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Dutch general practitioners experience burden by euthanasia requests from people with dementia: a quantitative survey

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Euthanasia, dementia, general practitioners, support, burden

Abstract

Background In the Netherlands during the past decade, a growing number of people with dementia (PWDs) requested euthanasia, and each year more of such requests were granted.

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Aim We aimed to get quantitative insights in problems and needs general practitioners (GPs) have when confronted with a euthanasia request by a person with dementia (PWD).

Design and Setting A concept survey was composed. Expert validity of the survey was achieved through pilot testing

Method A postal survey was sent to a random sample of 900 Dutch GPs, regardless their opinion on or practical experience with euthanasia. Collected data were analysed with descriptive statistics.

Results Of 894 GPs, 423 (47.3%) completed the survey, of whom 176 (41.6%) had experience with euthanasia requests from PWDs. Emotional burden was reported most frequently (86; 52.8%), as well as feeling uncertain about the mental competence of the PWD (77; 47.2%), pressure by relatives (70; 42.9%) or the PWD (56; 34.4%), and uncertainty about handling advance euthanasia directives (AEDs) (43; 26.4%). GPs would appreciate more support by a SCEN physician (an independent physician for support, information and formal consultation around euthanasia).

(291; 68.8%), a geriatric consultation team (185; 43.7%), the end-of-life clinic (184; 43.5%), or a palliative care consultation team (179; 42.3%). Surprisingly the need for moral deliberation was hardly mentioned.

Conclusion The reported burden and the rise in numbers and complexity of euthanasia requests from PWDs warrants primary care support by easier access to colleagues with expertise and training on end of life care needs of patients with dementia and their caregivers.

How this fits in

Gradually there is an increase in legalization of euthanasia of countries all over the world. The Netherlands was one of the first countries that legalized euthanasia, in 2002. A growing number of people with dementia request euthanasia, and a growing number receives it. Mostly, GPs are confronted with such requests, and a previous qualitative study showed that dealing with such requests is burdensome. This study provides quantitative insights in GPs' burden and needs for support when dealing with euthanasia requests from people with dementia.

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Background

Worldwide, euthanasia and physician-assisted suicide is legalized in an increasing but still low number of countries. In all countries where it is legalized, euthanasia primarily concerns patients with cancer. Existing data do not indicate widespread abuse of these practices,[1] but there is much debate concerning performing euthanasia, physician assisted suicide or other life-ending procedures to vulnerable patients.[2] Since 2002, euthanasia has, under strict conditions, been regulated by the Dutch law, as stated in Article 2 of The Termination of Life on Request and Assisted Suicide Act.[3] At the first stage of its implementation, most requests and performances concerned terminal patients with cancer.[4] However, during the last decade the number of euthanasia cases in people with dementia (PWDs) has increased six fold, from 25 (of 3136 cases in total) in 2010 to 146 cases (of 6125 in total) in 2018.[4] As most PWDs, especially in the early stages of the disease, live at their own home,[5] particularly GPs are confronted with euthanasia requests of PWD.[4] A recent interview study showed that these requests and procedures are burdensome for GPs; they experience pressure from relatives, have problems with judging mental capacity of PWDs, and the Dutch society's stigmatization of dementia.[6]

Indeed, Dutch society considers dementia a horrible disease and synonymous with unbearable suffering, which is sustained by the growing media attention.[7-9] Although most PWDs live at home and will never reach an advanced stage of the disease, many people expect a catastrophic disease course, and fear to end up in a nursing home without any quality of life. Consequently, a growing number of people in the Netherlands draw up an advance euthanasia directive (AED) and share it with their GP.[10] Although an increasing number of countries legalises euthanasia,[1] only in the Netherlands an AED can replace a verbal request for euthanasia in a later stage of dementia, if all other due care criteria are met.[11] Despite the options given, dealing with AEDs of PWDs appeared burdensome for GPs.[6] Not having the same expectations as and disagreeing with relatives about AEDs and the timing of euthanasia contributes to this burden.[12, 13] (Re)discovering the right balance between the physician's professional responsibility and the patient's and relatives' autonomy in such cases has been recommended.[14]

