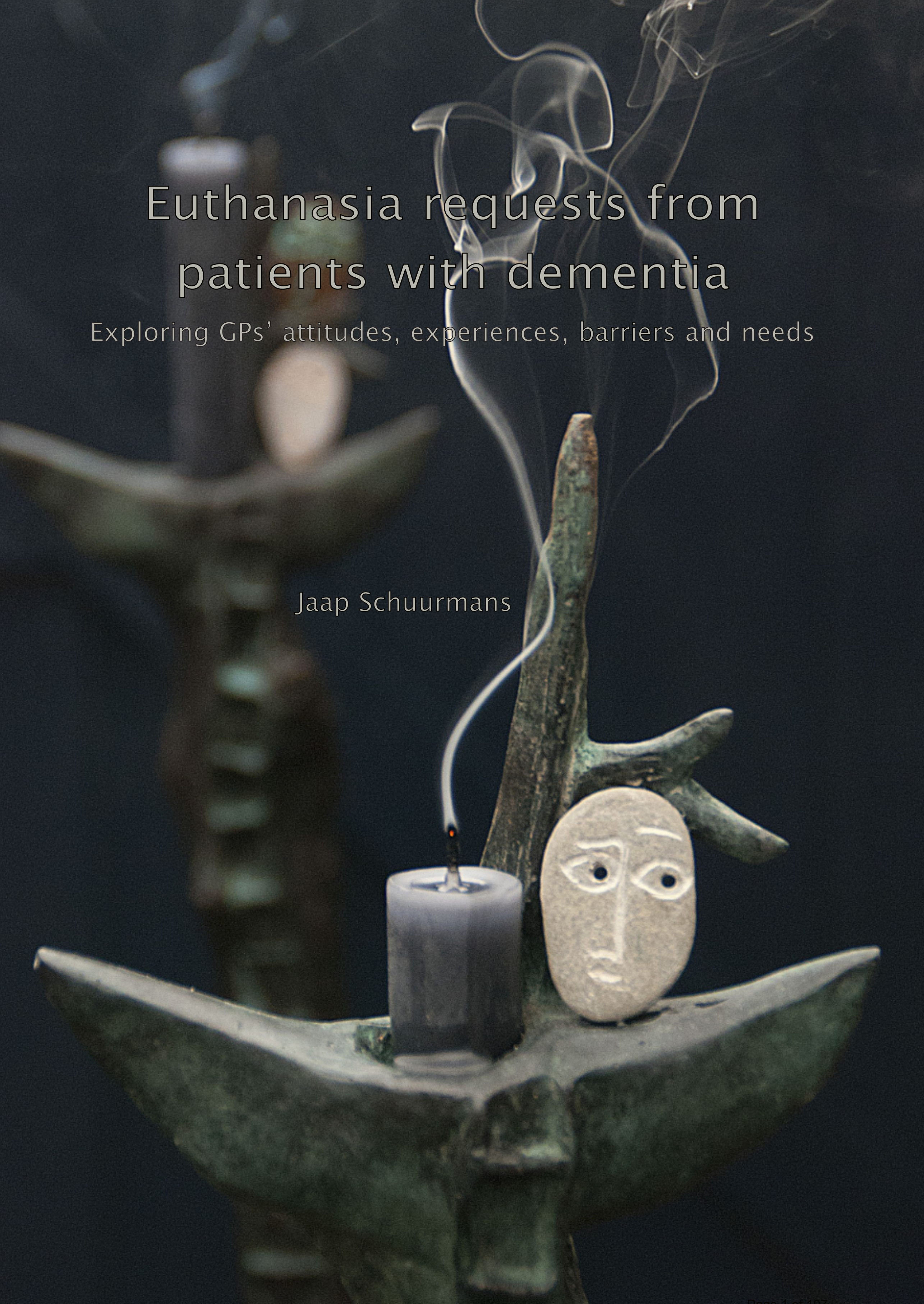

Euthanasia requests from patients with dementia

Exploring GPs' attitudes, experiences, barriers and needs

Jaap Schuurmans

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door

Jaap Schuurmans
Born on March 17, 1961, in Geleen (The Netherlands)

Promotion commission

Supervisors:

Prof. dr. Y.M.P. Engels
Prof. dr. M.G.M. Olde Rikkert

Manuscript committee:

Prof. dr. M.E.T.C. van den Muijsenbergh
Prof. dr. D.L. Gerritsen
Prof. dr. C.W.J. Leget (Universiteit voor Humanistiek)

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PROLOGUE AND GENERAL INTRODUCTION

CHAPTER 1

Prologue

Autumn 2011. Mrs. C., 65+, was a married woman who lived independently with her husband. She had two grown-up children and several grandchildren. I had been their GP for over 16 years when I made my first home visit after her husband, during a consultation, expressed concerns about his wife's memory. During the conversation, signs of forgetfulness became clear to me, and I paid much attention to her hobby of painting bouquets and still lifes. For her, that always gave meaning to life. After a few visits, she agreed to a consultation with the geriatrician. Both dementia of the Alzheimer's type and an imminent overburdening of the husband as a carer were diagnosed. Support from home care could be arranged quickly, and I brought up the living will document, developed by our practice. This was completed and signed by her. Her will contained care restrictions such as never immediately calling 112, but always first the GPs practice. It also included the wish not to resuscitate and the right to discuss euthanasia at any time. The living will was also shared with the GPs practice. Additional support from home care and the municipality (care pathway guidance) was provided to the husband in order to learn to cope with her behavioural changes. At the same time, Mrs C. was visited by me once every three weeks. We sat at the coffee table and discussed things that gave her pleasure- the garden and painting. At the same time, I build up a clearer impression of the husband. Was he able to find space and time for himself? The dementia image progressed rapidly, and in the spring of 2012, her euthanasia wish was discussed for the first time. I intensified the search for what could still give meaning to her life but did not feel that I was meeting those needs sufficiently. The euthanasia question "doctor, you must help me" was asked insistently and repeatedly. In support of this I recommended the book "Uitweg" by Boudewijn Chabot; we discussed the method of stopping eating and drinking and in the end, which she attempted by starvation. In my opinion, as her dementia still was relatively mild, this would have a chance of success. But she and her husband called me after a few days, crying. After three days, she broke down emotionally and said, "I want to keep seeing my grandchildren". This prompted a family discussion in which everyone expressed their gratitude. Life still had meaning, and the wish for euthanasia had faded into the background.

A few months later, the ability to paint disappeared and the euthanasia wish was repeatedly expressed as "I am disappearing". It was poignant to see a woman who, in my view, could no longer take her fate into her own hands due to her advancing dementia. A woman who still could and had the willpower to clearly express her wishes and convictions; her idea of a dignified end of life was only one way, the way of euthanasia. I increasingly recognised her suffering. Her demented appearance confirmed her firm conviction that euthanasia was the only dignified way to end her life. I committed myself to her wish and had to defend my choice to the euthanasia consultant, who, contrary to my expectation of quick approval, seemed to opt for a delay and postponement strategy.

First, an assessment of her capacity to give consent and, later, to see whether an antidepressant would help. Yet, I didn't have that time, given her rapidly progressing dementia. After an initial rejection the consulting SCEN (support and consultation during euthanasia procedures) doctor agreed with the request. In my opinion, I ended her life while she could still confirm that wish, even though her words almost lost meaning. This case, with my reflection, was published in 2013 on DVD entitled ‘Dying in Control’ [1]. In this case, the most gracious path to take was euthanasia because she could not stop herself from eating and drinking.

In this case, my work as GP and as a palliative care consultant for the Integral Cancer Centre and social developments have essentially been the impetus for what is to follow. It raised my awareness and personal drive to include the concept op palliative care in a broader view of care towards patients with frailty. My curiosity reached beyond personal experiences. Not based on moral judgements, but on a genuine and increasingly keen curiosity about what is happening in this field, socially, legally and within the medical profession.

General introduction

As stated in the prologue, the subject of euthanasia and patients with advanced dementia became of my interest. This thesis will focus on different aspects concerning dementia and early palliative care, but mainly on requests for euthanasia for patients with advanced dementia. What does this means for their general practitioners (GPs), what are their experiences and needs? This thesis is based on four individual researched questions, which focus on different aspects regarding euthanasia for patients with advanced dementia, exploring the thought processes, its ethical and juridical limitations and the need for support to GPS.

General practice and early proactive palliative care

Almost each inhabitant of the Netherlands is registered on the patient list of a specific GP; this GP is responsible of the generalist care of the patient, 24 hours a day, 7 days a week. As patients often have a longstanding relationship with their GP [2], this makes the GP the professional with the best position to talk about personal and difficult choices [2-4]. The GP theoretically knows what health issues the patient has as well as the patient's relevant context. By this central position in the health care system the GP is the professional who coordinates and provides palliative care for home dwelling patients. Within the trajectories of late-life illness, patients with frailty or dementia have a long period of slow functional decline until death [5].

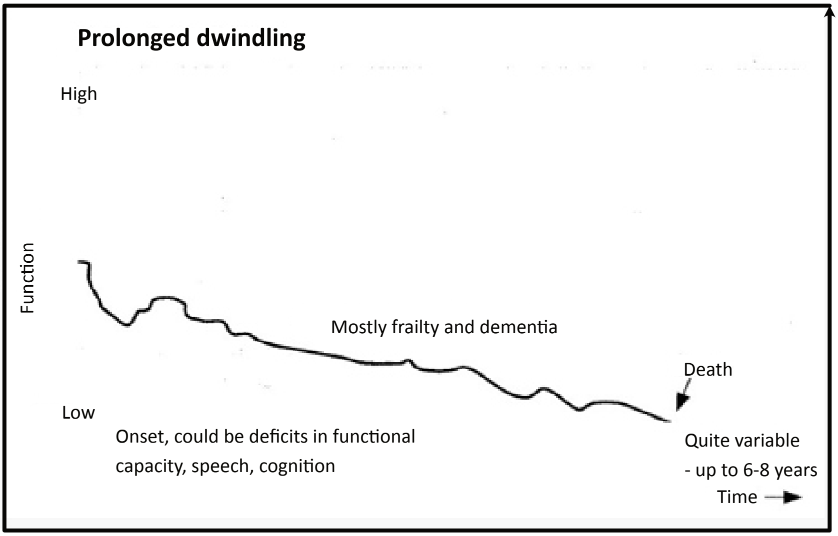

Figure 1 (Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330(7498):1007-11

Such an archetypical representation of a disease trajectory has its limitations. Per patient the moment of diagnosing dementia is different, types of dementia differ greatly, multimorbidity is common and the complexity of other conquering life limiting diseases differ greatly [6]. Moreover, having a life limiting disease is often denied. Previous studies have shown that advance care planning (ACP) is not an easy topic to talk about. Some patients are afraid to talk about their future care, because it forces them to think of severe illness and death [7]. GPs are often unwilling to initiate the conversation as they do not want patients to feel uncomfortable or distressed [8, 9]. Therefore, GPs tend to wait until the patient initiates such a conversation [10]. Over the last couple of years, attempts have been made to promote and implement ACP in (primary) health care [11]. Taking these deliberations into account, a flexible attitude of the GP and the home care team seems most adequate to find the moment to start proactive palliative care planning. ACP does not only concern choices on future physical care, but it also covers quality of life, relationships, mental health and the spiritual dimension starting from the present [33]. It asks for a series of conversations with the person with dementia, family caregiver and home care team. During such conversations, plans, wishes and needs can be adapted to new insights over time as often as needed. Structured palliative care has shown to increase the chance to die at home, to decrease transfers, length of hospitalisation and aggressive interventions, and has proven to be cost-effective [12, 13]. All these aspects contribute to the quality of remaining life of patients and their family. If GPs provide realistic information about the dementia trajectory and its consequences, unrealistic fear for future suffering and loss of control may be relieved [14-16].

Over the last couple of years, attempts have been made to promote and implement ACP in (primary) health care [11].

Dementia in the Netherlands

Dementia is the loss of cognitive functioning — thinking, remembering, and reasoning — to such an extent that it interferes with a person's daily life and activities. Some people with dementia cannot control their emotions, and their personalities may change. Dementia ranges in severity from the prodromal early stage, when it is just beginning to affect a person's functioning, to the most severe stage, when the person must depend completely on others for basic needs to live. Dementia is more common as people grow older (about one-third of all people aged 85 or older may have some form of dementia) [17], but it is not a normal part of aging. Many people live into their 90s and beyond without any signs of dementia. There are several forms of dementia, including Alzheimer's disease. A person's symptoms can vary depending on the type. People with dementia live a mean of 6.5 years with the disease [17]. During the disease process, both the number and severity of the complaints increase. Currently there is no cure nor effective disease modifying drug for dementia, and new drugs registered in the USA (not in Europe) such as aducanumab have hardly clinically relevant impact. Therefore, palliative care remains a cornerstone of medical treatment in caring for patients with dementia. In the Netherlands, 290,000 people have dementia, according to the estimation of Alzheimer Netherlands (www.alzheimer-nederland.nl). The number of people with dementia will rise to more than half a million by 2040 as a result of the aging population. In 2050, the number will further increase to more than 620,000. 79% of people with dementia live at home and are cared for by their close family and/or friends, the so-called informal carers. According to the Nivel primary care register, in 2020 114,800 people with a diagnosis of dementia were known to the GP [18]. This figure is age-related. For the age group of 85 years and older, the annual prevalence is 135 per 1000 people for women and 115 per 1000 inhabitants for men [19].

Euthanasia in the NL

In the Netherlands, in 2002, euthanasia became a legitimate medical act, allowed only when the due care criteria and procedural requirements are met [20]. Being faced with a euthanasia request can have a major impact on physicians; [21, 22] 25% of the physicians who received such a request, experienced problems during the decision making process [23]. These problems mainly concerned the evaluation of the due care criteria. A survey showed that nearly one-third of all physicians experienced pressure from the patient (29%) or from the family (34%) during the decision-making process. Moreover, more than half of the GPs, (56%) and 40% of the elderly care physicians experienced pressure to hasten the procedure [24]. This is related to the changing views in Dutch society with a shift in the direction of wanting to be in control of your own life and being convinced to have a right to die [25].

Euthanasia for patients with dementia

Initially, as in other countries, the large majority of euthanasia requests and acts concerned terminal patients with cancer [26]. However, during the last decade, the Dutch number of euthanasia cases in persons with dementia (PWDs) has increased as shown in Table 1.

Table 1 number of reported cases of euthanasia in dementia (2012-2020) in the Netherlands[27]

Year	Reported
2012	42
2013	97
2014	81
2015	109
2016	141
2017	169
2018	146
2019	162
2020	170
2021	215
2022	288

https://www.rijksoverheid.nl/documenten/rapporten/2023/04/04/regionale-toetsingscommissies- euthanasie-jaarverslag-2021/2022

More than a decade ago, several studies focused on the debate on advanced euthanasia directives (AEDs) for patients with dementia [28, 29], and on experiences of physicians in nursing homes on this topic [30]. At that time, elderly care physicians and relatives appeared to be reluctant to adhere to AEDs. However, since then a lot has changed in the public debate, in the opinion of physicians and in daily practice. In 2012, 40% of the physicians found it conceivable that they would grant a euthanasia request of a person with early-stage dementia, and 30% in persons with advanced dementia [31]. Moreover, in 2010, euthanasia for patients with dementia took place in 25 cases (of 3136 cases in total), and in 2020 in 170 cases [32, 33]. The numbers of AEDs and euthanasia requests from patients with dementia are larger, as not every request or AED ends up in euthanasia [33-35].

Dutch society, influenced by the growing media and political attention, considers dementia as a debilitating and degrading disease and, by many, as synonymous with unbearable suffering [36-38].

As most patients with dementia, especially in the early stages of the disease, live at their own home [17], GPs are confronted with euthanasia requests of patients with dementia [26]; a growing number of people in the Netherlands discuss and share an AED with their GP [39].

BOX 1. The requirements of due care in Dutch law as stipulated in the Article 2 of The Termination of Life on Request and Assisted Suicide Act.

Under the law, the definition of euthanasia applies when a physician ends the life of a patient at his express request due to unbearable and lasting suffering. Euthanasia means that the physician administers a lethal substance to the patient. In the case of assisted suicide, the physician supplies a lethal substance that the patient takes in the physician's presence. The physician must:

a. Be satisfied that the patient's request is voluntary and well considered.
b. Be satisfied that the patient's suffering is unbearable, with no prospect of improvement.
c. Have informed the patient about his situation and his prognosis.
d. Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation.
e. Have consulted at least one other independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled.
f. Have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

The Act stipulates in section 2.2 that a patient aged 16 or over who is decisional competent may draw up an advance directive, setting out a request for euthanasia. If at some point the patient is no longer capable of expressing his will, the physician may accept the advance directive as a request pursuant to section 2 (1)(a) of the Act.1 2 The advance directive thus has the same status as an oral request for euthanasia.

Assessing the euthanasia due care criteria and the timing when it concerns a patients with dementia is difficult [23, 31]. Until 2015, the Royal Dutch Medical Association (KNMG) directed that, on medical-ethical grounds, it was necessary that the patient confirmed his or her actual death wish, verbally or non-verbally, when receiving euthanasia, regardless of having an AED. In 2021, the KNMG published its latest guideline, following the more liberal possibilities as given by law, in which an oral request was not required as stipulated in section 2.2 (Box 1) [40]. This can be considered a baseline shift, responding to the society expectations to provide maximum juridical space for patients with dementia.

Shortly before we, started the survey study described in this thesis in 2018, three cases were reported in which persons with advanced dementia received euthanasia on the basis of an AED [32]. This led to several campaigns by physicians who opposed an AED authorisation of euthanasia in case of advanced dementia due to their ethical concerns [41, 42]. At that time a first judicial criminal investigation was opened on a physician's actions regarding a euthanasia case in a person with advanced dementia [42]. Although this case concerned an elderly care physician working in a nursing home, this first ever euthanasia court case was also considered as threatening in primary care across the Netherlands, as typically GPs are confronted with euthanasia requests and AEDs; they carry out 85% of all euthanasia procedures [43].

