euthanasia Act in 2002.

Few publications have reported on requests for E/PAS and the rate of these which is actually granted in the Netherlands.[4-6] Van der Maas et al described an increase in the number of requests between 1990 and 1995 of 37% in terminally ill patients.[4] Trend analysis by Marquet et al, on the incidence of requests for E/PAS with Dutch GPs in the period 1977 to 2001 showed an increase which stabilised during the nineties.[5] Other studies reported that about 44% of the requests actually results in E or PAS.[6] The 56% of requests not resulting in an actual E/PAS was also evaluated. In 13% of the cases the patient passed before E, 13% of patients died even before completion of the preparation process.[6] In 13% of the cases the patient withdrew the request and in 12% of the cases the physician considered the request not eligible.[6]

Several studies examined patients' reasons for requesting E/PAS, in the last decades.[5,7,8] Marquet et al found that hopelessness and deterioration are frequent reasons for a request

and that pain and dyspnoea are declining in frequency as a reason.[5] Emanuel et al considered pain, depressive symptoms and dependence as the most frequent reasons to consider E/PAS.[7] Especially patients with depressive symptoms and pain are changing their minds over time.[7]
This study examines the impact of the Euthanasia Act (2002) on the incidence and reasons for E/PAS in Dutch general practice during the period 1977 to 2007.

2. Methods

Data were collected annually by a standardized questionnaire on requests for E/PAS in Dutch general practice in the period from 1977 to 2007. The GPs included participate in the Dutch Sentinel Practice Network. This network of 45 general practices represents 0.8% of the Dutch population and is representative at a national level for age, gender, geographic distribution and population density. Annually the GPs were requested to report the number of and reasons for requests of E/PAS, they were consulted for in the past year. Definition for E and PAS were applied as formulated in the Dutch Euthanasia Act (2002). Only serious requests of terminally ill patients were noted. Therefore, requests for possible E/PAS in the future, not related to an existing disease, were excluded. Age, gender, underlying disease, reason for the request and presence of a living will were recorded on the questionnaire. GPs reported a maximum of three reasons per request by open question. No age group was excluded. Stemming from the period when euthanasia was not legalized in the Netherlands purposely there is no registration whether the requests were executed or not.
Incidence was calculated as the number of requests per 10,000 patients on GP's lists. Diseases were classified using the International Classification of Primary Care (ICPC) system. Incidence analyses were stratified by patient and practice characteristics. Linear regression trend analysis was performed on the incidence of requests for E/PAS and presented in graphs. Data for the period 1997 to 2000 were adapted to fit in the regression analysis.
The reasons for requesting E/PAS were classified into 22 different subcategories, e.g. pain, dyspnoea, deterioration, and hopelessness. For the most frequently claimed reasons the data were calculated into proportions per category and entered into graphs using linear regression analysis.

3. Results

In the period from 1977 to 2007 the GPs of the Dutch Sentinel Network were consulted for 1011 requests for E/PAS; 54% (546) male and 46% (465) female. In 74.8% the patient was diagnosed with cancer and in 6.4% with a cardiovascular disease. The age distribution showed a peak between 70 and 79 years (28.8%); 26.6% of patients between 60 and 69 years, and 17.3% between 80 and 89 years of age. A rather large group (23.7%) is younger than 60 years of age including 12.7% between 50 and 59, 6.5% between 40 and 49 and 3.3% between 30 and 39 years of age.

Requests for E/PAS, 1977-2007

The number of requests per 10,000 patients (figure 1) shows an increase in the period until 1990. After 1991 trends are slightly decreasing until 2004. After 2004 the incidence stabilised around 2.2 per 10,000 patients ($P<0.05$). No increase after the implementation of the Euthanasia Act in 2002 was observed.