Recently, a Dutch case was evaluated against criminal law which even more raised GPs' concerns around euthanasia in PWDs.[15] Finally a court in The Hague determined that the woman in question with advanced dementia who was given euthanasia, and whose AED adequately represented her wishes, received legally and professionally sound care. The case against the physician, accused of murder, was dismissed.[16] This first ever euthanasia court case is seen as threatening in primary care across the Netherlands, as GPs typically carry out 85% of all euthanasia cases. [17] This case demonstrates the challenges and ethical concerns GPs face when dealing with euthanasia requests

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and AEDs from PWDs. We therefore aimed to answer the following research question: What are the experienced burden and support needs of general practitioners when confronted with a euthanasia request by a person with dementia?

Methods

Study design and participants

We performed a quantitative survey in January 2019. The addresses of a representative sample of 900 Dutch GPs were received from a Dutch institute for healthcare research. GPs, with or without experience with euthanasia requests or euthanasia performance in general or with PWDs specifically, were invited to take part, regardless of their opinion about euthanasia. Exclusion criteria were being retired or not working as a GP anymore.

Survey

Since no validated questionnaire to answer our research question was available, and no comparable study had been performed before, a survey was developed (Appendix 1). Based on a literature search, a qualitative interview study[6] and two expert meetings,[18] a concept survey was composed. Expert validity of the survey was achieved through pilot testing by six GPs, an ethicist, a journalist, a geriatrician and an elderly psychiatrist, and adapted where necessary.

The survey took 15 minutes to complete. Response options included 'yes' or 'no' or multiple choice options, with free text room available when participants selected the option "other".

The survey starts with questions characterizing personal and clinical practice demographics. Next, questions follow that are focused on GPs' experience with AEDs, with euthanasia requests and euthanasia performance in general and regarding PWDs. Experienced burden with regard to euthanasia requests or performance was explored with eight multiple choice items (emotional burden, pressure from resp. the patient and relatives, uncertainty about the technical performance, uncertainty about the mental competence of the patient, uncertainty about the AED, time pressure, and no burden).

To get insights in support needs in the past and support wishes towards the future, eight multiple choice options could be chosen: consultation of resp. a palliative care expert, a geriatric consultation team, a spiritual care provider, the expert center for euthanasia, a PaTz-group (a group of GPs and district nurses who meet six times a year under the supervision of a palliative care consultant, and aim to early identify their palliative patients), and a SCEN-physician (Support and Consultation on Euthanasia in the Netherlands).

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To explore wishes for training to increase knowledge and skills around dementia, eight multiple choice options were provided: communicating end of life aspects, signaling symptoms in cognitively restricted people, dealing with pressure by relatives, legislation and its interpretation regarding euthanasia for this patient group, advance care planning, the dementia disease trajectory, AEDs, and no wishes to increase knowledge or skills.

Finally, we asked whether recent discussions around euthanasia in PWDs influenced the GP's own practice with five multiple choice option: yes, more reserved; yes more fearful for the legal process; yes, more likely to forward such a patient to a colleague or the expert center for euthanasia; yes, more often consulting other healthcare professionals; no influence.

Procedure

A code list was generated for the unique codes of the surveys and names of the GPs. The survey, for each GP with a unique code, an information letter and a self-addressed return envelope were sent in January 2019 to the GPs by mail. Non-responders received a reminder three weeks later. Participation in this study was voluntary and data were processed anonymously.

The study was approved by the Medical Ethics Committee of the Radboud University Medical Centre Nijmegen (2018/5003). In accordance with the Dutch law, Informed consent was not obtained as data processing was anonymous. Data of the completed surveys were entered in Castor, a valid database, and after closure of the database analyzed in SPSS.

Statistical analysis

All data were analyzed using SPSS software version 25. Frequencies with percentages and means with standard deviations (SDs) were used to describe the characteristics. To study differences in experienced burden of GPs between euthanasia and euthanasia request of other patient groups and of PWDs, we performed chi-square tests.