We hypothesised that dealing with euthanasia requests from patients with dementia, whether or not they are still competent, impacts physicians, and more specifically GPs and elderly care physicians. They are the physicians who receive almost all euthanasia requests from patients with dementia [32]. We aimed answer the following research question: What are the experiences and needs of Dutch GPs and elderly care physicians when handling a euthanasia request from a person with dementia? This interview study can be found in Chapter 2.

Since the debate about euthanasia for the treatment of patients with dementia has ethical, medical, political and juridical aspects, we invited a diverse group of experts to participate in a nominal group study, to identify ways of supporting GPs confronted with a patients with dementia euthanasia request. This study can be found in Chapter 3.

Next, we performed a broad survey study among GPs 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? This study can be found in Chapter 4.

During the completion of this survey by GPs in 2019, the coffee-euthanasia case [44] got well-known by all Dutch physicians, as it had attracted huge media attention. In this case an elderly care physician performed euthanasia following an AED from a patient with severe dementia rather than rely on her consent. And the doctor sedated this dementia patient before carrying out the procedure to stop the patient becoming agitated. However, at that point in time a judicial decision had not yet been made. Therefore in the qualitative study an imaginary identical case was put forward which aimed to see what the views of Dutch GPs are concerning a patient with advanced dementia. This study can be found in Chapter 5.

Summarized this thesis thus contains the four different empirical studies:

Chapter2; Euthanasia requests in Dementia Cases. What are the experiences and needs of Dutch physicians?
A qualitative interview study. What are the experiences and needs of Dutch general practitioners and elderly care physicians when handling a euthanasia request from a person with dementia?

Chapter 3; Supporting general practitioners around euthanasia requests from people with dementia: nominal group meetings. The overall aim of the current study was to identify and prioritize forms of support that should be used or implemented to help GPs confronted with euthanasia requests from Patients With Dementia.

Chapter 4; Dutch general practitioners experience burden by euthanasia requests from people with dementia: What are the experienced burden and support needs of general practitioners when confronted with a euthanasia request by a person with dementia?

Chapter 5; Euthanasia in Advanced Dementia; the view of the general practitioners in the Netherlands on a vignette case along the juridical and ethical dispute. What are the views of Dutch GPs on euthanasia concerning patients with advanced dementia (PWAD)?

References

1. Chabot B. Sterven in eigen regie: ooggetuigen. Netherlands2013.

2. Tilburgs B, Vernooij-Dassen M, Koopmans R, Weidema M, Perry M, Engels Y. The importance of trust-based relations and a holistic approach in advance care planning with people with dementia in primary care: a qualitative study. BMC Geriatr. 2018;18(1):184.

3. Sharp T, Malyon A, Barclay S. GPs' perceptions of advance care planning with frail and older people: a qualitative study. Br J Gen Pract. 2018;68(666):e44-e53.

4. Eynon T, Lakhani MK, Baker R. Never the right time: advance care planning with frail and older people. Br J Gen Pract. 2013;63(615):511-2.

5. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330(7498):1007-11.

6. Lum HD, Sudore RL, Bekelman DB. Advance care planning in the elderly. Med Clin North Am. 2015;99(2):391-403.

7. Tilburgs B, Koopmans R, Vernooij-Dassen M, Adang E, Schers H, Teerenstra S, et al. Educating Dutch general practitioners in dementia advance care planning: a cluster randomized controlled trial. Journal of the American Medical Directors Association. 2020;21(6):837-42. e4.

8. Tilburgs B, Vernooij-Dassen M, Koopmans R, van Gennip H, Engels Y, Perry M. Barriers and facilitators for GPs in dementia advance care planning: A systematic integrative review. PLoS One. 2018;13(6):e0198535.

9. Vanderhaeghen B, Van Beek K, De Pril M, Bossuyt I, Menten J, Rober P. What do hospitalists experience as barriers and helpful factors for having ACP conversations? A systematic qualitative evidence synthesis. Perspect Public Health. 2019;139(2):97-105.

10. Wichmann AB, van Dam H, Thoonsen B, Boer TA, Engels Y, Groenewoud AS. Advance care planning conversations with palliative patients: looking through the GP's eyes. BMC Fam Pract. 2018;19(1):184.

11. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol. 2017;18(9):E543-E51.

12. Boddaert MSA. Quality palliative care for all - WANT IT! - towards death, while alive. Leiden: Leiden University; 2023.

13. Wichmann AB, Adang EMM, Vissers KCP, Szczerbinska K, Kylanen M, Payne S, et al. Decreased costs and retained QoL due to the 'PACE Steps to Success' intervention in LTCFs: cost-effectiveness analysis of a randomized controlled trial. BMC Med. 2020;18(1):258.

14. Petty S, Harvey K, Griffiths A, Coleston DM, Dening T. Emotional distress with dementia: A systematic review using corpus-based analysis and meta-ethnography. Int J Geriatr Psychiatry. 2018;33(5):679-87.

15. Lloyd-Williams M, Mogan C, Dening KH. Identifying palliative care needs in people with dementia. Curr Opin Support Palliat Care. 2017;11(4):328-33.

16. Dixon J, Karagiannidou M, Knapp M. The Effectiveness of Advance Care Planning in Improving End-of-Life Outcomes for People With Dementia and Their Carers: A Systematic Review and Critical Discussion. J Pain Symptom Manage. 2018;55(1):132-50 e1.

17. Nederland A. Factsheets cijfers en feiten over dementie. (Fact sheets dementia figures and facts): Alzheimer Nederland; 2019 [Available from: https://www.alzheimer-nederland.nl/factsheet- cijfers-en-feiten-over-dementie.

18. Nivel. Factsheet 7-12 Register Dementiezorg en Ondersteuning: Nivel; 2021 [Available from: https://www.nivel.nl/nl/nieuws/situatie-en-kenmerken-mensen-met-dementie-bleef-tussen-2017- 2020-grotendeels-gelijk.

19. Nederland NeA. Dementiemonitor Mantelzorg 2022. Utrecht/Amersfoort; 2022 November 2022. Report No.: ISNB: 978-94-6122-768-3.

20. Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Law evaluation of life termination upon request and assisted suicide) The Hague: Dutch government; 2018 [Available from: https://wetten.overheid.nl/BWBR0012410/2018-08-01.

21. Georges JJ, The AM, Onwuteaka-Philipsen BD, van der Wal G. Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. Journal of medical ethics. 2008;34(3):150-5.

22. van Marwijk H, Haverkate I, van Royen P, The AM. Impact of euthanasia on primary care physicians in the Netherlands. Palliat Med. 2007;21(7):609-14.

23. Buiting HM, Gevers JK, Rietjens JA, Onwuteaka-Philipsen BD, van der Maas PJ, van der Heide A, et al. Dutch criteria of due care for physician-assisted dying in medical practice: a physician perspective. Journal of medical ethics. 2008;34(9):e12.

24. Onwuteaka-Philipsen B, Legemaate J, van der Heide A, van Delden H, Evenblij K, El Hammoud I, et al. Third evaluation of the Act on Termination of Life on Request and Suicide Assistance; English summary on page 19
Den Haag: ZonMw; 2017 [cited 2018 October 14]. Third evaluation of the Act on Termination of Life on Request and Suicide Assistance; English summary on page 19;

Available from: https://www.rijksoverheid.nl/documenten/rapporten/2017/05/23/derde- evaluatie-wet-toetsing-levensbeeindiging-op-verzoek-en-hulp-bij-zelfdoding.

25. Kouwenhoven PSC, van Thiel GJMW, van der Heide A, Rietjens JAC, van Delden JJM. Developments in euthanasia practice in the Netherlands: Balancing professional responsibility and the patient's autonomy. The European journal of general practice. 2019;25(1):44-8.

26. RTE. Year reports 2010-2018 of the Regional Evaluation Commissions Euthanasia (RTE) 2018 [Available from: https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen.

27. (RTE) RTE. Jaarverslag 2021. Den Haag: RTE; 2021 April 2022.

28. Hertogh CM, de Boer ME, Droes RM, Eefsting JA. Would we rather lose our life than lose our self? Lessons from the Dutch debate on euthanasia for patients with dementia. Am J Bioeth. 2007;7(4):48-56.

29. de Boer ME, Hertogh CM, Droes RM, Jonker C, Eefsting JA. Advance directives in dementia: issues of validity and effectiveness. Int Psychogeriatr. 2010;22(2):201-8.

30. de Boer ME, Droes RM, Jonker C, Eefsting JA, Hertogh CM. Advance directives for euthanasia in dementia: how do they affect resident care in Dutch nursing homes? Experiences of physicians and relatives. J Am Geriatr Soc. 2011;59(6):989-96.

31. Bolt EE, Snijdewind MC, Willems DL, van der Heide A, Onwuteaka-Philipsen BD. Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? Journal of medical ethics. 2015;41(8):592-8.

32. Regionale Toetsingscomissies Euthanasie (RTE). RTE Jaarverslagen 2010-2018 [Internet] [place unknown]: euthanasiecommissie; 2010-2018 [cited 2018 Aug 10]. Available from: https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen.

33. Evenblij K, Pasman HRW, van der Heide A, Hoekstra T, Onwuteaka-Philipsen BD. Factors associated with requesting and receiving euthanasia: a nationwide mortality follow-back study with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age. BMC Medicine. 2019;17(1):39.

34. Evans N, Pasman HR, Deeg DJ, Onwuteaka-Philipsen BD. Older Dutch People's Self-Reported Advance Euthanasia Directive Completion Before and After the Enactment of the Euthanasia Law: A Time Trend Study (1998-2011). J Am Geriatr Soc. 2015;63(10):2217-9.

35. Harnas S TW. Rapport meldactie ‘Wilsverklaring’ Patiëntenfederatie Utrecht, Nederland: Patiëntenfederatie Nederland; 2018 Jun [cited 2019 Apr 25]. Available from: https://www.patientenfederatie.nl/images/stories/dossier/Levenseinde/RapportWilsverklaringenDef.pdf.

36. Landeweer M. Radeloze Joop (81): Soms loopt de urine langs haar enkels (Distraughted Joop: Sometimes her urine drops down her ankles) 2016 [Available from: https://www.ad.nl/gezond/radeloze-joop-81-soms-loopt-urine-langs-haar-enkels~af8145d5/.

37. Grooters L. Drie inzichten uit de Leeuwenhoektour (Three insights from 'the Leeuwenhoek tour') 2018 [Available from: https://www.human.nl/in-de-leeuwenhoek/lees/inzichten-tour.html

38. Working together to tackle dementia The Hague: Government of the Netherlands; 2017 [Available from: https://www.government.nl/latest/news/2017/05/16/working-together-internationally-to-tackle-dementia

39. Van Twillert M. Meer mensen hebben schriftelijke wilsverklaring (A growing number of people have a written advance directive) 2018 [Available from: https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/meer-mensen-hebben-schriftelijke- wilsverklaring.htm.

40. KNMG. Handreiking schriftelijk euthanasieverzoek (guideline written advanced euthanasia directive) Utrecht: KNMG; 2015 [Available from: https://www.rijksoverheid.nl/documenten/brochures/2015/12/17/handreiking-schriftelijk- euthanasieverzoek-artsenversie.

41. Chabot B. Dood nooit weerloze die het niet beseft [Internet] [place unknown]: de Volkskrant; 2017 Jan [cited 2018 Aug 29]. Available from: https://www.volkskrant.nl/columns-opinie/dood- nooit-weerloze-die-het-niet-beseft~b96e0536/.

42. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controversial case and its ethical implications. Journal of medical ethics. 2018.

43. Annual Report 2017 Dementia Cases in the Netherlands 2018 [cited 2019 August 2019]. Available from: https://english.euthanasiecommissie.nl/the- committees/documents/publications/annual-reports/2002/annual-reports/annual-reports.

44. Boztsas S. Dutch euthanasia doctor cleared over death of dementia patient. The Telegraph. 2019 11th september 2019.

CHAPTER 2

EUTHANASIA REQUESTS IN DEMENTIA CASES. WHAT ARE THE EXPERIENCES AND NEEDS OF DUTCH PHYSICIANS? BMC MEDICAL ETHICS (2019) 20;66

Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study

Jaap Schuurmans[1,3*], Romy Bouwmeester[2], Lamar Crombach[2], Tessa van Rijssel[2], Lizzy Wingens[2], Kristina Georgieva[2], Nadine O'Shea[2], Stephanie Vos[2], Bram Tilburgs[3] and Yvonne Engels[3]

Abstract

Background: In the Netherlands, in 2002, euthanasia became a legitimate medical act, only allowed when the due care criteria and procedural requirements are met. Legally, an Advanced Euthanasia Directive (AED) can replace direct communication if a patient can no longer express his own wishes. In the past decade, an exponential number of persons with dementia (PWDs) share a euthanasia request with their physician. The impact this on physicians, and the consequent support needs, remained unknown. Our objective was to gain more insight into the experiences and needs of Dutch general practitioners and elderly care physicians when handling a euthanasia request from a person with dementia (PWD).

Methods: We performed a qualitative interview study. Participants were recruited via purposive sampling. The interviews were transcribed verbatim, and analyzed using the conventional thematic content analysis.

Results: Eleven general practitioners (GPs) and elderly care physicians with a variety of experience and different attitudes towards euthanasia for PWD were included. Euthanasia requests appeared to have a major impact on physicians. Difficulties they experienced were related to timing, workload, pressure from and expectations of relatives, society's negative view of dementia in combination with the 'right to die' view, the interpretation of the law and AEDs, ethical considerations, and communication with PWD and relatives. To deal with these difficulties, participants need support from colleagues and other professionals. Although elderly care physicians appreciated moral deliberation and support by chaplains, this was hardly mentioned by GPs.

Conclusions: Euthanasia requests in dementia seem to place an ethically and emotionally heavy burden on Dutch GPs and elderly care physicians. The awareness of, and access to, existing and new support mechanisms needs further exploration.

Keywords: Euthanasia, Dementia, Elderly, Elderly care physician general practitioners, Primary care, Support

Background

In the Netherlands, in 2002, euthanasia became a legitimate medical act, allowed only when the due care criteria and procedural requirements are met [1]. Being faced with a euthanasia request can have a major impact on physicians [2, 3]; 25% of the physicians who received such a request, experienced problems during the decision making process [4]. These problems mainly concerned the evaluation of the due care criteria. A survey showed that nearly one-third of all physicians experienced pressure from the patient (29%) or from the family (34%) during this process. Moreover, more than half of the general practitioners (GPs; 56%) and 40% of the elderly care physicians experience pressure to hasten the procedure [5]. This is related to changing views in Dutch society in the direction of being in control of your own life and a right to die [6].

More than a decade ago, several studies focused on the debate on euthanasia and on advance euthanasia directives (AEDs) for patients with dementia (PWD) [7, 8], and on experiences of physicians in nursing homes on this topic [9]. At that time, elderly care physicians and relatives appeared to be reluctant to adhere to AEDs. However, since then a lot has changed in the public debate, the opinion of physicians and in daily practice. In 2012, 40% of the physicians found it conceivable that they would grant a euthanasia request of a per- son with early-stage dementia, and 29–33% in persons with advanced dementia [10]. Moreover, in 2010, euthanasia for PWD took place in 25 cases (of 3136 cases in total), in 2014 in 81 cases (of 5306 in total), and in 2018 in 146 cases (of 6126 in total), mostly in competent PWD [11, 12]. The numbers of AEDs and euthanasia re- quests from PWD are larger, as not every request or AED ends up in euthanasia [12–14].

Assessing the due care criteria and the timing when it concerns a PWD is difficult [4, 10]. Therefore, until 2015, the Royal Dutch Medical Association (KNMG) directed that it was necessary that the patient verbally or non-verbally confirmed his or her actual death wish when receiving euthanasia. Though, in 2015 the KNMG published its latest guideline in which this was no longer required [15]. Although the number of countries where euthanasia and physician-assisted suicide is legalised is increasing [16], legally replacing verbal communication by an AED if a patient can no longer express his own wishes is only possible in the Netherlands.

In the past few years, three cases were reported in which patients with advanced dementia received euthanasia on the basis of an AED [11]. This led to several campaigns by physicians who opposed AED authorisation of euthanasia in case of advanced dementia due to their ethical concerns [17, 18]. Recently, a first judicial criminal investigation was opened on a physician's actions regarding a euthanasia case in a person with advanced dementia [18].

We hypothesised that dealing with euthanasia requests from PWD, whether or not they are still competent, impacts physicians. As it is mainly general practitioners (GPs) and elderly care physicians who receive euthanasia requests from PWD [11], we aimed to get more insights in the impact of discussing euthanasia requests by PWD on these physicians by answering the following research question: what are the experiences and needs of Dutch general practitioners and elderly care physicians when handling a euthanasia request from a person with dementia?

Methods

Design

We performed a qualitative interview study with a direct content analysis approach. The Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist was followed to present the findings [19]. Interviews were performed between January and April 2018, at a place chosen by the interviewee. The study protocol was approved by the Radboudumc medical ethical committee (NL2017–3862).

Participants and recruitment

Between December 2017 and February 2018 participants were recruited. In order to find physicians with different attitudes towards euthanasia for PWD, we purposively recruited physicians with a variety of experience in granting euthanasia for this patient group, male and fe- male doctors, GPs and elderly care physicians. We used two different sources for recruitment. One was a list of doctors who signed a critical statement published in Dutch national newspapers about euthanasia procedures for persons with advanced dementia, and who had provided their email addresses [17, 20]. This critical statement opposed euthanasia in non-competent persons with advanced dementia. Taking account of the above- mentioned criteria, physicians from this list were invited by e-mail to take part.
The other source was the End of Life clinic. This clinic

deals with euthanasia requests, and when due care criteria are met, offers euthanasia or assisted suicide to people whose own physicians are not able to, or do not want to, perform it [21]. The physicians of the End of Life clinic are less reluctant to perform euthanasia in case of PWD [22]. Via the director, two physicians employed at the End of Life clinic agreed to participate. We also used snowballing. After we reached saturation, we stopped inviting physicians to take part.All participants signed an informed consent before the interview took place.