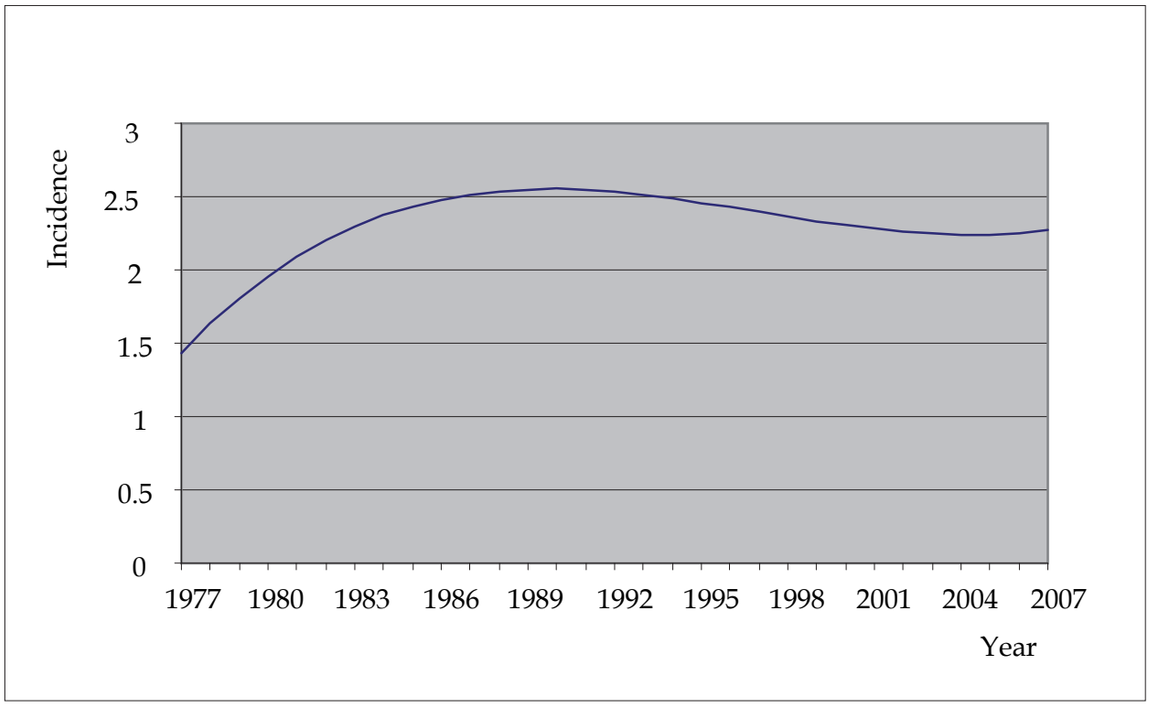

Fig. 1. Annual requests for E/PAS to GPs in the Netherlands, per 10,000 patients (1977-2007).

	B (SE)	95% CI	P-value
Intercept	1.434412 (0.152603)	---	---
1977-1990	0.208166 (0.04684)	0.11127 – 0.305061	0.000186
1991-2004	-0.012 (0.003834)	-0.01993 – (-0.00407)	0.004693
2005-2007	0.0002 (8.56E-05)	2.28E-05 – 0.000377	0.028625

Table 1. Annual requests for E/PAS to GPs in the Netherlands, per 10,000 patients (1977-2007). Results from linear regression analysis.

Reasons to request E/PAS

The most frequently mentioned reason for requesting E/PAS was pain in 31.4% (table 2). Deterioration (26.1%), hopelessness (19.0%) and dyspnoea (12.6%) were also frequent reasons for patients to ask for E/PAS. Fear in general was in 9.7% a reason for the request; fear without a specific reason 4.0%, fear of pain 2.1%, fear of losing dignity 2.2%, fear of deterioration 1.8%, and fear of dependency in 0.7% of the requests. Loss of dignity was one of the reasons for requesting E/PAS in 7.9% of the cases and dependency in 5.1%. Metastatic disease, vomiting and depression were less frequently reported, respectively 3.9%, 3.0%, and 2.8% of all requests in general practice in the Netherlands in the period of 1977 to 2007.

Reason request	N	Percentage of requests
Somatic reasons		
Pain	317	31.4%
Deterioration	264	26.1%
Dyspnoea	127	12.6%
Metastatic disease	36	3.9%
Vomiting	27	3.0%
Bowel disorder	20	2.2%
Swallowing disorder	19	2.1%
Dementia	4	0.4%
Pressure ulcers	3	0.3%
Psychosomatic reasons		
Hopelessness	192	19.0%
Humiliation	80	7.9%
Dependency	47	5.1%
Fear not specified	37	4.0%
Depression	26	2.8%
Fear of humiliation	20	2.2%
Fear of pain	19	2.1%
Fear of deterioration	16	1.8%
Loneliness	11	1.2%
Fear of dependability	6	0.7%
Other medical disorders	112	12.3%
Other reasons	72	7.9%

* Combined group of Fear not specified, Fear of losing dignity, Fear of pain, Fear of deterioration and Fear of dependability.

Table 2. Percentage of reasons for request E/PAS representing different subgroups.

Through the years *pain* is declining in frequency as (one of) the reason(s) for a patient to request E/PAS ($p<0.001$) (Figure 2 and Table 3). In 1977 in almost half of the cases listed by the GPs *(fear of) pain* was mentioned as one of the reasons for the request; in 2007 in one fifth of the cases. Despite this decrease *(fear of) pain* is still the most frequent reason to request in 2007. *(Fear of) deterioration* was increasingly one of the reasons until 1991, but during the last 16 years this trend has decreased ($p<0.01$). *Dyspnoea* shows a declining frequency during the period 1977 to 2007 ($p>0.05$). *Hopelessness* as the reason for a request initially increased and later decreased during the years ($p>0.05$).