Results

Recruitment

Of the 894 included GPs, 423 (47.3%) completed the survey before closure after eight weeks. **Figure 1** is the study flow diagram, describing the procedure and response rate initially and after a reminder.

Figure 1 about here

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Characteristics and experience with euthanasia and AEDs

There was an equal division between males and females, and the majority of the GPs worked as a regular in a general practice. The mean age was 48 years with a mean of 17 years' experience. (Table1)

Of the responding 423 GPs, 340 (86.5%) had at least once performed euthanasia. Two out of five (176; 41.6%) had at least once received a request for euthanasia from a PWD. Of those 176 GPs, 40 in total also had performed euthanasia in a PWD0 (22,7%: 37 on patients judged competent for this decision and 3 judged incompetent).

Of the 384 GPs who had never performed euthanasia in a PWD, 173 (45.1%) could imagine to perform euthanasia in such a patient in the future. An almost equal number of 180 GPs (47.9%) would always refer such a patient to a colleague or the Dutch expert center for euthanasia. Only a small number of GPs (31, 7.0%) was convinced that they would never perform euthanasia in PWDs and also never refer a patient with such a request to a colleague.

Over half of the GPs (228; 53.3%) estimated that they received one or more AEDs per month, and that more than half contained preferences around euthanasia in case of dementia.

Table 1 about here

Burden

Regarding euthanasia requests or procedures of persons with another disease than dementia, the majority of the GPs experienced emotional burden (284; 69.0% versus 86; 52.8%; p= 0.000), or uncertainty around the technical performance (107; 26.1% versus 12; 7.4%; p= 0.000). (Table 2)

When it concerned a PWD, much more GPs experienced uncertainty about the mental competence of the patient (77; 47.2% versus 51; 12.4%; p=0.015 in the other patients), and about dealing with AED (26.4% versus 4.1%; 0.046). Pressure from patients (resp. 155; 37.8% and 56; 34.4%; p=0.167) or relatives (resp. 42.2% and 42.9%; p=0.560) and time pressure (resp. 167; 40.7% and 16; 9.8%; p=0.121) did not significantly differ between patients with and without dementia.

Table 2 about here

A third of the GPs declared that they had become more reserved with performing euthanasia in PWD in the light of the recent public debate related to the case under court (**Table 3)**. One out of four GPs (102; 24.2%) had become more fearful for the legal processes, 82 (19.4%) were more likely to refer

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these patients to a colleague or the expert centre for euthanasia, and 89 (21.1%) intended to consult other healthcare professionals more often. One in three GPs (153; 36.3%) stated not to be influenced by the media attention.

Table 3 about here

Support needs

The anticipated need for support in future euthanasia procedures with PWDs appeared much higher than support asked in the past (Table 4). About half of the GPs who had experience with such procedures, had consulted a SCEN physician in earlier trajectories (83; 50.9%), and of all respondents even more would prefer this in the future (291; 68.8%). Furthermore, support of a geriatric consultation team (185; 43.7%), a palliative care consultation team (179; 42.3%) or the expert center for euthanasia (184; 43.5%) were most often mentioned as support sources needed. Support of a spiritual care provider had rarely been asked in the past (2; 1.2%) and hardly mentioned as needed in the future (16; 3.8%). Hardly any GP (2; 1.2%) had experience with a moral deliberation around such cases, and only a minority (30; 7.1%) expected to need this kind of support in the future.

Table 4 about here

Wishes to increase skills and knowledge related to dementia

Most GPs (363; 85.8%) would like to increase their knowledge and skills about dementia care issues (Table 5). GPs especially needed training in legislation and interpretation of the law regarding euthanasia in PWDs (240; 56.7%), and in increasing communication skills to deal with pressure from relatives (165; 39%), and knowledge assessing AEDs (167; 39.5%).