Data collection

Based on scientific and grey literature, the public debate and two pilot interviews which were not included in the analysis, a topic guide with four open questions was developed. (Table 1) All authors were trained in qualitative interviewing and analysis. There were two core inter- viewers (LC and LW); one of them was always leading

Table 1 The Topic Guide Key Items

Topics	
1.	General opinion of and experience with euthanasia requests and procedures
2.	Determinants for deciding whether euthanasia should be performed
3.	Experience with euthanasia requests and procedures in dementia cases in particular
4.	Effects on work
5.	Need for support mechanisms
6.	Suggestions

the interview. During each interview, an additional researcher was present (RB, TR, LC, LW), who took notes and could ask additional questions. Anonymity of data processing was guaranteed and each participant was assured that the published results would preclude any identification of physician or patients.

Data analysis

Interviews were audio-recorded, and within a few days transcribed verbatim. After two interviews, we applied conventional thematic content analysis of the transcripts to develop a codebook [23]. Two researchers independently coded each interview line-by-line, after which they discussed differences until consensus was reached. If no consensus was reached, the codes were discussed with the project leaders (YE and JS). Finally, during a meeting with all researchers, codes were merged into categories and themes, and an affinity diagram was made [24, 25]. During the coding and merging processes, quotes that best reflected the codes within a category were selected. Each quote received a letter (A to K), representing the physician who mentioned it.

Results

After ten interviews no new codes were revealed. To confirm data saturation, one additional interview was conducted; in total eleven physicians took part. Ten of them had signed the critical statement about euthanasia in non-competent PWD [17]. Two physicians were employed at the End of Life clinic [21]. Characteristics and background of the eleven interviewees are provided in Table 2. Each interview took between 40 and 90 min.

In all cases consensus about the coding was reached. The final code book consisted of 45 codes, which were merged into five themes: evaluation of the euthanasia re- quest, difficulties experienced by doctors, alternatives for euthanasia, expertise, support & coping, and doctors' emotions. (Table 3)

Evaluation of the euthanasia request

Nine of the eleven interviewees stated they would be willing to accept a euthanasia request of a PWD when he or she would still be competent and they would be convinced that the patient has, or will have unbearable, refractory existential suffering in the near future. One of the participants pointed out 'people suffer most from the suffering that is yet to come (A)'.

Most participants mentioned that they would reject a request or AED from a patient with an advanced stage of dementia, as they consider these patients lack mental capacity. They felt strong moral objections to perform- ing euthanasia if they could no longer communicate effectively with their patient. 'Patients expect they can give you their filled-out form and that's it. They think that it [an AED] is enough to receive euthanasia at the moment they want it'(D). Another participant stated '*I have recently rejected euthanasia requests from four people. Each of these persons no longer understood what we were talking about*' *(C)*

Difficulties experienced by doctors

Timing

Most participants said that physicians often postpone disclosure of the dementia diagnosis because of the difficulties surrounding the diagnosis process itself, but also because of the related difficulties which arise once the diagnosis is given. "There is a conspiracy against this diagnosis, also amongst physicians. It's Alzheimer, isn't it? Is it D …? And to avoid the term they will say you've got a mild cognitive impairment …." (C) Postponing this disclosure conflicts with needing considerable time to consider euthanasia in a PWD, as stated by several participants. Moreover, doctors mentioned that they often have different agendas and timing regarding the actual moment of euthanasia compared to the expectations of the patients and their family. "I think as a doctor you need to prepare this really well, not just at that particular moment, but you need to start years before. You need to discuss things and document them repeatedly."(D).

Particularly in dementia cases, it is difficult for the patient and for the physician to predict unbearable suffer- ing in the future. One of the elderly care physicians said "I find this a very difficult and complex matter, … .if they ask for death, well.., in the early stages of dementia people will say; What a waste; you've still got some good years ahead of you". But if they're late, they will say: "Well, it's too late now, he's gone completely nuts." And to plan this. "That's just as difficult as everyone thinks it is, you see."(C)

Workload

All participants agreed that spending sufficient time on the request, on consultations for comprehensive consideration, and on the actual euthanasia procedure improves the quality of care. Consequently, as stated by some participants, being confronted with euthanasia re- quests and procedures has a negative impact on the overall quality of care and time left for other patients. The majority of physicians underlined the time investment needed around euthanasia requests as challenging: "genuine, unprejudiced attention … that takes time …. Yeah, because it interferes with daily affairs, you need to plan extra time for it, I often do this on my day off, … when I cannot be disturbed by other patients."(G)

Table 2 Characteristics and Participants Background (n = 11)

PARTICIPANTS		**No. (%)**
Gender		
Male		7 (64)
Female		4 (36)
Age		
40–50		3 (27)
50–60		3 (27)
60–70		2 (12)
70–80		3 (27)
Current workplace[a]		
General practice		2 (18)
End of life clinic		2 (18)
Nursing home		2 (18)
Hospital		1 (11)
Retired		2 (18)
Hospice		1 (11)
Palliative consulting team		1 (11)
Elderly care trainer		1 (11)
Participants’ basic training		
Elderly care physician		6 (55)
General practitioner		5 (45)
Participants’ experience		
Total of euthanasia procedures		2 (18)
0		2 (18)
1		2 (18)
2		2 (18)
3		1 (11)
> 100		2 (18)
Unknown		4 (36)
Euthanasia in dementia cases		
Requests	Procedures	1 (11)
0	0	1 (11)
1	0	2 (18)
2	1	1 (11)
2	0	1 (11)
3	0	1 (11)
10	6	> 40 (11) 1(11)
Unknown > 40		1 (11)

SCEN, ‘support and consultation during euthanasia procedure’

[a] *Multiple categories per participant possible*

Table 3 Overview of themes, categories and codes

THEMES	CATEGORIES	CODES
Evaluation of the euthanasia request	Reasons for rejection	· too late in the dementia trajectory · no repeated clear request · mental incompetence
	Reasons for acceptance	· unbearable suffering in future · has to feel right · repeated clear convincing request
Difficulties experienced by doctors	Timing	· different timing and agenda's of doctors and patients · diagnosis takes too long
	Workload	· work pressure · long preparation · labor-intensive
	Pressure by relatives	· pressure by family · request from family · part of the suffering lies with the family
	Influence from society	· society not dementia-friendly · euthanasia is considered a good death · negative perspective on dementia · slippery slope regarding granting euthanasia · changed perspective on death and dying · autonomy is leading
	Patient-doctor communication	· difficult communication due to dementia · conversation with or without family
	Law, due care criteria and the guidelines	· unbearable suffering is unclear · judging mental competence difficult · vague guidelines · AED not useful in dementia cases · AED are complicated
Expertise	Individual (GPs + elderly care physicians)	· improves quality on care · experiences reduces fear · infrequency
	Organizational (SCEN and end-of-life clinic)	· pros: more time for patients, safety net, legal support · cons: stigmatization, contributes to slippery slope, no negative view on euthanasia
Support and coping	Improvement of existing conditions	· colleagues and other professionals · buddy system · emotional support by own family · too costly to implement
	Alternatives to euthanasia	· assisted suicide · palliative care (palliative sedation)
Doctor's emotions	Negative	· nervous · frustrated · angriness · restless·
	Positive	· relief and satisfaction · feeling of control · heroism

Pressure by relatives

According to most participants, euthanasia requests often come from the family and not from the patient. Many participants had experienced situations in which family members said their parent's life was not dignified anymore: "Children in particular feel they are their mother's spokesperson and will continue knocking on the GP's door … There you have to ...there a line needs to be drawn. I get very few requests from the patients suffering from dementia themselves. It is more often a family member who says "father wouldn't have wished this". So a real question from the patient him- or herself, hardly ever. ...It frequently happens that family members put pressure: "Is this necessary?" and "Please administer extra syringes to make it happen more quickly" I think GPs need to be protected against this kind of pressure when the patient is suffering from dementia and does not ask for it himself."(K)

Influence from society

According to some participants, society considers dementia as a disease with hardly any quality of life, with euthanasia often being perceived as a more dignified alternative. One participant stated: *"The focus in the Netherlands is very much on euthanasia, whereas this is something to be discussed: How do we as a society deal with dementia, because most people suffering from dementia live at home and continue to do so for quite a while. Are we as a society friendly towards them and how well is their care and support organised? Not much has been arranged, so in a way they and their family caregivers have to face things alone."(A)* Some participants argued that euthanasia is a dignified and accepted death and that the difficulty lies within our society's emphasis on autonomy: *"Because our primary value has be- come taking autonomous decisions. And what happens with loss of cognition is that the autonomy is disintegrating." (D).*

Others argued that viewing euthanasia as a synonym for dignified dying, raises questions about the dignity of our society as a whole. *"In my opinion we should not just be a dementia-friendly society, but a society which treats the elderly with more respect. A society which does not estimate people's value by their economic contributions and by whether people still go on holidays or those kind of things"(E)*

Patient-doctor communication

Nearly all participants expressed difficulties in communication with PWD. They stated that it is often not clear whether a previously expressed wish to die is still really this patient's actual desire, especially if a patient is not able to repeat his request anymore. Even if the patient has an AED it is difficult to check if this request is still valid. "'If I become demented and do not recognize my family anymore I want euthanasia'. And if such a person at a later moment in time happily engages in activities and his daughter comes to visit him and he doesn't recognize his daughter anymore I could of course say; *'Good afternoon, I am the doctor and I am going to give you an injection'. This was* *written down at one point by this person, but is it what he wants now?"(B)*

Law, due care criteria and the guidelines

Several participants considered the due care criteria as rather vague and open to differing interpretations. Particularly 'unbearable suffering' was seen as subjective and unclear. *"That's the problem:.... it's very difficult to establish to what extent the patient is suffering." (E)* Participants also explained that recent guidelines are rather vague about the role of AEDs. One participant said: *"Patients expect they can give you their filled out form and that's it, they think that is enough to receive euthanasia at the moment they want it." (G).*

This opinion was not shared by all participants. For some, the law and guidelines were quite clear. A euthanasia request, according to one participant, can sometimes be accepted despite the patient's mental incompetence or the patient's lack of insights in the dis- ease: *"You know, so, (the criterion of) being of sound mind and judgement should always be related to a particular situation. And if it is about euthanasia, I think that people with advanced dementia are still capable of expressing 'I don't want this, I'm suffering, I'm unhappy, I want out of this.' Here I don't need a statement, I can tell from their misery. For example if someone is continuously banging on the door all day."(H).*

Physician Assisted Suicide in the form of a lethal drink was mentioned several times as a better option than euthanasia through intravenous injection. It was seen as a more autonomous decision and expression of free will. *"To me this is very important, that people do it them- selves, yes. Is this what this person wants? Then drink it yourself!"(C)*

Expertise

Individual level

Most interviewees were not often confronted with euthanasia requests and procedures, despite the increasing frequency of euthanasia cases. Some participants stated that the more experience a doctor gains, the lower the emotional impact. *"Look, a GP will give euthanasia about once every two years- you see, that's the frequency- well they will never get used to it. Every time, they have to climb the Himalaya again."(C)*

Organisational level

According to some participants, the End-of-Life clinic also provides additional expertise and has more time to spend on euthanasia requests. But some participants had controversial views regarding the End-of-Life clinic, as they felt that performing euthanasia should not become the main practice of any physician, which often is the case for physicians working for this clinic. *"In 2017 the End-of-Life Clinic had 2700 requests, of which 850 were granted. And ehm, 8% of all the cases of euthanasia are accomplished by this club. This weird club. And ehm, we might see a development where euthanasia ends up with a small group of doctors who say 'we'll take care of it'. I don't approve of* *it, but it might well happen."(C)*

Support and coping

Improving existing services

All participants acknowledged the importance of support for physicians and agreed the existing services could be improved, as well as the professionals' awareness of these services. They all acknowledged that support and consultation provided by colleagues or by other medical professionals in the direct work environment, as well as peer review sessions, are helpful. Informal support from their own family was also mentioned several times. *"That is, for me at least, very important, that I can share this at home."(G)* All elderly care physicians mentioned other forms of support they already used, such as a moral debate, consultation with a spiritual caregiver or a psychologist. One GP also mentioned the need for such support: *"Involve spiritual caregivers in the process. They are experienced in ethics and will ask questions which we as practitioners and diagnosticians often do not ask ourselves."(F)*

Alternatives to euthanasia

Palliative care or allowing death from natural causes was mentioned by many participants as possible alternatives to euthanasia in particular cases. One participant stated that palliative sedation as a possible alternative to euthanasia should be further explored. *"In one case in our nursing home we chose palliative sedation because here there is a legal framework. And we may have to liberalize the guideline for palliative sedation [which states that it is only allowed for patients with a maximum remaining life expectancy of two weeks]. For dying within two weeks of dementia … that doesn't seem realistic. And I've noticed that with palliative sedation there are fewer concerns so to speak."(D).*

Some interviewees saw assisted suicide by a lay person as a more autonomous decision which should be legalized. [in the Netherlands, there is an organisation with trained consultants who provide information about self-euthanasia (the carefully considered realisation of the end of human life under own control); *'the Einder' [26]. As one participant stated: "An organisation which assists with suicide. … When it became too much I referred to this club. There were some people who excelled in talking to people who were able to express their death wish. Sometimes this led to assisted suicide; then they were skirting the line of what is allowed."(I)*

Doctor's emotions

Many participants mentioned that dealing with euthanasia requests is emotionally very intense. They described the euthanasia experience itself, and for most of them this concerned patients without dementia, as an unnatural experience.

Negative emotions they experienced when dealing with euthanasia were feeling insecure, frustration, anger, moral distress, being judged by society and isolation. Some of them also felt stressed about the technical issues, such as administering the injection correctly, and about the possible legal consequences. *"Scared of the upheaval, the scandal, having killed some- one, also the stigma and then the irreversibility of death. And that you killed someone .... Well, that fear."(C).*

Positive emotions like heroism, being in control, satis- faction and relief were also mentioned. The following quote illustrates this with the legitimation of the physician's power when having performed euthanasia: *"It's wonderful … and also this feeling of power.. That's, it's a form of heroism. The feeling that I did something good, also for the profession."(C)*

Discussion

Using in-depth interviews, we explored the impact of euthanasia requests from PWD on Dutch GPs and elderly care physicians and their need for support. We inter- viewed eleven physicians with a wide variety of experience of euthanasia requests from PWD and differing attitudes towards euthanasia for this group of patients. Difficulties they experienced were related to timing, workload, pressure from relatives, society's negative view of dementia in combination with the 'right to die' view, the interpretation of the law and AEDs, ethical considerations, and communication with PWD and relatives. The physicians we interviewed showed a larger variety of opinions than was found twelve years ago [9]. The adaptation of the KNMG guideline on this topic in 2015 might have contributed to these obvious changes. We also found that there is a lack of professional support.

Finding sufficient time to fully discuss a euthanasia re- quest and, if applicable, perform euthanasia was considered problematic, in line with the findings of previous research [18, 27, 28]. Most participants in our study felt that the decision-making process with PWD takes more time. In our study the 'culture of non-disclosure' of the dementia diagnosis came forward. This is in line with an international systematic review study which showed that only 34% of GPs usually tell the PWD their diagnosis [29]. In addition, a Dutch study stated that physicians in general are not proactive when diagnosing dementia [30]. This has implications for PWD regarding participating in care planning and having sufficient time to dis- cuss euthanasia requests.

Also dealing with an AED and evaluating the due care criteria in cases of mental incapacity was considered challenging. This confirms previous research also show- ing that physicians experience more difficulties evaluating the due care criteria in cases of dementia [4, 10, 28]. For instance, communication problems can make it very difficult to decide whether or not suffering is unbearable [28, 31].

Several participants experienced difficulties in dealing with pressure from relatives. This confirms findings of recent studies on dealing with euthanasia requests in general [22, 32, 33]. Also, most participants mentioned the negative view of Dutch society of dementia and the process of dying of PWD, which was phrased by Allan Kellehear as 'shameful' dying: 'Dementia …. will deny most of us a good death or even a well-managed one.'

[34] Furthermore, some participants argued that the societal influences they experienced also result from our culture's emphasis on autonomy and the view that euthanasia is synonymous with dignified dying. Kouwenhoven et al. also found this increased emphasis on the patient's autonomous wish to be the primary basis for euthanasia [35]. Indeed, in a recent large national survey, keeping autonomy was in the top three of end-of-life aims of the Dutch population [36]. Society's increasing focus on autonomy 'as a right' [6] has policy implications. A recent study, exploring the pressures experienced by Dutch GPs when dealing with euthanasia requests, called for more awareness in order to prevent physicians having to cross their own personal boundaries when dealing with AES requests [33]. Our participants considered the KNMG guideline to be vague and to pro- vide too little guidance. The use of heuristics might be helpful in applying legal rules in daily practice when it concerns euthanasia [37].

The physicians in our study experienced both negative and positive emotions when confronted with a euthanasia request from a PWD; as has also been described regarding euthanasia requests in general [3, 38]. Participants mentioned feelings of insecurity, frustration, anger, moral distress, isolation and the feeling of being judged by society. Positive emotions mentioned by our participants were being in control, satisfaction, relief and even heroism. This feeling of heroism in the performance of euthanasia has not been described before, although a Dutch GP described 'a feeling of power that ran through his body at the moment he performed his first euthanasia in a critical opinion article on euthanasia'. [39] Interestingly, one participant stated that as a physician's experience with euthanasia increases, negative emotions tend to decrease and positive emotions to increase, which was considered undesirable. As, within the End-of- Life clinic, a limited number of physicians handle the euthanasia requests from PWD, meaning they have a much higher case load per physician, the emotional impact on this specific group of physicians needs further exploration.