4. Discussion

The number of requests per 10,000 patients showed an increase in the first phase of the study 1977-1990, then slightly decreased and stabilised during the past three years. The number of requests remained low since the implementation of the Euthanasia Act in 2002

and through the years concerned a small proportion of all deaths in general practice. Three quarter of the patients that requested E/PAS were suffering from malignant diseases. Reasons for requesting E/PAS were changing over time. *Pain* was declining in frequency as the reason for a request over the years, but remained the most frequent reason for requesting E/PAS throughout the study period. *Deterioration* and other *non somatic reasons* for requesting E/PAS were increasing until the beginning of the nineties, whereafter these reasons declined again.

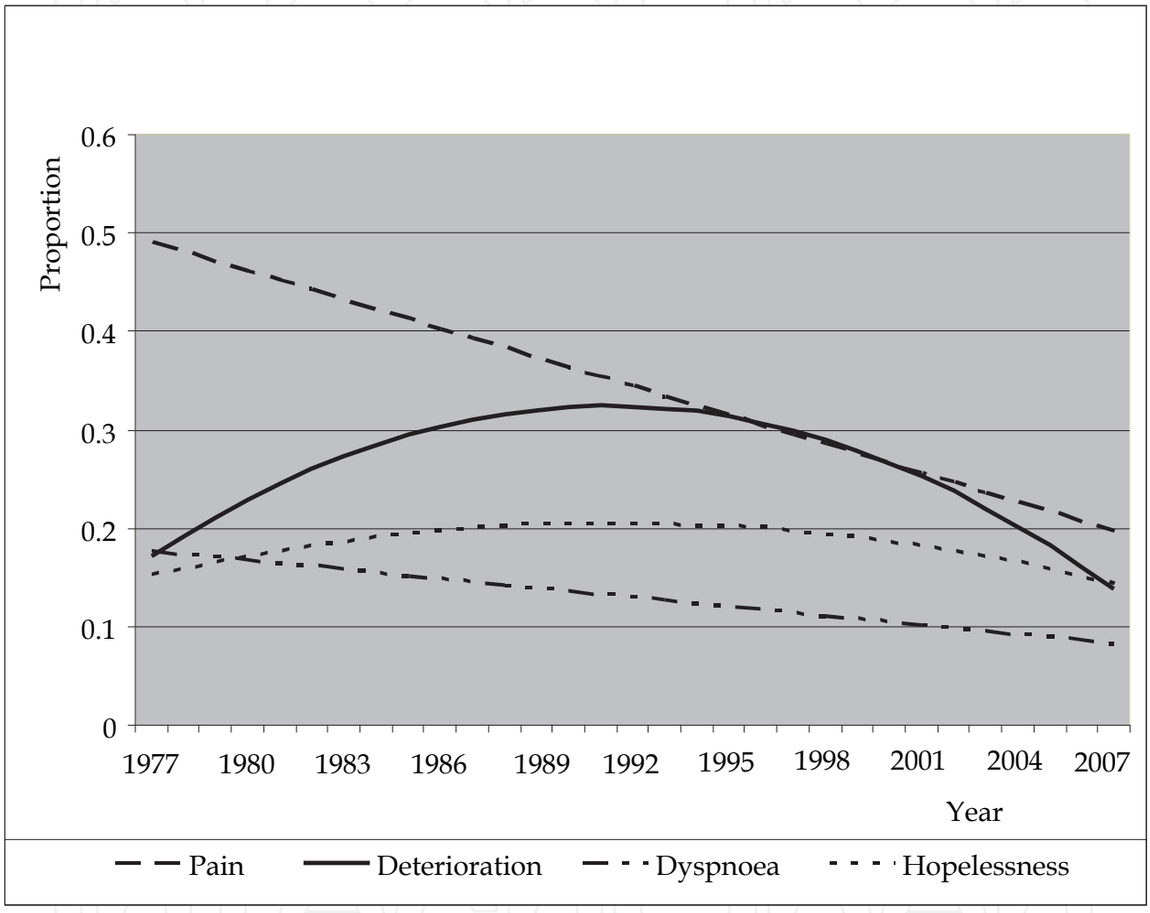

Fig. 2. Reasons for requesting Euthanasia or physician assisted suicide with GPs in the Netherlandsin proportion per category (1977-2007)

This study presents data collected over a 31 year period, partly before any regulation or law had passed. Some limitations need to be mentioned. First, the retrospective design of the study could have induced recall bias among the GPs and, therefore, could have influenced the results. However, we assumed serious consultations about E/PAS would be the consultations least subjective to such bias due to the impact of such consultations on the GP. In addition, the GPs know in advance they will be requested to report their cases of E/PAS each year which enhances correct registration.