Table 5 about here

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Discussion

We quantitatively explored experiences and subjective burden of euthanasia practice for PWD among Dutch GPs. Emotional burden, pressure from relatives and patients and uncertainties, assessment of mental competence and dealing with AEDs were mentioned as most burdensome issues. The latter two were significantly more often mentioned when it concerned PWDs in comparison to other patient groups. The majority of the respondents appeared in need of more support than they had used in the past when it concerned a euthanasia request by or procedure of a PWD. Most often, more support needs from a SCEN physician, a geriatric consultation team, a palliative care consultation team or the expert centre for euthanasia were mentioned.

The large majority of the GPs had at least once performed euthanasia in patients with another disease than dementia, and nearly all had received such requests. About 40% at least once had received a euthanasia request from a PWD, while less than 10% had actually performed euthanasia in such a patient. Of the respondents who never had had a euthanasia request from a PWD, almost half would consider euthanasia when they would be confronted with such a request of such a patient. This is in line with the rise of euthanasia for PWDs in the Netherlands and with previous findings.[4, 19] About half of those who would not consider euthanasia for such patients, would always refer such a patient to a colleague or the Dutch expert center for euthanasia. Indeed, in 2017, of all euthanasia cases, 11.3% were performed by this national expert center for euthanasia, however when it concerned PWDs, this figure was 44.4%.[20] As just a small number of physicians at the expert center for euthanasia handles all these euthanasia requests from PWDs, each of them has a high case load. The emotional impact on this group of physicians is unknown and needs further exploration.

About half of the GPs estimated to receive and discuss one or more AEDs per month, in which often euthanasia in case of future dementia is described. One in four GPs in our study felt uncertainty about dealing with AEDs, and even more GPs wanted training to increase their knowledge around AEDs. As an AED can replace an actual, oral euthanasia confirmation in case a person is not capable to decide on this anymore, either due to cognitive impairment, emotional - or behavioral problems, carefully discussing and regularly updating it is extremely important.

As advance care planning (ACP) in PWDs should start early in the disease trajectory,[21-23] we recommend that GPs use the moment that a PWD shares or wants to discuss an AED to also start ACP. This advance care directive talk should not only touch end of life preferences but also, based on the PWDs' values and norms, non-medical issues that concern their quality of life and care preferences.[24] When such consultations are used to also provide realistic information about the dementia trajectory and its consequences, unrealistic fear for future suffering might be relieved.[25] This needs further exploration in prospective, controlled studies.[26, 27]

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The high percentages of GPs that experienced emotional burden, pressure by patients or relatives concerning euthanasia or euthanasia requests by PWDs, confirms quantitatively recent qualitative studies on this topic.[6 28] The high percentages of GPs that would like to be supported by a SCEN physician, a geriatric consultation team, a palliative care expert or the expert center for euthanasia, is in accordance with the recommendations resulting from two nominal group meetings with all kind of experts in this field.[18] Strikingly, moral deliberation or spiritual counseling was hardly mentioned by the respondents. Probably, GPs mistakenly may associate those kinds of support with religion.[29] Moreover, in primary care such forms of support are hardly available.[30] To increase attention for and provision of spiritual care for elderly and palliative patients in primary care, the Dutch Ministry of Health Affairs currently invests 7.5 million euro per year in this domain.[31] This might increase the awareness of GPs for this kind of support.

The fact that GPs expressed a need of more support from a SCEN physician than they had experienced in the past is remarkable, as in each euthanasia procedure consulting a SCEN physician is obliged. Besides the formal consultation and assessment of the due medical criteria, these physicians can give expert information and advice about legal, ethical and communicative aspects as well as emotional support around the procedure.[32] Apparently, not all GPs experience such support.

Strengths and limitations

This quantitative study is unique in focusing on the burden and support needs of GPs when confronted with a euthanasia request or trajectory of a PWD. We had a high response rate from all regions of the Netherlands. The relatively high response rate emphasizes GPs' high involvement in this topic,[19] as other surveys among Dutch GPs mostly had much lower response rates (29.6% - 41%).[33-35] Respondents were representative for the Dutch GP practice with regard to age and gender,[36] and came from all Dutch regions.