Our participants mentioned using different forms of support when dealing with euthanasia requests from PWD. They mentioned existing services of support such as SCEN (support and consultation during euthanasia procedures), consultation with palliative care teams, de- liberation with other physicians and even their own family for emotional support. Some of these forms of support were also suggested in a study into the complexities in euthanasia perceived by Dutch physicians and relatives [40]. A striking finding of our study was that, although the participating elderly care physicians mentioned their use and appreciation of prospective ethical discussions or moral deliberation, this was hardly expressed by GPs. Such services are not easily available and accessible in primary care, hence they may be un- aware of these options. As recently the Dutch government started to fund spiritual care in primary care, this might raise the awareness of GPs and give an opportunity to develop such support services.

Strengths and limitations

In our study, both general practitioners and elderly care physicians, the groups of professionals who are most frequently confronted with euthanasia requests by PWD, were involved. However, this study also has limitations. Although we included physicians with a wide variety of opinions and experience on this topic and tried to pro- vide a broad perspective, the majority of participants signed the critical statement about euthanasia in persons with advanced dementia [17]. Although saturation was reached, by interviewing just a small number of physicians on such a sensitive issue, we might have missed essential information.

Conclusions

Euthanasia in dementia places an ethically and emotion- ally heavy burden on elderly care physicians and GPs in the Netherlands. The majority of the participants wish for more clarification of their professional guidelines. Existing useful support mechanisms, such as moral de- liberation and support from chaplains are available for elderly care physicians. The awareness of, and access to, such support for GPs needs further exploration. Apart from the legal perspective, the interpretation of unbearable suffering and competence for people unable to ex- press themselves needs more debate from psychological and ethical perspectives.

Quantitative insights into the problems and needs of physicians confronted with euthanasia requests from PWD are necessary. We suggest further research to identify ways of supporting physicians confronted with such requests.

References

1. Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding, Artikel 2, lid 2. [updated 2018 Aug 1; cited 2018 Aug 17]. Available from: http:// wetten.overheid.nl/BWBR0012410/2018-08-01.

2. Georges JJ, The AM, Onwuteaka-Philipsen BD, van der Wal G. Dealing with requests for euthanasia: a qualitative study investigating the experience of general practitioners. J Med Ethics. 2008;34(3):150–5.

3. van Marwijk H, Haverkate I, van Royen P, The AM. Impact of euthanasia on primary care physicians in the Netherlands. Palliat Med. 2007;21(7):609–14. 4.

4. Buiting HM, Gevers JK, Rietjens JA, Onwuteaka-Philipsen BD, van der Maas PJ, van der Heide A, et al. Dutch criteria of due care for physician-assisted dying in medical practice: a physician perspective. J Med Ethics. 2008;34(9): e12.

5. Onwuteaka-Philipsen B, Legemaate J, van der Heide A, van Delden H,
Evenblij K, El Hammoud I, et al. Third evaluation of the Act on Termination of Life on Request and Suicide Assistance; English summary on page 19 Den Haag: ZonMw; 2017 [cited 2018 October 14].
Third evaluation of the act on termination of life on request and suicide assistance; English summary on page 19;]. Available from: https://www.rijksoverheid.nl/ documenten/rapporten/2017/05/23/derde-evaluatie-wet-toetsing- levensbeeindiging-op-verzoek-en-hulp-bij-zelfdoding.

6. Kouwenhoven PSC, van Thiel G, van der Heide A, Rietjens JAC, van Delden JJM. Developments in euthanasia practice in the Netherlands: balancing professional responsibility and the patient's autonomy. Eur J Gen Pract. 2019;25(1):44–8.

7. Hertogh CM, de Boer ME, Droes RM, Eefsting JA. Would we rather lose our life than lose our self? Lessons from the Dutch debate on euthanasia for patients with dementia. Am J Bioeth. 2007;7(4):48–56.

8. de Boer ME, Hertogh CM, Droes RM, Jonker C, Eefsting JA. Advance directives in dementia: issues of validity and effectiveness. Int Psychogeriatr. 2010;22(2):201–8.

9. de Boer ME, Droes RM, Jonker C, Eefsting JA, Hertogh CM. Advance directives for euthanasia in dementia: how do they affect resident care in Dutch nursing homes? Experiences of physicians and relatives. J Am Geriatr Soc. 2011;59(6):989–96.

10. Bolt EE, Snijdewind MC, Willems DL, van der Heide A, Onwuteaka-Philipsen BD. Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? J Med Ethics. 2015;41(8):592–8.

11. Regionale Toetsingscomissies Euthanasie (RTE). RTE Jaarverslagen 2010– 2018 [Internet] [place unknown]: euthanasiecommissie; 2010–2018 [cited 2018 Aug 10]. Available from: https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen.

12. Evenblij K, Pasman HRW, van der Heide A, Hoekstra T, Onwuteaka-Philipsen BD. Factors associated with requesting and receiving euthanasia: a nationwide mortality follow-back study with a focus on patients with psychiatric disorders, dementia, or an accumulation of health problems related to old age. BMC Med. 2019;17(1):39.

13. Evans N, Pasman HR, Deeg DJ, Onwuteaka-Philipsen BD. Older Dutch People's self-reported advance euthanasia directive completion before and after the enactment of the euthanasia law: a time trend study (1998-2011). J Am Geriatr Soc. 2015;63(10):2217–9.

14. Harnas S TW. Rapport meldactie 'Wilsverklaring' Patiëntenfederatie Utrecht, Nederland: Patiëntenfederatie Nederland; 2018 Jun [cited 2019 Apr 25]. Available from: https://www.patientenfederatie.nl/images/stories/dossier/ Levenseinde/RapportWilsverklaringenDef.pdf.

15. Handreiking schriftelijke euthanasieverzoek- Artsenversie. Den Haag: ministerie van Volksgezondheid, Welzijn en Sport; 2015.

16. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. JAMA : the journal of the American Medical Association. 2016;316(1):79–90.

17. Chabot B. Dood nooit weerloze die het niet beseft [Internet] [place unknown]: de Volkskrant; 2017 Jan [cited 2018 Aug 29]. Available from: https://www.volkskrant.nl/columns-opinie/dood-nooit-weerloze-die-het-niet-beseft~b96e0536/.

18. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controversial case and its ethical implications. J Med Ethics. 2018.

19. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International journal for quality in health care : journal of the International Society for Quality in Health Care / ISQua. 2007;19(6):349–57.

20. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controversial case and its ethical implications. J Med Ethics. 2019;45(2):84–9.

21. Stichting Levenseindekliniek (End of Life Clinic). Home [Internet] [place unknown]: Stichting Levenseindekliniek; [date unknown] [cited 2018 Oct 20]. Available from: http://www.levenseindekliniek.nl/en/.

22. Snijdewind MC, Willems DL, Deliens L, Onwuteaka-Philipsen BD, Chambaere K. A study of the first year of the end-of-life Clinic for Physician-Assisted Dying in the Netherlands. JAMA Intern Med. 2015;175(10):1633–40.

23. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. Qual Health Res. 2005;15(9):1277–88.

24. Attride-Stirling J. Thematic networks: an analytic tool for qualitative research. 2001;1(3):385–405.

25. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3(2):77–101.

26. https://www.deeinder.nl/contact/contact/english/ [cited 2019 30-07-2019]. Available from: https://www.deeinder.nl/contact/contact/english/.
27. de Beaufort ID, van de Vathorst S. Dementia and assisted suicide and euthanasia. J Neurol. 2016;263(7):1463–7.

28. Kouwenhoven PS, Raijmakers NJ, van Delden JJ, Rietjens JA, van Tol DG, van de Vathorst S, et al. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. BMC Med Ethics. 2015;16:7.

29. Low LF, McGrath M, Swaffer K, Brodaty H. Communicating a diagnosis of dementia: A systematic mixed studies review of attitudes and practices of health practitioners. Dementia (London). 2018; 1471301218761911.

30. Prins A, Hemke F, Pols J. Moll van Charante EP. Diagnosing dementia in Dutch general practice: a qualitative study of GPs' practices and views. The British journal of general practice : the journal of the Royal College of General Practitioners. 2016;66(647):e416–e22.

31. Tulsky JA. Beyond advance directives: importance of communication skills at the end of life. JAMA. 2005;294(3):359–65.

32. de Boer ME, Depla M, den Breejen M, Slottje P, Onwuteaka-Philipsen BD, Hertogh C. Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners. Journal of medical ethics. 2019.

33. Snijdewind MC, van Tol DG, Onwuteaka-Philipsen BD, Willems DL. Developments in the practice of physician-assisted dying: perceptions of physicians who had experience with complex cases. J Med Ethics. 2018;44 (5):292–6.

34. Kellehear A. A social history of dying. Cambridge: Cambridge University Press; 2007.

35. de Boer A, de Klerk M. Informele zorg in Nederland. Een literatuurstudie naar mantelzorg en vrijwilligerswerk in de zorg. Sociaal en Cultureel Planbureau: Den Haag; 2013.

36. van der Velden A, Engels Y, Nanninga M, Francke A, Fritsma J, Boddaert M, et al. What Matters Most for the Dutch Public in Palliative Care: A Survey; 2018. p. e107.

37. Davies N, Manthorpe J, Sampson EL, Lamahewa K, Wilcock J, Mathew R, et al. Guiding practitioners through end of life care for people with dementia: The use of heuristics. PLoS One. 2018;13(11): e0206422.

38. Haverkate I, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. The emotional impact on physicians of hastening the death of a patient. Med J Aust. 2001;175(10):519–22.

39. Amons R. 'Wat kijk je moeilijk, dood is dood'. Euthanasie is voor de uitvoerende arts over de rand van het draaglijke. [Internet] [place unknown]: Medisch Contact; 2018 [cited 2019 Feb 22]. Available from: https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/wat-kijk-je- moeilijk-dood-is-dood.htm.

40. Snijdewind MC, van Tol DG, Onwuteaka-Philipsen BD, Willems DL. Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives. J Pain Symptom Manag. 2014;48(6): 1125–34.

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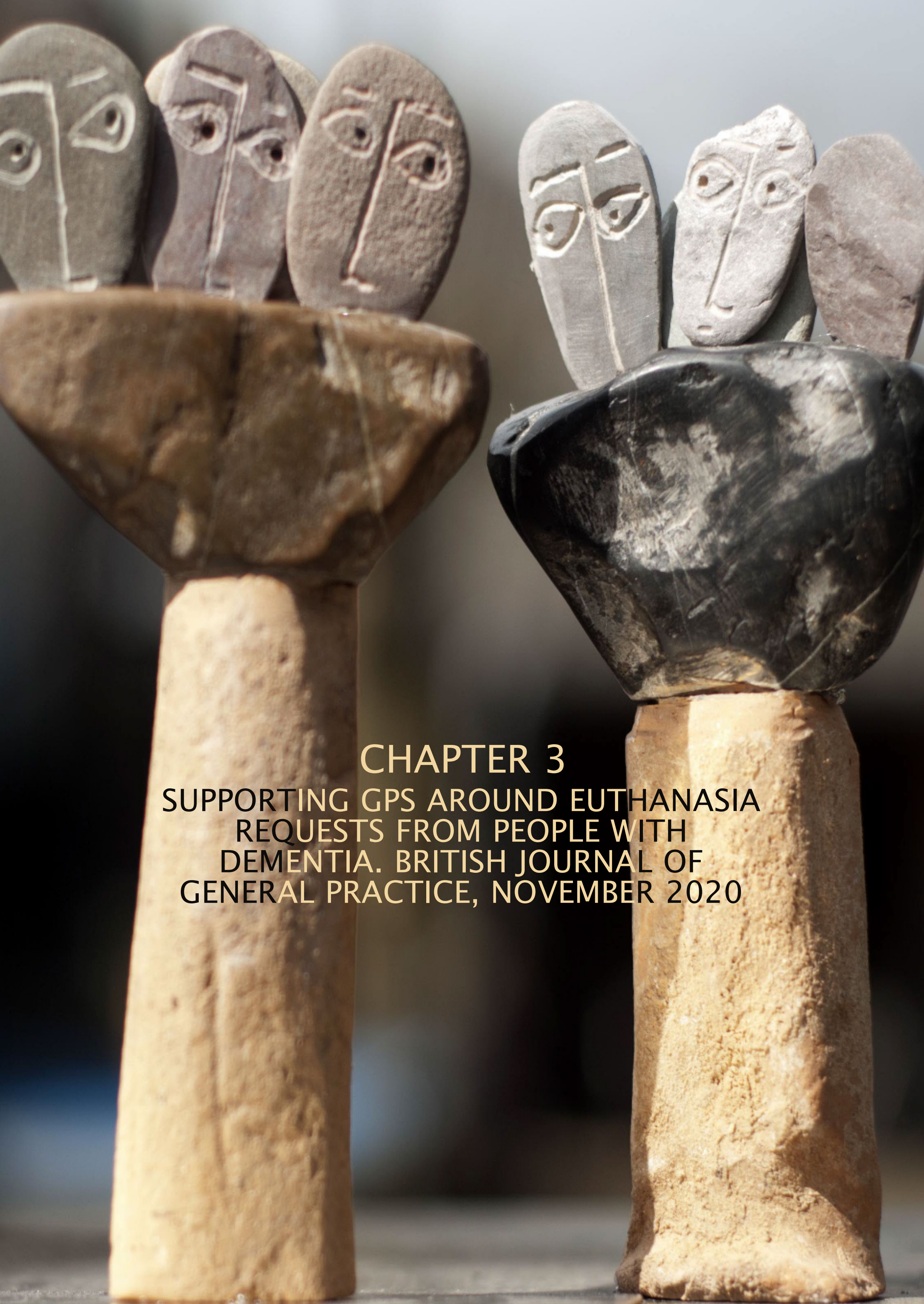

CHAPTER 3

SUPPORTING GPS AROUND EUTHANASIA REQUESTS FROM PEOPLE WITH DEMENTIA. BRITISH JOURNAL OF GENERAL PRACTICE, NOVEMBER 2020

SUPPORTING GPS AROUND EUTHANASIA REQUESTS FROM PEOPLE WITH DEMENTIA: A QUALITATIVE ANALYSIS OF DUTCH NOMINAL GROUP MEETINGS. BRITISH JOURNAL OF GENERAL PRACTICE, NOVEMBER 2020

Supporting GPs around euthanasia requests from people with dementia:

a qualitative analysis of Dutch nominal group meetings

Jaap Schuurmans, Stephanie Vos, Pim Vissers, Bram Tilburgs and Yvonne Engels

Abstract

Background: Euthanasia has been regulated by law under strict conditions in the Netherlands since 2002. Since then the number of euthanasia cases has constantly increased, and increased exponentially for patients with dementia (PWD). The number of euthanasia requests by such patients is even higher. Recently, an interview study showed that physicians who are confronted with a PWD's euthanasia request experience problems with communication, pressure from relatives, patients, and society, workload, interpretation of the law, and ethical considerations. Moreover, if honoured, the physician and patient may interpret the right moment for euthanasia differently.

Aim: To identify ways of supporting GPs confronted with a PWD's euthanasia request.

Design and setting: Two expert nominal group meetings were organised with Dutch care physicians for older people, GPs, legal experts, a healthcare chaplain, a palliative care consultant, and a psychologist.

Method: A total of 15 experts participated in the meetings. Both meetings were audio-recorded, transcribed verbatim, and analysed using thematic analysis.

Results: Four themes emerged from the meetings: support provided by healthcare professionals, influencing public opinion, educational activities, and managing time and work pressure. The need for support was considered highest for GPs for all of these themes.

Conclusion: Consensus was reached with the help of experts on support needs for GPs confronted with euthanasia requests from PWD. A concise and clear explanation of the law is strongly desired. Changing public opinion seems the most challenging and a long-term aim. Communication training for finding the right balance between the physician's professional responsibility and the patient's autonomy should be made available, as a short-term aim.

Keywords: dementia; euthanasia requests; general practitioners; health services, primary health care; support.

INTRODUCTION

Euthanasia has been regulated in the Netherlands since 2002, as stated in article 2 of the Termination of Life on Request and Assisted Suicide Review Act [1]. There are strict conditions: only a physician can perform euthanasia and the statutory due- care criteria have to be met. Moreover, after euthanasia has been carried out, physicians are obliged to send a report describing the entire procedure to a review committee [1]. Until 2015, the physicians' professional standard, endorsed by the Royal Dutch Medical Association (KNMG), was that a person with a euthanasia request should verbally non-verbally confirm their actual wishes, and also when an advance euthanasia directive (AED) was available. This standard was adapted following criticisms that it was more conservative than the law itself. Recently, an extensive interpretation of the law was published that confirmed the importance of an AED in view of 'precedent autonomy' [2]. This new guideline resulted in not only an ongoing professional debate, but also a public one, on euthanasia in patients with dementia (PWD) [3-6].

Recently, a Dutch euthanasia case fuelled this public debate. It was one of the few euthanasia cases in an advanced stage of dementia where no verbal or non-verbal confirmation was provided by the patient [7-8]. This case led, for the first time since the implementation of the euthanasia law, to a criminal court case. This controversial case demonstrates the challenges and ethical concerns of euthanasia and AEDs in PWD, as AEDs are seen as an ultimate possibility to take autonomous decisions before the autonomy, because of the loss of cognition, disintegrates. Moreover, in Dutch society, a growing number of people think they have a right to die [9]; a public initiative aiming to legalise assisted suicide of older people who consider their life completed already has over 100 000 declarations of support [10]. Also one of the political parties, D66, a Dutch social liberal party, is pleading for extension of the euthanasia law [11]. These developments have impact on physicians. A recent study on developments in euthanasia practice in the Netherlands recommended to (re)discover the right balance between the physician's professional responsibility and the patient's autonomy [9]. It underlines the importance of looking at means to support the difficult decision-making process GPs have to go through.

In the past decade, an exponentially growing number of actual cases of euthanasia in PWD has occurred: from 25 cases in 2010 (of the total 3136 performed euthanasia cases in 2010) towards 146 in 2018 (of 6126 cases in total) [12]. As not every request results in euthanasia [13], the number of requests for euthanasia from PWD, which do not always result in euthanasia, will have increased too and will further increase. However, exact figures are unknown.