Secondly, the definition of E changed over the period 1977 to 2007. In the first years, before the discussion about E in The Netherlands started, the term 'passive euthanasia' was used for various conditions, now called palliative treatment. E as included in our study is

formulated as deliberate use of a treatment that was assumed to be life shortening. This definition has not changed during the study period of more than 30 years.

Pain	B (SE)	95% CI	P-value
Intercept	0,491129 (0,038781)	---	---
1977-2007	-0,00977 (0,002221)	-0,01432 – (-0,00523)	0,000133
Deterioration			
Intercept	0,171239 (0,046684)	---	---
1977-1991	0,021448 (0,007203)	0,006693 - 0,036203	0,005938
1992-2007	-0,00075 (0,000232)	-0,00123 – (-0,00028)	0,003063
Dyspnoea			
Intercept	0,177379 (0,027109)	---	---
1977-2007	-0,00314 (0,001552)	-0,00631 - 3,76E-05	0,052598
Hopelessness			
Intercept	0,152416 (0,04465)	---	---
1977-1991	0,007352 (0,006889)	-0,00676 - 0,021464	0,295027
1992-2007	-0,00025 (0,000222)	-0,00071 - 0,0002	0,261701

Table 3. Reasons for requesting Euthanasia or Physician assisted suicide with GPs in the Netherlands (1977-2007). Results from linear regression analysis.

Furthermore, there are no data on the amount of granted requests for E/PAS. This variable was not included in the past due to the illegal condition of E/PAS before the implementation of the Euthanasia Act in The Netherlands in 2002. Onwuteaka-Philipsen et al described 44% of the requests for E/PAS is granted by GPs in The Netherlands.[6] In 12% of requests it was considered not eligible by the physician and in 13% it was withdrawn by the patient.[6] The patient died before the E/PAS was actually carried out in the rest of the cases (31%).[6]

Our study is unique in collecting data about E/PAS in general practice over a long time period, even before these practices were legalized. The major contribution of this study is the finding that requests for E/PAS in general practice did not increase after implementation of the Euthanasia Act in 2002. As The Netherlands was the first country worldwide to do so, a cohort study embracing a period of over 30 years assessing the impact of the implementation of a Euthanasia Act has not been performed elsewhere.

For the interpretation of the results the representativeness of the network is important. The network is designed to be nationally representative for geographical distribution and distribution in population density.[9] As far as type of practice is concerned, solo practices are slightly overrepresented.[9] There is no indication, however, that this would bias the results.

This network is well-suited for reporting in retrospect, prospectively-collected data through a continuous morbidity registration (CMR) process. Results are typically used for monitoring and harmonising health information.[9-12] In the Netherlands, registration with a GP is compulsory for access to health care.[9,12] The Dutch primary care system is equally accessible to all socio-demographic subgroups.[12] However, it is important to realize that in The Netherlands in general nursing home residents are not under the care of a GP. Therefore, we consider our data representative for euthanasia requests in general practice, but not for nursing homes and other institutions not cared for by GPs, such as prisons and mental health institutions.

Earlier research showed that comparing the five years before and after the implementation of the Euthanasia Act did not show an increased demand for euthanasia after implementation of the new guidelines as well.[13] However, some gender differences in the reasons for requesting euthanasia were revealed in that study. Loss of dignity as a reason declined especially in females. Excellent communication skills including gender sensitivity are important in exploring end of life wishes and underlying reasons for requesting for euthanasia with patients.[13]

5. Conclusions

The incidence of requests for E/PAS in Dutch General Practice increased considerably in the years between 1977-1990 after which it slightly decreased and stabilised in the period 2005-2007. No increase during the first five years after the implementation of the Dutch Euthanasia Act in 2002 was observed. Pain has declined, but remained the most frequent reason for requesting E/PAS in Dutch General Practice despite improved palliative care.

6. Acknowledgement

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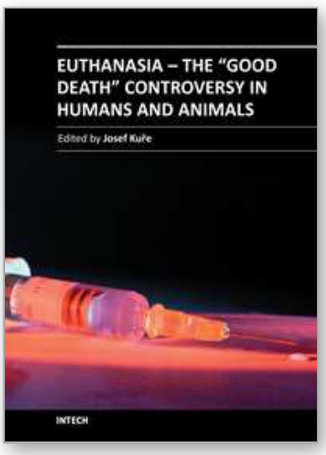

Euthanasia - The "Good Death" Controversy in Humans and Animals

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No one really wants to die, or do they? From classical times to our post-modern era of medical high tech, societies have struggled with the thorny issue of euthanasia, and what it entails. Who shall be entitled to a "good death" and in what form shall it arrive? This book provides the reader with insight and enlightenment on the medical, philosophical, social, cultural and existential aspects of "good death" amid our digitized, individualized and ageing society, hampered by rising health care costs but unchained from one standardized level of care.

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