A limitation is the fact that we did not use a validated questionnaire, as this did not exist. However, the concept questionnaire was based on two previous studies and a literature review, and was adapted after having received feedback from six experts.

Conclusion

We found that many Dutch GPs experience emotional burden, uncertainty on assessment of patients' mental competence, handling AEDs and pressure from relatives and the patient concerning euthanasia requests from a PWD. In line with this, GPs look for more support from other healthcare professionals and training to improve their knowledge and skills on this complex topic. Together with the rise in number and complexity of this case load, this warrants primary care support and training for the quickly growing end of live care needs of patients with dementia and their caregivers.

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LIST OF ABBREVIATIONS

AED:	advance euthanasia directive
GP:	General Practitioner
KNMG:	Royal Dutch Medical Association
PWD:	Person with Dementia
PWDs:	People with Dementia
SCEN:	Support and Consultation on Euthanasia in the Netherlands

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Figure 1. Study flow diagram

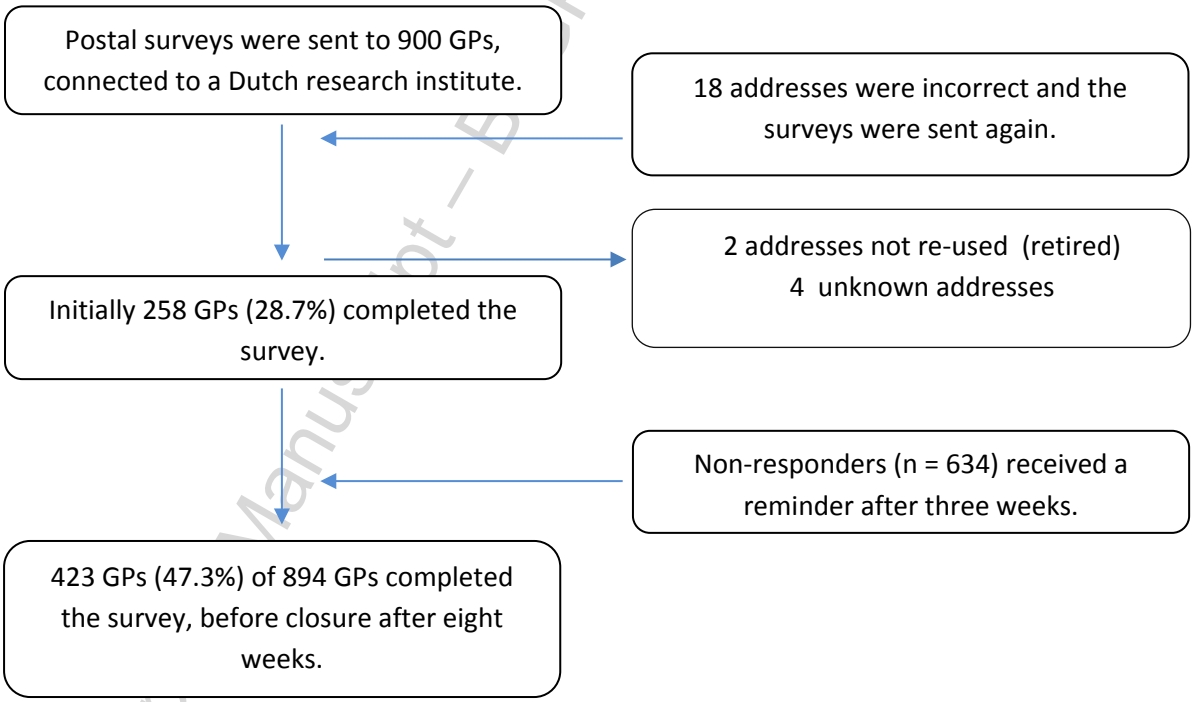

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Table 1. GPs' characteristics (*N* = 423)