Although euthanasia in case of dementia is possible, GPs do not take these complicated requests lightly [5,14,15].

In a recent interview study with GPs who had experienced pressure around dealing with euthanasia requests in general, the risk of crossing their own personal boundaries if not being able to stand up for their own values was reported, for which education and support were recommended [16]. A recent qualitative study on Dutch physicians' experiences in dealing with euthanasia requests of PWD confirmed this experienced pressure [17]. GPs experience problems with communication, pressure from relatives, patients, society, workload, interpretation of the law, and ethical considerations. Moreover, if honoured, the GP and patient may interpret the right moment for euthanasia differently. Furthermore, dealing with the decreased cognition, also in relation to AED, was considered problematic in this patient group.

There are different sources of support for GPs dealing with euthanasia requests, such as Support and Consultation on Euthanasia in the Netherlands (SCEN), GPs or other colleagues, practice guidelines, and clinical ethical support (CES) services [17-21]. Moreover, with regard to euthanasia requests from PWD, improving existing conditions, for example, interdisciplinary team meetings and support groups, and increasing awareness of alternatives for euthanasia, for example, palliative care or assisted suicide, were mentioned [17]. GPs are particularly in need of support, as they are responsible for approximately 85% of all euthanasia cases [22].
The overall aim of the current study therefore was to identify and prioritise forms of support that should be used or implemented to help GPs confronted with euthanasia requests from PWD.

Table 1 Participant characteristics

Characteristic	Group 1 n	Group 2 n
Sex		
Male : female	5:3	4:3
Occupation		
GP	2	1
Care physician for older people	1	1
Professor in geriatric medicine	1	–
Professor in care medicine for older people, especially long-term care	1	–
Physician and palliative care consultant for older people	1	–
Professor-emeritus in jurisprudence	1	–
Jurist	1	–
Healthcare chaplain in palliative care and consultant spiritual care Healthcare	–	1
psychologist	–	1
Assistant professor in care ethics	–	1
Professor in religion and care	–	1
Professor in medical care and decision making at the end of life	–	1

How this fits in

The number of countries that have a euthanasia law is increasing, as well as the number of euthanasia cases and requests. Previous studies show that physicians confronted with euthanasia requests experience pressure from patients, relatives, and society. Where people with dementia are concerned, they also experience problems with communication, workload, interpretation of the law, and ethical considerations. Influencing public opinion and better training of healthcare professionals were also advised by the experts. Moreover, if honoured, the physician and patient may interpret the right moment for euthanasia differently.

METHOD

Study design

This study is reported in accordance with the COREQ guidelines [23] (see Supplementary Appendix S1). A qualitative consensus study was performed using the nominal group technique (NGT). This technique was chosen because of its structured and evaluative method for obtaining group consensus and is often used to generate, clarify, and prioritise ideas and/or solutions around a specific topic within a small-group discussion [24-26].

Participants

Because the debate about euthanasia in cases of dementia has ethical, medical, political, and juridical aspects, the authors invited a diverse group of experts covering these fields to participate. Experts were recruited through the first and last authors' professional networks. They were approached by email, telephone, or face to face. Experts who expressed interest in the meeting, and were available to participate, received additional information that included the study goals, the research question, and the procedure of the NGT meeting. A total of 15 experts from a variety of professions took part in this study: eight participated in the first meeting and seven in the second. Participant ages ranged from 31–74 years; see Table 1 for participant characteristics. No financial or other compensation was provided for participation.

NGT meetings

Two NGT meetings were conducted in September 2018. Both meetings, each lasting about 2.5 hours, consisted of five structured phases and were led by two experienced moderators: a female professor in spiritual health care, experienced in facilitating NGTs and focus groups (last author), and a male psychologist, nurse, and PhD candidate in advance care planning for PWD with previous experience in conducting focus groups (fourth author) [26-32].

All expert participants were asked to sign informed consent. It was explained that the meetings would be audio-recorded and processed anonymously [28].

In addition the second and third authors kept detailed minutes of the meetings. All written records were sent to the participants in order to obtain consent.

The five steps (phases) that were followed during both NGT meetings are described in Box 1.

Box 1. Nominal group process

Phase	**Description**
1. Introduction and explanation	Experts were introduced to the main objective of the study using a PowerPoint presentation, namely identifying and prioritising forms of support, presented with the problems as reported by GPs and care physicians for older people in a qualitative interview study on the same topic.[17] These problems concerned pressure from and expectations of relatives, the consequences of society's negative view of dementia on their practice in combination with the growing 'right to die' conviction of many people, the interpretation of the law and of AEDs, ethical considerations, communication with PWDs and their relatives, timing, and workload. The experts were asked to approach the period from the moment a patient expresses a euthanasia wish or request until a decision has been made as one process, regardless of the outcome. Furthermore, the different phases of the NGT were explained.
2. Silent generation	The research question was presented: 'What forms of support should be used or implemented to help GPs confronted with euthanasia requests from PWDs?' Experts were asked to individually make a list of favourable forms of support, such as (improvement of) existing conditions, as well as new alternatives. Suggestions based on the present qualitative study[17] and other literature on this topic were in both meetings presented to the group on a large screen.
3. Round robin	Experts were asked to share their favourable forms of support one at a time, which were then written on a flipchart. When every idea was shared and no new ideas were mentioned, this phase ended. Explanation and discussion during this phase were kept to a minimum.
4. Discussion/clarification	Experts were invited to clarify and discuss all suggested forms of support. Items were removed, reworded, merged, or added to the list. At the end experts were asked if they agreed with the final list.
5. Voting	Experts were provided with a ranking sheet and asked to select and rank their top five favourable forms of support as presented in phase 4 from 5 to 1 points. The moderator specified and emphasised that higher numbers represented more importance.

Analysis

A combination of qualitative and quantitative methods was used [31-34].

Two strands of data were obtained from the NGT meetings:

- a qualitative list of discrete ideas, which were organised into in-situ categories (original categories generated during the meeting) and refined based on the transcript of phases 3 and 4 obtained from the audio-recording; and
- a quantitative list of individually scored favourite forms of support.

The steps of the analysis process are described in Box 2.

Box 2 Analytical process

Step	Description
1. Content analysis	Content analysis of the qualitative data in two phases with two approaches was used. First, conventional thematic content analysis of raw data generated during the first meeting was conducted. Suggested forms of support ranged from very detailed to quite general. For that reason, the second and third researchers independently grouped similar suggested forms of support into themes and categories, using ATLAS-ti (version 8), and then discussed differences until consensus was reached. Second, the same two researchers added the forms of support mentioned during the second nominal group meeting into this thematic list. This list was then presented to the entire research team and discussed until consensus was reached, resulting in a final thematic list of ideas. To obtain information about the decision-making process and insights into the argumentation regarding each statement, audio-recordings of the round robin phase and discussion/clarification phase were transcribed verbatim and analysed using direct content analysis, again independently, by the first and second authors using ATLAS.ti (version 8). This also enabled the addition of ideas not written down during the meeting.
2. Nominal group ranking	Quantitative analysis of the nominal group ranking. First, individual group scores, that is, the top five priorities, were calculated separately for both meetings. The researchers ranked a top four by calculating the summed score and relative importance of each in-situ category as obtained from the voting phase. When two categories obtained the same score, the categories were ranked not only via scores but also via frequency (the number of times a category was voted for). Next, the themes were ranked based on the scores of the five overarching themes. The total score per theme was calculated by summing the scores of the in-situ categories (calculated in the first step) falling under the new (overarching) theme.

RESULTS

Identified and prioritised forms of support: overall group analysis

During the first NGT meeting 10 in-situ categories of potential forms of support emerged, and five in-situ categories during the second meeting. Almost all categories mentioned in both meetings were similar or overlapping. Only one category (time and work pressure) was not mentioned during the second meeting.

Themes

Thematic analysis revealed four themes with a total of 10 categories of support, as displayed in Table 2. The four themes, ranked in descending order, were: support provided by healthcare professionals, influencing public opinion, educational activities, and managing time and work pressure (Table 2).

Support provided by healthcare professionals. Direct support from other healthcare professionals of various expertise was considered the most important form of support in both groups and consisted of three categories (Box 3):

a) Support during the decision-making process by individual healthcare professionals: this was often mentioned. In both groups a buddy system was suggested. This is a service where a physician can ask a healthcare professional to assist and support them during the entire communication and decision-making process and, if applicable, during the euthanasia process. An expert added:
'That the GP can always count on someone else for support ... That it is actually always a two-person job.'

Several types of professionals were mentioned to be suited for this buddy function: an end-of-life clinic physician or nurse, a care physician for older people, a SCEN physician, and a spiritual care provider (healthcare chaplain). Experts also mentioned support by healthcare professionals in organisations and teams, such as the Netherlands Comprehensive Cancer Organisation (IKNL), ABC-teams (geriatric consultation teams), palliative consultation teams and groups palliative care at home (PaTz). The PaTz groups are teams consisting of GPs and community nurses, who, supervised by a physician with expert training in palliative care, discuss their palliative patients five to six times a year.[35] Furthermore, multidisciplinary team meetings were mentioned, such as interdisciplinary consultation and moral case deliberation. Ethical discussions or moral deliberation services are not easily available and accessible in primary care in the Netherlands, hence they may be unaware of these options.

b) Emotional-moral guidance and care (for the confronted physician) by a healthcare professional: for example, a spiritual care provider or existential counsellor, was considered to be very important. One participating physician commented:
'The emotional guidance for the doctor, after euthanasia. That is quite [silence] ... I have experienced it myself; no attention is paid to that.'
Another expert added support via reflection meetings for GPs in which *'not only complex dilemmas are discussed in which you got stuck, but also cases which did not result in euthanasia'.*

c) Awareness and easy access: experts stated that awareness of the availability of these healthcare professionals and their specific roles is of great importance. One expert emphasised the future professional role of the

spiritual care provider (existential counsellor) in primary care as follows:
'At short notice, the financing of primary care spiritual care providers will be arranged ...'

Furthermore, easy access to such healthcare professionals and an up-to-date list with contact details of available healthcare professionals per region was suggested.

Influencing public opinion. Experts mentioned the need of indirect support through influencing public opinion and raising awareness about the different aspects related to decision making around euthanasia and its impact, with the aim of reducing the burden experienced by the physician. This theme consisted of the following three categories (Box 3):

a) Provision of accurate and valid information via campaigns, brochures, flyers, movies/commercials, and books: Using a brochure was deemed particularly important:
'I seriously plead for a clear, in layman's terms, brochure, with pictures.'

According to the experts, various topics should be addressed in this brochure. Many topics were mentioned and explained. For example, dementia does not necessarily mean suffering: *'dementia automatically stands for suffering. And that is — often — not necessarily the case'*, and euthanasia is not a right:
'Make clear that euthanasia is no right. That there is no right to euthanasia, but that it must remain an exception, and you cannot just decide about this.'

Also, the impact of euthanasia on a physician was stressed:
'It's not like: "ask and we deliver"; there should also be awareness of the professional consequences for the physician.'

Another expert added:
'I can imagine that it would be pleasant for the physician if there was more attention in the public debate for the "amazon. com mentality" (ordered today, delivered tomorrow): take it down a notch.'
Moreover, advance care planning, fear of the future, for example, loss of autonomy, *'Who will take care of me?'*, and attention to alternatives to euthanasia, such as palliative care and assisted suicide, were important topics.

b) Activities: some experts mentioned influencing the public opinion through activities, for example, influencing the negative image of nursing homes ('which is hardly ever correct') via a 'Nursing Home Open Day', a day where nursing homes open their doors for the local community. Two experts mentioned the concept of 'Café Doodgewoon' (café 'Death is normal'), an informal meeting place for expert volunteers, people, and their close family

members to discuss end-of-life issues. One of the experts added:
'This is a model that works excellently ... within this framework, you can raise the whole issue of euthanasia, suffering and death.'

c) Legislation clarification: this was widely discussed. In both NGT meetings experts stated that there is a need for a clear and understandable explanation of the law, including of AEDs, for the general public and for physicians. They again emphasised the need for a brochure on the legislation and AED in layman's terms:
'More clarity with regard to the AED, within what timeframe, how often, what should be in it...'
and
'The awareness that, with the writing of an AED alone, you're not there yet.'

Box 3 Forms of support mentioned by experts during both NGT meetings, themes, and categories

Support provided by healthcare professionals

- Support during decision-making process, for example, by individual healthcare professionals, organisations/ teams, moral case deliberation
- Emotional-moral guidance and care for physician, for example, by spiritual care provider, reflection meetings
- Awareness and easy access

Influencing the public opinion

- Provision of accurate, valid information, for example, campaigns, brochure
- Activities,for example,'NursingHomeOpenDay',café 'Death is normal'
- Legislation clarification Educational activities
- Training, for example, communication skills, signalling existential questions
- Tools, for example, vision paper observation al tools assessing (unbearable) suffering

managing time and work pressure

- Time and space availability, for example, regular time for weekly reflection
- Facilitators, for example, administrative assistant

NGT = nominal group technique.

Experts discussed methods to obtain guidance in clarifying the law. Collaboration and deliberation between the notary and the KNMG came forward: 'this is very necessary ... because notaries give the impression that an AED is just the same as a will, and therefore valid', as well as linking knowledge and sharing experience with other disciplines dealing with euthanasia requests and mental incapacitation.

Educational activities. Experts stated that it was important that GPs acquire skills that are necessary to properly deal with euthanasia requests from PWD and the decision making related to this. This theme consisted of two categories (Box 3):

a)Training: during(medical) education and as post-academic training was recommended. First, acquiring communication skills, for example,

specialised conversational techniques, discussing end-of-life issues, and conducting family meetings:
'I have learned that there is a need for support in conducting conversations with patients, also to be able to really give good information about the possibilities and impossibilities. Also, broader than just euthanasia alone. We often hear from confronted physicians, that they are in need of support ... How to cope with this?'

Next, signalling existential questions and learning to deal with uncertainties, which was emphasised by the following statement:
'I think that many questions about euthanasia come from not being able to deal with uncertainty, like prognosis and all kinds of aspects, which we are insufficiently trained.'

Experts argued for expanding knowledge related to this topic, such as attention to the impact on and nature of suffering that PWD can experience. One of the experts explained this:
'Nowadays in our society, people experience great difficulties with relating to and dealing with suffering. We have a strong tendency to solve, and otherwise we tend to look away. While recognition of this tragic, insoluble side of suffering is of great importance for both the patient and the physician.'

Further, the following topics were discussed: advance care planning and multiculturalism with regard to death, suffering and person-centred end-of-life care: *'these issues are so culturally defined'.*

b) Tools that facilitate and support the decision-making process: Experts mentioned the following options: First, observational tools for assessing (unbearable) suffering, such as a discomfort scale or existential distress. Next, a service for GPs where euthanasia decisions can be reviewed prospectively among a group of (legal) experts, as a solution for 'the tension between the jurist who says: *"I can only review it in retrospect"* and the physician who says: *"Yes, but if I could know in advance about what I can do and what I cannot ..."'* In both meetings a vision document by the KNMG was considered to be important:
'In 2018 the KNMG started a project in which a vision on euthanasia and the different stages of dementia will be developed. This joint project of the KNMG and its federation partners is among other things intended to provide doctors with guidance during the decision-making process in this complex matter.'

Managing time and work pressure. Particularly in the first meeting, experts mentioned forms of support that could reduce time and work pressure, related to euthanasia requests, especially in case of dementia. They described that these difficult requests require more time than is currently

available in regular care. A financial incentive was not seen as a solution; one expert explained this clearly:
'I do think this should not be done with a financial incentive. I would be terrified of that. You see, wherever there is a financial incentive, it will be used ... That seems incredibly harmful to me. So, you have to support this problem in a different way.'

This theme consists of the following two categories (Box 3):
a) Time and space availability: one solution was discussed in the form of scheduling regular time for weekly reflection. Another expert emphasised: *'Time and space for moral case deliberation under the supervision of an ethicist.'*

b) Facilitators: an administrative assistant during the decision-making process, *'someone who has experience with the procedure and who will make sure that the administration is handled correctly'*, and colleagues to take over routine tasks of the (confronted) physician were mentioned.

DISCUSSION

Summary

This explorative study has taken the first step to reduce the current knowledge gap regarding sources of support for GPs who are confronted with euthanasia requests in dementia cases. Four themes of forms of support were identified and prioritised: support provided by healthcare professionals — which was considered most important, influencing public opinion, educational activities, and managing time and work pressure. Four concrete examples were emphasised: the possibility of a buddy who is available for the physician throughout the entire decision-making process, moral case deliberation, a spiritual care provider for emotional moral guidance for the confronted physician, and a brochure in layman's terms about the different aspects related to euthanasia in PWD including legislation clarification.
In this study the nominal group technique was used to further explore forms of support for GPs confronted with euthanasia requests from PWD. Not all recommended sources of support appeared to be specifically targeted at dealing with euthanasia requests from this specific patient group. Particularly, a specific focus on dementia was evident in 'influencing the public opinion', 'dealing with AEDs and legislation', 'training GPs in dementia-related aspects', and 'managing time and work pressure'. Moreover, the experts in this study mentioned that it was essential to make the public aware that euthanasia is not a right, as well as the impact of euthanasia on a physician.

Strengths and limitations

The inclusion of a multidisciplinary group of experts, including healthcare professionals, care physicians for older people and GPs, legal experts, an ethicist, and researchers is one of the main strengths of this study. The fact that they all had a professional background related to this topic provided a broad perspective. Another strength of this study was the use of the NGT, which ensured time efficiency and encouraged equal participation and discussions among experts [28]. In addition, the method directly facilitated researchers in making a prioritised list of solutions to answer the research question. It also provided an efficient approach to construct a survey for further research [29].