Characteristics	*N* (%)*	Mean (SD)
Age in years		48.1 (9.8)
Experience as GP in years		16.5 (9.4)
Gender		
Male	207 (49.2)	
Female	214 (50.8)	
Kind of GP		
Regular	390 (92.6)	
Locum	30 (7.1)	
Having had at least one euthanasia request from a patient with another disease than dementia	410 (96.9)	
Having at least once performed euthanasia in a patient with another disease than dementia	340 (86.5)	
Having had at least one euthanasia request from a PWD		
Yes, competent	135 (32.9)	
Yes, incompetent	41 (10.0)	
No	249 (60.7)	
Having at least once performed euthanasia in a PWD		
Yes, competent	37 (8.7)	
Yes, incompetent	3 (0.7)	
No	384 (90.7)	
Having no experience with euthanasia in PWD, but possibility of performing it in future		
Yes	173 (45.1)	
No, but will refer to a colleague	180 (47.9)	
No, and will not refer to a colleague	31 (7.0)	
Estimated number of AEDs received per month		
<1	195 (46.7)	
≥1	228 (52.6)	
Estimated percentage of AEDs containing euthanasia requests in case of dementia ≥50%	222 (52.6)	

* *Number of missing variables among 2-17 GPs.*

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Table 2 Burden experienced by GPs in euthanasia practice for people with dementia (PWD) and other diseases *(Several answers possible)*

Burden experience	Patients with another disease than dementia *N* (%)[2]	PWD *N* (%)[3]	Chi[2]
Emotional burden GP	284 (69.0)	86 (52.8)	0.000
Pressure from the patient	155 (37.8)	56 (34.4)	0.167
Pressure from relatives	173 (42.2)	70 (42.9)	0.560
Uncertainty technical performance	107 (26.1)	12 (7.4)	0.000
Uncertainty mental competence	51 (12.4)	77 (47.2)	0.015
Uncertainty AED	17 (4.1)	43 (26.4)	0.046
Time pressure	167 (40.7)	16 (9.8)	0.121
No burden experience	22 (5.4)	14 (8.6)	0.001

[2] *N = 410 (experiences with request or performance)*

[3] *N = 163*

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Table 3 The impact of a 2019 debate on euthanasia in PWDs on GPs future behavior in questions for euthanasia in PWD (n=422)

Yes, I am more reserved in performing euthanasia	132 (31.3)
Yes, I am more fearful for the legal processes	102 (24.2)
Yes, I am more likely to forward these patients to a colleague/end-of-life clinic	82 (19.4)
Yes, I consult other healthcare professionals more often	89 (21.1)
No, no influence	153 (36.3)

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Table 4. Support asked by GPs in the past and needed in the future by other healthcare professionals with regards to euthanasia procedures for PWDs

	Support asked in the past N (%)[1]	Support needs future N (%)[2]
Consult palliative care	34 (20.9)	179 (42.3)
Geriatric consult team	38 (23.3)	185 (43.7)
Spiritual care provider	2 (1.2)	16 (3.8)
Expert center for euthanasia	52 (31.9)	184 (43.5)
Moral deliberation	2 (1.2)	30 (7.1)
PaTz-group[3]	16 (9.8)	83 (19.6)
SCEN physician[4]	83 (50.9)	291 (68.8)
Other	52 (31.9)	57 (13.5)

[1] N = 163 (experience with request or performance in PWDs)

[2] N = 423

[3] Group of general practitioners and district nurses that debate six times a year under the supervision of a palliative care consultant to identify palliative care early, to act proactively.

[4]

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Table 5. Wishes of respondents to increase knowledge or skills related to dementia care

Training	*N* (%)
Communicating end of life aspects	119 (28.1)
Signaling symptoms in cognitive restricted people	137 (32.4)
Dealing with pressure by relatives	165 (39)
Legislation and interpretation of euthanasia regarding PWDs	240 (56.7)
Advance care planning	98 (23.2)
Disease trajectory of dementia	86 (20.3)
AED	167 (39.5)
No wishes to increase knowledge or skills	60 (14.2)

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