However, the present study also has some limitations. Because of last-minute cancellations, no politician participated. Besides this, group dynamics and the absence of anonymity might have influenced the responses and discussions.[36] The last phase of the NGT process consisted of prioritising the generated forms of support. All experts cooperated during this phase, though some experts felt reluctance when prioritising owing to the different aspects of the generated solutions. The small number of GPs among the participants is also a limitation as the study aim was to find support needs for GPs, and warrants further research among these professionals.

Comparison with existing literature

To the authors' knowledge, this study is unique in exploring existing and new forms of support for GPs confronted with
euthanasia requests from PWD. Generally, in studies on euthanasia, 'support provided by other healthcare professionals' has already been suggested [19,37-40]. For example, in a qualitative survey, Hanssen-de Wolf et al [19] found that GPs value due-care criteria discussions with other professionals. In the present study, experts expressed not only the need for support provided by other professionals in a short consultative way, but also the possibility of a more long- term form of assistance. Examples they mentioned were a buddy who is available for the physician throughout the entire decision-making process, or support by taking part in regular meetings of GPs and nurses on proactive palliative care. In general, within such PaTz groups, members indeed receive informational and emotional support from each other [41].

Furthermore, moral case deliberation (MCD), a specific form of a clinical ethical support (CES) service, was deemed important and seen as a form of multidisciplinary moral support during the decision-making process. It is known that CES services are increasingly available in Dutch health care [37,38]. A qualitative interview study among Dutch care physicians for older people and GPs described that only care physicians for older people mentioned MCD as a form of support when dealing with a PWD's euthanasia request[17]. The fact that this form of support was hardly mentioned by GPs was probably due to the unfamiliarity and unavailability of MCD in general practices [17]. In addition, a former ethicist of one of the regional euthanasia review committees recently stated publicly that in complex cases, like euthanasia in PWD, ethical and moral reflection is largely lacking. The former ethicist called for a ‘more severe proactive review’ that is ‘broader in scope’ for complex cases using a multidisciplinary approach [42]. This implies that there is also a need for a proactive, broader, multidisciplinary decision-making process for complex euthanasia requests from PWD, for instance supported by a CES service.

Emotional and moral guidance and care for the physician by a healthcare professional was emphasised by several experts during the meetings. This is in line with a previous study that recommended that physicians who are confronted with euthanasia should be aware of their own needs [40]. A recent study specially focused on support for GPs and other physicians in recognising sources of pressure and recommended investment in support for GPs, and guiding them towards adequate use of sources of support. During the present meetings, but also in earlier research [17,43-45], the spiritual care provider was characterised as someone who could provide such emotional and moral support. However, awareness of spiritual care providers'
availability for general practice and clear job descriptions including the provision of non-denominational spiritual support are lacking and limit their involvement in regarding euthanasia and the different stages of dementia [51]. Finally, GPs might profit from interactive communication training to find the right balance between the physician’s professional responsibility and the patient’s autonomy.

Implications for research and practice

Because of global ageing, GPs in high-, intermediate-, and low-income countries will have to serve a rapidly increasing number of persons with dementia and their caregivers. As no effective treatment of any form of dementia is available or within reach, the number of persons with severe dementia and questions around end-of-life care will also rise. The forms of discussed in detail by the patient and physician. Besides, the KNMG is currently developing a tool that will give physicians guidance during the complex decision-making process [50] people have a wide variety of reasons [53] experienced problems and support needs [54].

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REFERENCES

1. Termination of Life on Request and Assisted Suicide Review Act; Article 2, paragraph 2. [In Dutch]. http://wetten.overheid.nl/BWBR0012410/2018-08-01 (accessed 21 Aug 2020).

2. General A. Case number ECLI: NL:PHR:2019:1338. https://uitspraken.rechtspraak.nl/inziendocument?id=ECLI: NL:PHR:2019:1338 (accessed 28 Sep 2020).

3. Hertogh CMPM, de Boer ME, Droes RM, Eefsting JA. Would we rather lose our life than lose our self? Lessons from the Dutch debate on euthanasia for patients with dementia. Am J Bioeth 2007; 7(4): 48–56.

4. Chabot B. Never kill a defenceless person who does not realize. [In Dutch]. de Volkskrant: https://www.volkskrant.nl/columns-opinie/dood-nooit-weerloze-die-het-niet-beseft~b96e0536/ (accessed 21 Aug 2020).

5. den Hartogh GA. Euthanasia on the basis of a living will: old and new legal questions. Nederlands Juristenblad 2017; 92: 2226–2233.

6. van Steenbergen E. Physicians: people with dementia can get euthanasia too easy. https://www.nrc.nl/nieuws/ 2017/02/09/artsen-tegen-euthanaseren-van- dementen-op-basis-van-wilsverklaring-a1545325 (accessed 5 May 2020).

7. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controversial case and its ethical implications. J Med Ethics 2019; 45(2): 84–89.

8. Asscher ECA, van de Vathorst S. First prosecution of a Dutch doctor since the Euthanasia Act of 2002: what does the verdict mean? J Med Ethics 2019; 46(2): 71–75.

9. Kouwenhoven PSC, van Thiel GJMW, van der Heide A, et al. Developments in euthanasia practice in the Netherlands: balancing professional responsibility and the patient’s autonomy. Eur J Gen Pract 2019; 25(1): 44–48.

10. Out of free will. Citizen initiative completed life. http://uitvrijewil.nu/ (accessed 21 Aug 2020).

11. Anonymous. Assisted dying could be legalised for over-75s who have had ‘enough of life’. Dutch News.nl 2020; 21 Aug: https://www.dutchnews.nl/ news/ 2016/12/assisted-dying-could-be-legalised-for-over-75s-who-have-had-enough-of-life (accessed 21 Aug 2020).

12. Regional Euthanasia Review Committees. Regional evaluation committee year reports 2010–2018. RTE. https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen (accessed 21 Aug 2020).

13. Onwuteaka-Philipsen BD, Rurup ML, Pasman HR. The last phase of life: who requests and who receives euthanasia or physician-assisted suicide? Med Care 2010; 48(7): 596–603.

14. Bolt EE, Snijdewind MC, Willems DL, et al. Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? J Med Ethics 2015; 41(8): 592–598.

15. Kouwenhoven PS, Raijmakers NJ, van Delden JJ, et al. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. BMC Med Ethics 2015; 16: 7.

16. de Boer ME, Depla M, den Breejen M, et al. Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners. J Med Ethics 2019; 45(7): 425–429.

17. Schuurmans J, Bouwmeester R, Crombach L, et al. Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study. BMC Med Ethics 2019; 20(1): 66.

18. Jansen-van der Weide MC, Onwuteaka-Philipsen BD, van der Wal G. Quality of consultation and the project ‘Support and Consultation on Euthanasia in the Netherlands’ (SCEN). Health Policy 2007; 80(1): 97–106.

19. Hanssen-de Wolf JE, Pasman HR, Onwuteaka-Philipsen BD. How do general practitioners assess the criteria for due care for euthanasia in concrete cases? Health Policy 2008; 87(3): 316–325.

20. Hesselink BA, Pasman HR, van der Wal G, et al. Awareness and use of practice guidelines on medical end-of-life decisions in Dutch hospitals. Patient Educ Couns 2010; 80(1): 21–28.

21. van der Dam S, Abma TA, Kardol MJ, Widdershoven GAM. ‘Here’s my dilemma’. Moral case deliberation as a platform for discussing everyday ethics in elderly care. Health Care Anal 2012; 20(3): 250–267.

22. Regional Euthanasia Review Committees; annual report 2017. RTE, 2017. https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports (accessed 21 Aug 2020).

23. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007; 19(6): 349–357.

24. Delbecq AL, de Ven V. A group process model for problem identification and program planning. J Appl Behav Sci 1971; 7(4): 466–492.

25. Gallagher M, Hares T, Spencer J, et al. The nominal group technique: a research tool for general practice? Fam Pract 1993; 10(1): 76–81.

26. McMillan SS, King M, Tully MP. How to use the nominal group and Delphi techniques. Int J Clin Pharm 2016; 38(3): 655–662.

27. Centres for Disease Control and Prevention. Gaining consensus among stakeholders through the nominal group technique. CDC, 2018. http://www.cdc.gov/HealthyYouth/evaluation/pdf/brief7.pdf (accessed 21 Aug 2020).

28. Harvey N, Holmes CA. Nominal group technique: an effective method for obtaining group consensus. Int J Nurs Pract 2012; 18(2): 188–194.

29. Rice DB, Canedo-Ayala M, Turner KA, et al. Use of the nominal group technique to identify stakeholder priorities and inform survey development: an example with informal caregivers of people with scleroderma. BMJ Open 2018; 8(3): e019726.

30. van Riet Paap J, Vissers K, Iliffe S, et al. Strategies to implement evidence into practice to improve palliative care: recommendations of a nominal group approach with expert opinion leaders. BMC Palliat Care 2015; 14: 47.

31. Sav A, McMillan SS, Kelly F, et al. The ideal healthcare: priorities of people with chronic conditions and their carers. BMC Health Serv Res 2015; 15: 551.

32. McMillan SS, Kelly F, Sav A, et al. Using the nominal group technique: how to analyse across multiple groups. Health Serv Outcome Res Method 2014; 14: 92–108.

33. Aspinal F, Hughes R, Dunckley M, et al. What is important to measure in the last months and weeks of life? A modified nominal group study. Int J Nurs Stud 2006; 43(4): 393–403.

34. Owen A, Arnold K, Friedman C, et al. Nominal Group Technique: an accessible and interactive method for conceptualizing the sexual self-advocacy of adults with intellectual and developmental disabilities. Qual Social Work 2015; 15(2): 175–189.

35. van der Plas AG, Pasman HRW, Schweitzer B, et al. Improving palliative care provision in primary care: a pre- and post-survey evaluation among PaTz groups. Br J Gen Pract 2018; DOI: https://doi.org/10.3399/bjgp18X695753.

36. Vander Laenen F. Not just another focus group: making the case for the nominal group technique in criminology. Crime Science 2015; 4: 5.

37. Dauwerse L, Stolper M, Widdershoven G, Molewijk B. Prevalence and characteristics of moral case deliberation in Dutch health care. Med Health Care Philos 2014; 17(3): 365–375.

38. de Snoo-Trimp J, Widdershoven G, Svantesson M, et al. What outcomes do Dutch healthcare professionals perceive as important before participation in moral case deliberation? Bioethics 2017; 31(4): 246–257.

39. Lillemoen L, Pedersen R. Ethical challenges and how to develop ethics support in primary health care. Nurs Ethics 2013; 20(1): 96–108.

40. van Marwijk H, Haverkate I, van Royen P, The A-M. Impact of euthanasia on primary care physicians in the Netherlands. Palliat Med 2007; 21(7): 609–614.

41. van der Plas AG, Hagens M, Pasman HRW, et al. PaTz groups for primary palliative care: reinventing cooperation between general practitioners and district nurses in palliative care: an evaluation study combining data from focus groups and a questionnaire. BMC Fam Pract 2014; 15: 14.

42. van Baarsen B. The evaluation of euthanasia: caring for quality, argumentation and development of norm. TGE 2018; 28: 79-87. https://vangorcumtijdschriften. nl/tge/artikel/de-toetsing-van-euthanasie-zorgen-om-kwaliteit-argumentatie- en-normontwikkeling/ (accessed 21 Aug 2020).

43. Anbeek CW, Palmboom G. The philosophical professional in transition. Handelingen Tijdschrift voor praktische theologie en religiewetenschappen 2014; 2014(3): 5–19.

44. de Jonge H. Kamerbrief over aanpak geestelijke verzorging/ levensbegeleiding [Internet] Letter to parliament on approach to spiritual care/life
guidance. Rijksoverheid 2018: https://www.rijksoverheid.nl/documenten/kamerstukken/2018/10/08/kamerbrief-over-aanpak-geestelijke-verzorging-levensbegeleiding (accessed 21 Aug 2020).

45. Hamilton IJ, Morrison J, Macdonald S. Should GPs provide spiritual care? Br J Gen Pract 2017; DOI: https://doi.org/10.3399/bjgp17X693845.

46. van Twillert M. Also spiritual counsellor in primary care. [In Dutch]. Medisch Contact 2018: https://www. medischcontact.nl/nieuws/laatste-nieuws/artikel/ ook-geestelijk-verzorger-in-de-eerste-lijn.htm (accessed 21 Aug 2020).

47. van Twillert M. Still 10 million extra for spiritual counsellor first line. [In Dutch]. Medisch Contact 2019: https://www.medischcontact.nl/nieuws/laatste-nieuws/ artikel/toch-10-miljoen-erbij-voor-geestelijk-verzorger-eerste-lijn.htm (accessed 21 Aug 2020).

48. de Boer ME, Depla M, den Breejen M, et al. Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners. J Med Ethics 2019; 45(7): 425–429.

49. de Nooijer K, van de Wetering VE, Geijteman EC, et al. [Written advance euthanasia directives in mentally incompetent patients with dementia: a systematic review of the literature]. Ned Tijdschr Geneeskd 2017; 161: D988.

50. van Wijmen MPS, Pasman HR, Widdershoven GA, et al. Motivations, aims and communication around advance directives: a mixed-methods study into the perspective of their owners and the influence of a current illness. Patient Educ Couns 2014; 95(3): 393–399.

51. Royal Dutch Medical Association (KNMG). KNMG starts project on euthanasia and advanced dementia. [In Dutch]. https://www.knmg.nl/actualiteit-opinie/ beleidsprogrammas/passende-zorg-in-de-laatste-levensfase/knmg-project- euthanasie-bij-dementie.htm (accessed 28 Sep 2020).

52. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. JAMA 2016; 316(1): 79–90.

53. Kellehear A. A social history of dying. Cambridge: Cambridge University Press, 2007.

54. Schuurmans J, Crol C, Olde Rikkert M, Engels Y. Dutch general practitioners experience burden by euthanasia requests from people with dementia; a quantitative survey. BJGP Open. In press.

DUTCH GPS EXPERIENCE OF BURDEN BY EUTHANASIA REQUESTS FROM PEOPLE WITH DEMENTIA; A QUANTITATIVE SURVEY. BJGP OPEN 2020, DOI;10.3399

CHAPTER 4

Dutch GPs' experience of burden by euthanasia requests from people with dementia: a quantitative survey

Jaap Schuurmans[1,2]*, Chantalle Crol[3], Marcel Olde Rikkert[4], Yvonne Engels[5]

[1]GP, Radboud University, Groesbeek, The Netherlands; [2]Researcher, Department of anesthesiology, Pain and Palliative Medicine, Radboud University, Nijmegen, Netherlands; [3]Primary care Physician of the elderly, Department of anesthesiology, Pain and Palliative Medicine, Radboudumc, Nijmegen, The Netherlands; [4]Professor, Department Geriatric Medicine, Radboud University, Nijmegen, The Netherlands; [5]Professor in Meaningful healthcare, anesthesiology, Radboudumc, Nijmegen, The Netherlands

Abstract

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

Aim: To obtain quantitative insights into the problems and needs of GPs when confronted with a euthanasia request by a person with dementia.

Design & setting: A concept survey was composed for GPs in the Netherlands. 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 of 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 people with dementia. Emotional burden was reported most frequently (n = 86; 52.8%), as well as feeling uncertain about the mental competence of the person with dementia (n = 77; 47.2%), pressure by relatives (n = 70; 42.9%) or the person with dementia (n = 56; 34.4%), and uncertainty about handling advance euthanasia directives (AEDs) (n = 43; 26.4%). GPs would appreciate more support from the following: a support and consultation in euthanasia in the Netherlands (SCEN) physician (an independent physician for support, information, and formal consultation around euthanasia) (n = 291; 68. 8%); a geriatric consultation team (n = 185; 43.7%); the end-of-life clinic (n = 184; 43.5%); or a palliative care consultation team (n = 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 people with dementia warrants primary care support. There needs to be 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

There has been a gradual increase in legalisation on euthanasia in countries all over the world. The Netherlands was one of the first countries that legalised euthanasia in 2002. A growing number of people with dementia request euthanasia, and growing numbers are receiving 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 into GPs' burden and the need for support when dealing with euthanasia requests from people with dementia.

Background

Euthanasia and physician-assisted suicide have been legalised in a growing number of countries; although, the practices are still only legal in a small number of countries. In all countries where it is legalised, 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 in relation 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 past decade the number of euthanasia cases in people with dementia has increased sixfold, from 25 (of 3136 cases in total) in 2010 to 146 cases (of 6125 in total) in 2018 [4]. As most people with dementia, especially in the early stages of the disease, live at their own home [5], GPs in particular are confronted with euthanasia requests [4]. A recent interview study showed that these requests and procedures are burdensome for GPs; for example, they experience pressure from relatives, have problems judging the person with dementia's mental capacity, and have to deal with Dutch society's stigmatisation 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 people with dementia live at home and will never reach an advanced stage of the disease, many people expect a catastrophic disease course, and fear ending 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 have legalised 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 from people with dementia 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 that raised GPs' concerns even more around euthanasia in people with dementia [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 and AEDs from people with dementia. Therefore, the study aimed to answer the following research question: what are the experienced burden and support needs of Dutch GPs when confronted with a euthanasia request by a person with dementia?

Method

Study design and participants

A quantitative survey was performed 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 people with dementia specifically, were invited to take part, regardless of their opinion about euthanasia. Exclusion criteria were being retired or no longer working as a GP.

Survey

Since no validated questionnaire to answer the research question was available, and no comparable study had been performed before, a survey was developed (Supplementary 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 older persons' 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 started with questions characterising personal and clinical practice demographics. Next, questions followed that were focused on GPs' experiences with AEDs, with euthanasia requests and euthanasia performance in general, and regarding people with dementia. Experienced burden with regard to euthanasia requests or performance was explored with eight multiple-choice items (emotional burden; pressure from respectively the patient; emotional pressure from relatives; uncertainty about the technical performance; uncertainty about the mental competence of the patient; uncertainty about the AED; time pressure; and no burden).

To gain insights into the support needs of the past and support wishes for the future, eight multiple- choice options could be chosen: consultation of, respectively, a palliative care expert; a geriatric consultation team; a spiritual care provider; the expert centre 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 to identify early their patients who need palliative care); a SCEN physician (for support, information, and formal consultation around euthanasia); moral deliberation; and no support needs.

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

Finally, it was asked whether recent discussions around euthanasia in people with dementia influenced the GP's own practice with five multiple-choice options: yes, more reserved; yes, more fearful for the legal process; yes, more likely to forward such a patient to a colleague or the expert centre for euthanasia; yes, more often consulting other healthcare professionals; and 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 3 weeks later. Participation in this study was voluntary and data were processed anonymously.
Data of the completed surveys were entered in Castor, a valid database.

Statistical analysis

All data were analysed 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 requests of other patient groups and of people with dementia, χ^2 were performed.

Results

Recruitment

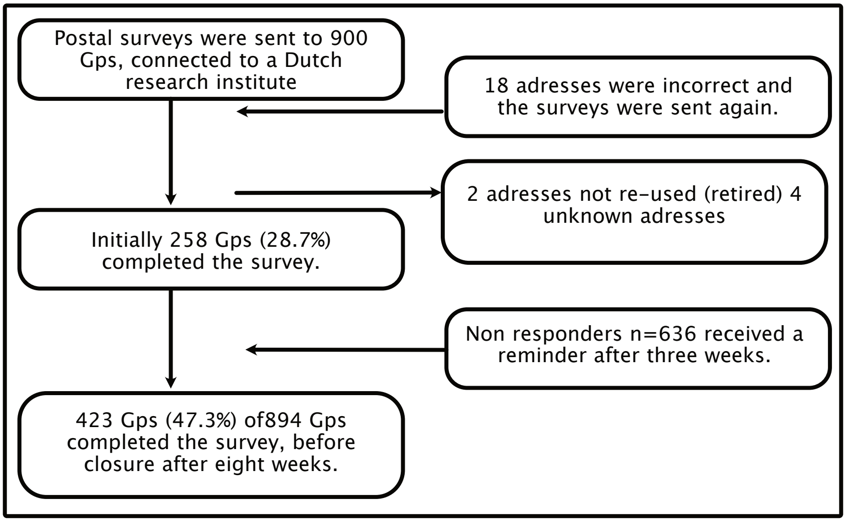
Of the 894 included Dutch GPs, 423 (47.3%) completed the survey before closure after 8 weeks. Figure 1 is the study flow diagram, describing the procedure and response rate initially and after a reminder.

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 (Table 1).

Of the responding 423 GPs, 340 (80.4%) had at least once performed euthanasia. Two out of five (n = 176; 41.6%) had at least once received a request for euthanasia from a person with dementia. Of those 176 GPs, 40 in total also had performed euthanasia in a person with dementia (22.7%: 37 on patients judged competent for this decision and three judged incompetent).

Figure 1, Study flow diagram



Of the 384 GPs who had never performed euthanasia in a person with dementia, 173 (45.1%) could imagine performing 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 centre for euthanasia. Only a small number of Gps (n = 31, 7.0%) were convinced that they would never perform euthanasia in people with dementia and also never refer a patient with such a request to a colleague.

Over half of the GPs (n = 228; 53.9%) estimated that they received one or more AEDs per month, and that more than half contained preferences around euthanasia in cases of dementia.

Burden

Regarding euthanasia requests or procedures for people with a disease other 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).

Table 1 GPs' characteristics (n = 423)

Characteristics	**n (%)[a]**
Mean age, years (SD)	48.1 (9.8)
Mean experience as GP, years (SD)	16.5 (9.4)
Sex	
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)[a]
Having had at least one euthanasia request from a patient with dementia	
Yes, competent	135 (32.9)
Yes, incompetent	41 (10.0)
No	249 (60.7)[a]
Having at least once performed euthanasia in a person with dementia	
Yes, competent	37 (8.7)
Yes, incompetent	3 (0.7)
No	384 (90.7)
Having no experience with euthanasia in people with dementia, 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 (53.9)
Estimated percentage of AEDs containing euthanasia requests in case of dementia ≥50%	222 (52.6)[a]

SD = standard deviation; AED = advanced euthanasia a directive. Number of missing variables among 2–17 Gps.

When it concerned a person with dementia, many 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 (respectively 155; 37.8% and 56; 34.4%; P = 0.167) or relatives (respectively 42.2% and 42.9%; P = 0.560) and time pressure (respectively 167; 40.7% and 16; 9.8%; P = 0.121) did not significantly differ between patients with and without dementia.

A third of the GPs declared that they had become more reserved with performing euthanasia in people with dementia in the light of a recent public debate related to the court case (Table 3).[15] One out of four GPs (n = 102; 24.2%) had become more fearful for the legal processes, 82 (19.4%) were more likely to refer 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 (n = 153; 36.3%) stated they were not influenced by the media attention.

Table 3 The impact of a 2019 debate on euthanasia in people with dementia on GPs future behaviour in questions for euthanasia in people with dementia (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 or end-of-life clinic	82 (19.4)
Yes, I consult other healthcare professionals more often	89 (21.1)
No, no influence	153 (36.3)

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

	Support asked in the past n (%)[a]	**Support needs future** n (%)[b]
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 centre for euthanasia	52 (31.9)	184 (43.5)
Moral deliberation	2 (1.2)	30 (7.1)
PaTz-group [c]	16 (9.8)	83 (19.6)
SCEN physician[d]	83 (50.9)	291 (68.8)
Other	52 (31.9)	57 (13.5)

a n = 163 (experience with request or performance in people with dementia). b n = 423. c Group of GPs 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. d SCEN: support and consultation on euthanasia in the Netherlands; SCEN physicians are available for support, information, and formal consultation around euthanasia.

Support needs

The anticipated need for support in future euthanasia procedures with people with dementia 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 (n = 83; 50.9%), and even more responders would prefer this in the future (n = 291; 68.8%). Furthermore, support of a geriatric consultation team (n = 185; 43.7%), a palliative care consultation team (n = 179; 42.3%) or the expert centre for euthanasia (n = 184; 43.5%) were most often mentioned as support sources needed. Support of a spiritual care provider had rarely been asked in the past (n = 2; 1.2%) and hardly mentioned as needed in the future (n = 16; 3.8%). Hardly any GPs (n = 2; 1.2%) had experience with a moral deliberation around such cases, and only a minority (n = 30; 7.1%) expected to need this kind of support in the future.

Wishes to increase skills and knowledge related to dementia

Most GPs (n = 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 people with dementia (n = 240; 56.7%), and in increasing communication skills to deal with pressure from relatives (n = 165; 39%), and knowledge assessing AEDs (n = 167; 39.5%).

Table 5 Wishes of responders to increase knowledge or skills related to dementia care (n = 423)

Training	n (%)
Communicating end-of-life aspects	119 (28.1)
Signalling symptoms in cognitive restricted people	137 (32.4)
Dealing with pressure from relatives	165 (39)
Legislation and interpretation of euthanasia regarding people with dementia	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)

AED = advanced euthanasia directive.

Discussion

Summary

The study quantitatively explored experiences and the subjective burden of euthanasia practice for people with dementia among Dutch GPs. Emotional burden, pressure from relatives and patients, uncertainties, assessment of mental competence, and dealing with AEDs were mentioned as the most burdensome issues. The latter two were significantly more often mentioned when it concerned people with dementia in comparison with other patient groups. The majority of the responders appeared in need of more support than they had used in the past when it concerned a euthanasia request by, or procedure of, a person with dementia. 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.

Comparison with existing literature

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% had at least once received a euthanasia request from a person with dementia, while less than 10% had actually performed euthanasia in such a patient. Of the responders who never had had a euthanasia request from a person with dementia, almost half would consider euthanasia when confronted with such a request. This is in line with the rise of euthanasia for people with dementia 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 centre for euthanasia. Indeed, in 2017, of all euthanasia cases, 11.3% were performed by this national expert centre for euthanasia; however, when it concerned people with dementia, this figure was 44.4% [20]. As just a small number of physicians at the expert centre for euthanasia handle all these euthanasia requests from people with dementia, each of them has a high caseload. 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 cases of future dementia is described. One in four GPs in the 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 no longer capable to decide on this, either owing to cognitive impairment, emotional or behavioural problems, carefully discussing and regularly updating it is extremely important.

As advance care planning (ACP) in people with dementia should start early in the disease trajectory [21-23], it is recommended that GPs use the moment that a person with dementia shares or wants to discuss an AED to also start ACP. This advance care directive talk should not only discuss end-of-life preferences, but also be based on the person's 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].

The high percentages of GPs that experienced emotional burden and pressure from patients or relatives concerning euthanasia or euthanasia requests by people with dementia, 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 centre 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 counselling was hardly mentioned by the responders. Perhaps, 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 older and palliative patients in primary care, the Dutch Ministry of Health Affairs currently invests 7.5 million Euros 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 person with dementia. The study had a relatively high response rate from all regions of the Netherlands. The relatively high response rate emphasises GPs' high involvement in this topic [19], as other surveys among Dutch GPs mostly had much lower response rates (29.6–41.0%) [33-35]. Responders were representative of the Dutch GP practice with regard to age and sex [36], and came from all Dutch regions.

A limitation is the fact that a validated questionnaire was not used, 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.

Implications for practice

It was found that many Dutch GPs experience emotional burden, uncertainty on assessment of patients' mental competence, handling AEDs, and pressure from relatives and patients concerning euthanasia requests from people with dementia. 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 caseload, this warrants primary care support and training for the quickly growing end-of-life care needs of patients with dementia and their caregivers.

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Ethical approval

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.

Provenance

Freely submitted; externally peer reviewed.

References

1. Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, et al. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada, and Europe. JAMA 2016; 316(1): 79–90. DOI: https://doi.org/10. 1001/ jama.2016.8499

2. Munday T, Poon P. Geriatricians' attitudes towards voluntary assisted dying: a survey of Australian and New Zealand Society for geriatric medicine members. Australas J Ageing 2020; 39(1): e40-e48. DOI: https://doi.org/10. 1111/ ajag.12681

3. overheid.nl. [Law evaluation of life termination upon request and assisted suicide] Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (in Dutch). 2018; https:// wetten.overheid.nl/ BWBR0012410/2018-08-01 (accessed 23 Nov 2020).

4. Regionale Toetsingscommissies Euthanasie (RTE). Annual reports 2010–2018 of the Regional Evaluation Commissions Euthanasia (RTE). 2018; https://www.euthanasiecommissie.nl/ de-toetsingscommissies/jaarverslagen (accessed 23 Nov 2020).

5. NOS. [Fight against prejudices about dementia: 'You can live well with it for a long time'] Strijd tegen vooroordelen dementie: 'Er valt nog lang goed mee te leven' (in Dutch). 2018; https://nos.nl/nieuwsuur/artikel/ 2210966-strijd-tegen-vooroordelen-dementie-er-valt-nog-lang-goed-mee-te-leven.html (accessed 23 Nov 2020).

6. Schuurmans J, Bouwmeester R, Crombach L, et al. Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study. BMC Med Ethics 2019; 20(1): 66. DOI: https://doi. org/10.1186/s12910-019-0401-y

7. Landeweer M. [Distraughted Joop: sometimes her urine drops down her ankles] Radeloze Joop (81): Soms loopt de urine langs Haar enkels (in Dutch). 2016; https://www.ad.nl/gezond/ radeloze-joop-81-soms-loopt-urine-langs-haar- enkels~af8145d5/ (accessed 23 Nov 2020).

8. Grooters L. [Three insights from 'the Leeuwenhoek tour'] Drie inzichten uit de Leeuwenhoektour (in Dutch). 2018; https://www.human.nl/in-de-leeuwenhoek/lees/inzichten-tour.html (accessed 23 Nov 2020).

9. Government of the Netherlands. Working together internationally to tackle dementia. 2017; https://www.government.nl/latest/news/2017/05/16/working-together-internationally-to-tackle-dementia (accessed 23 Nov 2020).

10. van Twillert M. [A growing number of people have a written advance directive] Meer mensen hebben schriftelijke wilsverklaring (in Dutch). 2018; https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/meer-mensen-hebben- schriftelijke-wilsverklaring.htm (accessed 23 Nov 2020).

11. Dworkin RH, O'Connor AB, Audette J, et al. Recommendations for the pharmacological management of neuropathic pain: an overview and literature update. Mayo Clin Proc 2010; 85(3 Suppl): S3–S14. DOI: https://doi.org/10.4065/mcp.2009.0649

12. de Nooijer K, van de Wetering VE, Geijteman ECT, et al. Written advance euthanasia directives in mentally incompetent patients with dementia: a systematic review of the literature. Ned Tijdschr Geneeskd 2017; 161: D988.

13. Kouwenhoven PSC, Raijmakers NJH, van Delden JJM, et al. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. BMC Med Ethics 2015; 16(1): 7. DOI: https://doi.org/10.1186/1472-6939-16-7

14. Kouwenhoven PSC, van Thiel GJMW, van der Heide A, et al. Developments in euthanasia practice in the Netherlands: balancing professional responsibility and the patient's autonomy. Eur J Gen Pract 2019; 25(1): 44–48. DOI: https://doi.org/10.1080/13814788.2018.1517154

15. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controversial case and its ethical implications. J Med Ethics 2019; 45(2): 84–89. DOI: https://doi.org/10.1136/medethics-2017-104644

16. The Telegraph. Dutch euthanasia doctor cleared over death of dementia patient. 2019; https://www.telegraph.co.uk/news/2019/09/11/dutch-euthanasia-doctor-cleared-death-dementia-patient/ (accessed 23 Nov 2020).

17. Regionale Toetsingscommissies Euthanasie (RTE). Annual report 2017. Dementia cases in the Netherlands. 2018; https://www.euthanasiecommissie.nl/uitspraken/jaarverslagen/2018/april/11/jaarverslag-2018 (accessed 2 Dec 2020).

18. Schuurmans J, Vos S, Vissers P, et al. Supporting GPs around euthanasia requests from people with dementia: a qualitative analysis of Dutch nominal group meetings. Br J Gen Pract 2020; 70(700): e833–e842. DOI: https://doi.org/10.3399/bjgp20X713093

19. Bolt EE, Snijdewind MC, Willems DL, et al. Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living? J Med Ethics 2015; 41(8): 592–598. DOI: https://doi.org/10.1136/medethics-2014-102150

20. KNMG. [Euthanasia in figures] Euthanasie in cijfers (in Dutch). 2019; https://www.knmg.nl/advies-richtlijnen/dossiers/euthanasie.htm (accessed 15 Sep 2020).

21. Tilburgs B, Vernooij-Dassen M, Koopmans R, et al. Barriers and facilitators for GPs in dementia advance care planning: a systematic integrative review. PLoS One 2018; 13(6): e0198535. DOI: https://doi.org/10.1371/journal.pone.0198535

22. Tilburgs B, Vernooij-Dassen M, Koopmans R, et al. The importance of trust-based relations and a holistic approach in advance care planning with people with dementia in primary care: a qualitative study. BMC Geriatr 2018; 18(1): 184. DOI: https://doi.org/10.1186/s12877-018-0872-6

23. Piers R, Albers G, Gilissen J, et al. Advance care planning in dementia: recommendations for healthcare professionals. BMC Palliat Care 2018; 17(1): 88. DOI: https://doi.org/10.1186/s12904-018-0332-2

24. Tilburgs B, Koopmans R, Vernooij-Dassen M, et al. Educating Dutch general practitioners in dementia advance care planning: a cluster randomized controlled trial. J Am Med Dir Assoc 2020; 21(6): 837–. DOI: https://doi.org/10. 1016/j.jamda.2019.09.010

25. Petty S, Harvey K, Griffiths A, et al. Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. Int J Geriatr Psychiatry 2018; 33(5): 679–687. DOI: https://doi.org/10.1002/gps. 4870

26. Lloyd-Williams M, Mogan C, Dening KH. Identifying palliative care needs in people with dementia. Curr Opin Support Palliat Care 2017; 11(4): 328–333. DOI: https://doi.org/10.1097/SPC.0000000000000295

27. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their carers: a systematic review and critical discussion. J Pain Symptom Manage 2018; 55(1): 132–150. DOI: https://doi.org/10.1016/j.jpainsymman.2017.04.009

28. de Boer ME, Depla MFIA, den Breejen M, et al. Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners. J Med Ethics 2019; 45(7): 425–429. DOI: https://doi.org/10.1136/medethics- 2018-105120

29. Vermandere M, De Lepeleire J, Smeets L, et al. Spirituality in general practice: a qualitative evidence synthesis. Br J Gen Pract 2011; 61(592): e749–e760. DOI: https://doi.org/10.3399/bjgp11X606663

30. Ummelen B, Schuurmans J, Molenaar C. [The spiritual caregiver is part of the basic package] Geestelijk verzorger hoort in t basispakket (in Dutch). 2018; https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/geestelijk- verzorger-hoort-in-het-basispakket.htm (accessed 15 Sep 2020).

31. Government of the Netherlands. [Letter to parliament on approach to spiritual care] Kamerbrief over aanpak geestelijke verzorging (in Dutch). 2018; https://www.rijksoverheid.nl/documenten/kamerstukken/2018/10/08/kamerbrief-over-aanpak-geestelijke-verzorging-levensbegeleiding (accessed 23 Nov 2020).

32. Deandrea S, Montanari M, Moja L, et al. Prevalence of undertreatment in cancer pain. A review of published literature. Ann Oncol 2008; 19(12): 1985–1991. DOI: https://doi.org/10.1093/annonc/mdn419

33. Plat FM, Peters YAS, Giesen P, et al. Availability of Dutch general practitioners for after-hours palliative care. J Palliat Care 2018; 33(3): 182–186. DOI: https://doi.org/10.1177/0825859718766947

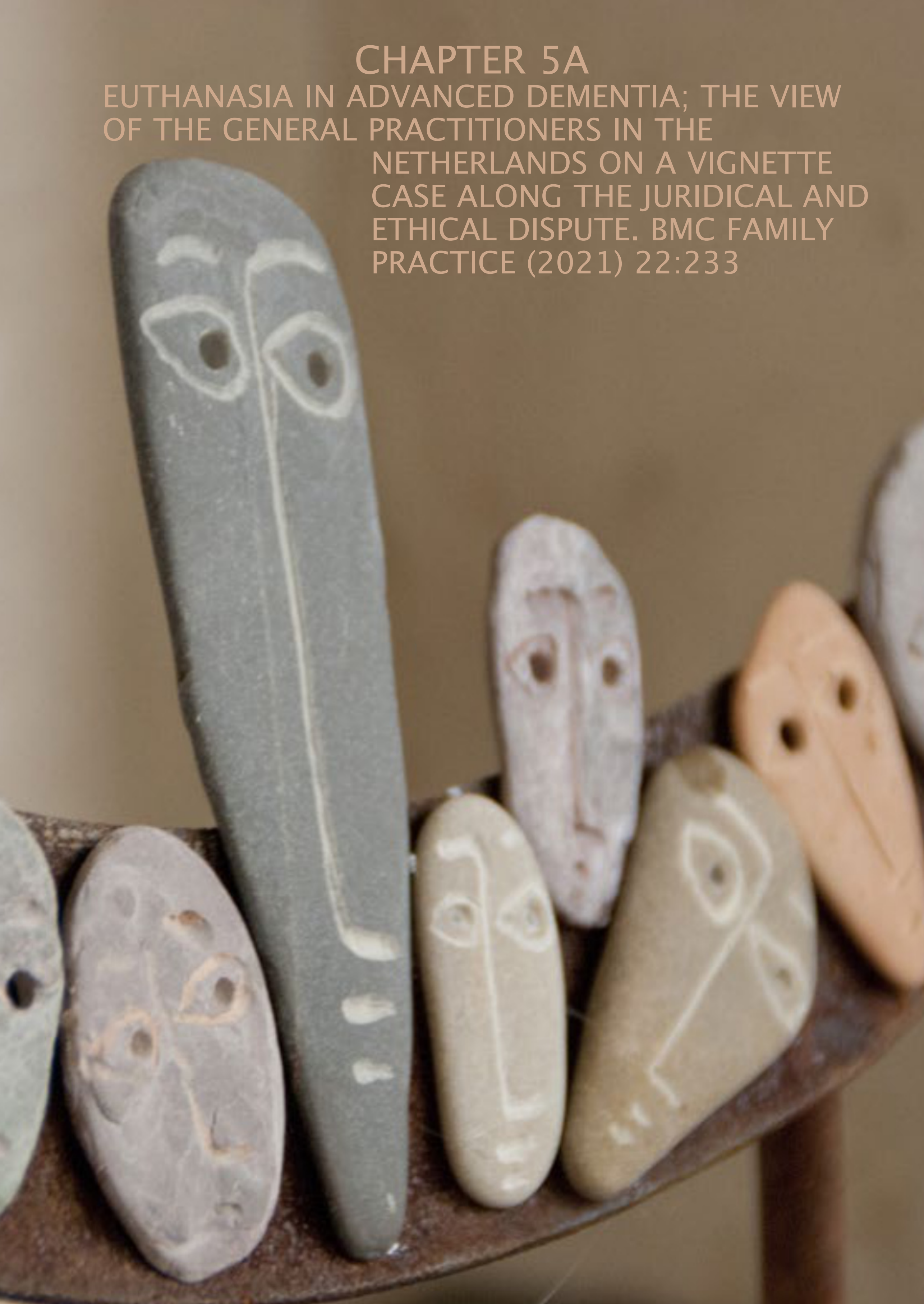
34. Hasselaar JGJ, Reuzel RPB, van den Muijsenbergh METC, et al. Dealing with delicate issues in continuous deep sedation. Varying practices among Dutch medical specialists, general practitioners, and nursing home physicians. Arch Intern Med 2008; 168(5): 537–543. DOI: https://doi.org/10.1001/archinternmed.2007.130

35. Kouwenhoven PSC, van Thiel GJMW, Raijmakers NJH, et al. Euthanasia or physician-assisted suicide? A survey from the Netherlands. Eur J Gen Pract 2014; 20(1): 25–31. DOI: https://doi.org/10.3109/13814788.2013.813014

36. Heins M, Donker G, Versteeg S, et al. [Developments in the number of euthanasia cases and related factors] Ontwikkelingen in het aantal euthanasiegevallen en achterliggende factoren (in Dutch). 2019; https://nivel.nl/sites/ default/files/bestanden/Ontwikkelingen_aantal_euthanasiegevallen_en_achterliggende_factoren.pdf (accessed 23 Nov 2020).

CHAPTER 5A

EUTHANASIA IN ADVANCED DEMENTIA; THE VIEW OF THE GENERAL PRACTITIONERS IN THE NETHERLANDS ON A VIGNETTE CASE ALONG THE JURIDICAL AND ETHICAL DISPUTE. BMC FAMILY PRACTICE (2021) 22:233



Euthanasia in advanced dementia; the view of the general practitioners in the Netherlands on a vignette case along the juridical and ethical dispute

Jaap Schuurmans , Chantalle Crol , Boudewijn Chabot , Marcel Olde Rikkert and Yvonne Engels

Abstract

Background: In the Netherlands, euthanasia has been regulated by law since 2002. In the past decade, a growing number of persons with dementia requested for euthanasia, and more requests were granted. A euthanasia request from a patient with advanced dementia (PWAD) can have a major impact on a general practitioner (GP). We aimed to get insights in the views of Dutch GPs on euthanasia concerning this patient group.

Methods: A postal survey was sent to 894 Dutch GPs. Questions were asked about a case vignette about a PWAD who was not able to confirm previous wishes anymore. Quantitative data were analyzed with descriptive statistics.

Results: Of the 894 GPs approached, 422 (47.3%) completed the survey. One hundred seventy-eight GPs (42.2%) did not agree with the statement that an Advance Euthanasia Directive (AED) can replace an oral request if communication with the patient concerned has become impossible. About half of the respondents (209; 49.5%) did not agree that the family can initiate a euthanasia trajectory, 95 GPs (22.5%) would accept such a family initiative and 110 GPs (26.1%) would under certain conditions.

Discussion: In case of a PWAD, when confirming previous wishes is not possible anymore, about half of the Dutch GPs would not accept an AED to replace verbal or non-verbal conformation nor consider performing euthanasia; a minority would. Our study shows that, probably due to the public debate and changed professional guidelines, conflicting views have arisen among Dutch GPs about interpretation of moral, ethical values considering AED and PWADs.

Keywords: Euthanasia, Dementia, General practitioners, Support, Burden, Jurisdiction, Human rights, Ethical implications

Background

Death according to personal preference and in a manner that resonates with the person's individuality is increasingly considered as an important element of 'a good death' in modern Western culture [1]. Consequently, an increasing number of countries legalizes euthanasia. Although there are more countries where euthanasia also can be provided to persons with dementia (PWDs), only in the Netherlands an advance euthanasia directive (AED) can replace a verbal request for euthanasia in a later stage of dementia, if all other obligatory criteria are met [2–4].

Initially, like in other countries, the large majority of euthanasia requests and acts concerned terminal patients with cancer [5]. However, during the last decade, the Dutch number of euthanasia cases in persons with dementia (PWDs) has increased from 25 (of 3136 cases in total) in 2010 to 162 cases (of 6361 in total) in 2019 [6]. Indeed, Dutch society, influenced by the growing media and political attention, considers dementia as a debilitating and degrading disease and by many as synonymous with unbearable suffering [7–9]. As most PWDs, especially in the early stages of the disease, live at their own home [10], particularly GPs are confronted with euthanasia requests of PWDs [5]; a growing number of people in the Nether- lands discuss and share an AED with their GP [11].

Recent studies showed that dealing with AEDs, euthanasia requests and procedures often have become a bur- den for GPs; they experience pressure from relatives, have problems with judging mental capacity of PWDs, and the Dutch society's stigmatization of dementia [12– 14]. Not having the same expectations as relatives, as well as disagreeing with relatives about AEDs, (un)willingness to perform euthanasia and if, its timing of euthanasia, contribute to this burden [15–17]. (Re)discovering the right balance between the physician's professional responsibility, and in such cases, the patient's and relatives' autonomy has been recommended [15].

Until 2015, the Royal Dutch Medical Association (KNMG) directed that, on medical-ethical grounds, it was necessary that the patient confirmed his or her actual death wish, verbally or non-verbally, when receiving euthanasia, regardless of having an AED. In 2015, the KNMG published its latest guideline, following more liberal possibilities than given by law, in which an AED was not required as stipulates in section 2.2 (Table 1) [18]. This can be considered a baseline shift, responding to the society expectations to provide maximum juridical space for PWDs.

Recently, a Dutch euthanasia case concerning a woman with advanced dementia was tested against criminal law, to acquire jurisprudence, thereby seeking formal ground for this legal option. This even increased GPs' concerns around euthanasia in PWDs [19]. The Supreme Court in The Hague determined that the woman with advanced dementia in question who was given euthanasia based on her AED without actual confirmation of her request, legally and professionally received sound care in line with the amendment of the law. This case, in which the physician had been accused of murder, was dismissed [20, 21].

Although this case concerned an elderly care physician working in a nursing home, this first ever euthanasia court case was considered as threatening in primary care across the Netherlands. As a result GPs typically are confronted with euthanasia requests and AEDs, and carry out 85% of all euthanasia procedures [22]. Clearly, there are professional and legal challenges and ethical concerns that GPs face when dealing with euthanasia requests and AEDs from PWDs. Therefore we aimed to answer the following research questions: What are the views of Dutch GPs on euthanasia concerning patients with advanced dementia (PWAD)?

Table 1 The requirements of due care in Dutch law as stipulated in the Article 2 of The Termination of Life on Request and Assisted Suicide Act

Under the law, the definition of euthanasia applies when a physician ends the life of a patient at his express request due to unbearable and lasting suffering. Euthanasia means that the physician administers a lethal substance to the patient. In the case of assisted suicide, the physician supplies a lethal substance that the patient takes in the physician's presence.

The physician must:

a. Be satisfied that the patient's request is voluntary and well considered.
b. Be satisfied that the patient's suffering is unbearable, with no prospect of improvement.
c. Have informed the patient about his situation and his prognosis.
d. Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient's situation.
e. Have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out in (a) to (d) have been fulfilled.
f. Have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

The Act stipulates in section 2.2 that a patient aged 16 or over who is decisional competent may draw up an advance directive, setting out a request for euthanasia. If at some point the patient is no longer capable of expressing his will, the physician may accept the advance directive as a request pursuant to section 2 (1)(a) of the Act.1 2 The advance directive thus has the same status as an oral request for euthanasia

Methods

Study design and participants

Between January and March 2019, we performed a quantitative postal survey. The addresses of a representative sample of 894 Dutch GPs were received from the Dutch institute for healthcare research (NIVEL), containing the majority of Dutch GPs. These GPs gave their consent for sharing their postal addresses for research purposes. GPs, with or without experience with euthanasia requests or procedures in general or with PWDs specifically, were invited to take part, regardless of their opinion about euthanasia. Exclusion criteria were being retired GPs 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 (Additional file 1). Based on a literature search, a qualitative interview study [12] and two expert meetings [23], a concept survey was composed. Face 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 min to complete.
The survey started with questions characterizing personal and clinical practice context. Next, questions on AED and euthanasia requests from PWD followed which have been published elsewhere [13]. Here, we focus on the questions that concern the view of GPs on euthanasia in PWADs. These concern:

1. A 5 point Likert scale (totally disagree-totally agree) on having problems with judging the specific criterion of unbearable suffering in a competent and in an incompetent patient.
2. After presentation of a case vignette, which was inspired on the recent juridical case that concerned euthanasia for a person with advanced dementia (Table 2), the respondents were asked their judgement whether or not the GP acted correctly. (yes or no) Next some additional questions (yes, no, maybe) were asked:

a. Can an AED replace an oral request if communication with a PWAD is not possible anymore?
b. Can the family initiate a euthanasia procedure and represent the interests of a PWAD?
c. Is it allowed that a PWAD is sedated before euthanasia is performed?

In an open text box, the GPs could explain their answers.

Table 2 Case Vignette

Mr. Smit is 70 years old and is indisputably diagnosed with dementia by a geriatrician. He does not recognize his wife and children anymore, refuses to eat, and increasingly isolates himself. Discussing his treatment is not possible anymore. Ten months ago, still being competent, he composed an advance euthanasia directive (AED), in which he declared that he would opt for euthanasia when suffering from dementia.

His family is now asking for performing this, given the patient’s AED and his unbearable suffering with no prospect of improvement. The general practitioner considers the patient incompetent, can imagine that the patient is unbearably suffering and is convinced that the patient’s AED can replace an oral request. The consulted SCEN physician[a] and elderly care physician confirmed this and approved euthanasia. A sedative was orally administered to prevent possible unpredictable behavior, agitation and startle reactions at which the patient might walk away, after which the GP performed the euthanasia. After having received the written report of the euthanasia procedure from the GP, the regional review committee invites him to give an explanation of his actions.

[a] SCEN; support and consultation on euthanasia in the Netherlands. SCEN physicians are available for support, information and formal consultation around euthanasia

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 regular mail. Non-responders received a reminder 3 weeks later. The study flow diagram is shown in Fig. 1.

Data of the completed surveys were entered in Castor EDC, a cloud-based clinical data management platform, and after closure of the database transported to SPSS.

Statistical analysis

All data were analyzed using SPSS software version 25. Frequencies with percentages and means with standard deviations (SDs) were used as descriptive variables.

Results

Recruitment

Of the 894 included GPs, 423 (47.3%) completed the survey. The study flow diagram, describing the procedure and response rate initially and after a reminder is shown in the Fig. 1.

Characteristics of the GPs’

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 48years with a mean of 17 years’ experience (Table 3).

Judging the due criteria

Of the responding GPs, 348 (82.4%) (totally) agreed that it is difficult to judge the due care criterion ‘unbearable suffering with no future improvement’ of an incompetent person with dementia (PWAD).

When it concerns a competent PWD who considers his perspective of future suffering as unbearable, 247 GPs (58.6%) (totally) disagreed that in such a case the due care criteria are met.

Case vignette

On the question if the GP in the case vignette acted correctly, 178 (42.2%) answered with ‘yes’ and 210 (49.8%) with ‘no’ (Table 4). Seventy-six GPs (18%) agreed that an AED can replace an oral request if communication with the concerned patient has become impossible, 178 did not agree (42.2%) and 158 (37.4%) answered ‘maybe’.

Figure 1 study flow diagram

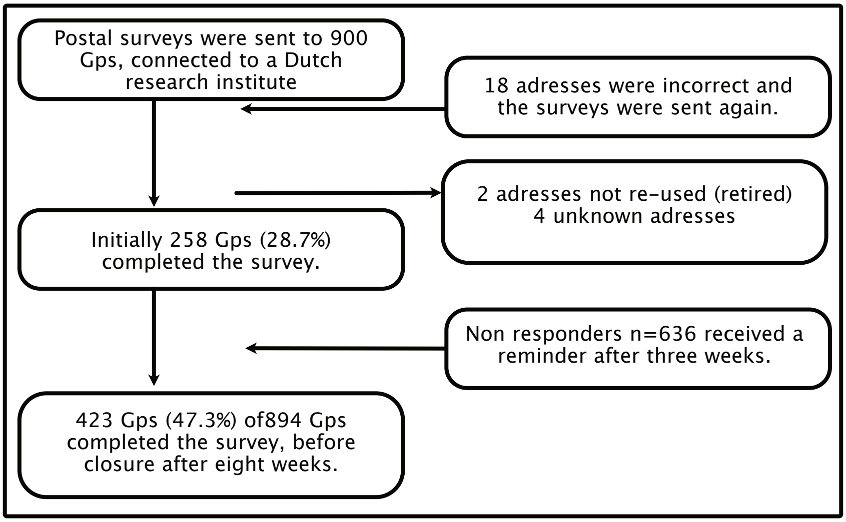


Table 3 GPs' characteristics (*N* =423)

Characteristics.	***N* (%)[a]**	**Mean (SD)**
Age in years		48.1 (9.8)
Experience as GP in years		16.5 (9.4)
Gender	207 (49.2)	
Male	214 (50.8)	
Female Kind of GP Regular	390 (92.6)	
Locum	30 (7.1)	

[a] *Number of missing variables among 2-17 GPs*

Table 4 Case Vignette and personal view

	Number of GPs that responded to the question	**Yes n (%)**	**No n (%)**	**Maybe N (%)**
25a Do you judge the way of acting of this GP as correct?	388	178 (45.8)	210 (54.1)	–
25b An AED can replace an oral request if communication with the concerned patient is impossible.	412	76 (18.4)	178 (43.2)	158 (38.3)
25c The family can initiate the start of a euthanasia procedure representing the interests of the concerned patient.	414	95(22.9)	209 (50.4)	110 (26.5)
25d A sedative medicine prior performing euthanasia to the concerned patient is allowed.	396	181 (45.7)	126 (31.8)	89 (22.4)

When stating that the family can initiate the start of a euthanasia procedure representing the interests of the concerned patient (in case this patient is not able any- more to confirm such a previously documented wish), 95 (22.5%) GPs agreed, while 209 (49.5%) disagreed, and 110 (26.1) said 'maybe'. GPs added in the open text box explanations like: 'this is only an option if I know the family and patient well'; 'if the patient has authorized this family member earlier when he or she was still mentally capable', or 'if the family participated in earlier conversations about euthanasia and if there is no pressure from relatives or conflict of interests'.

Administration of sedative medication prior the euthanasia performance was agreed by 181 GPs (42.9%) and disagreed by 126 (29.9%) GPs, while 89 GPs (21.1%) found this only acceptable if, as mentioned in the open text boxes, the patient is restless and if it was discussed and documented in the AED.

Discussion

When it concerns euthanasia in PWAD, the vast majority of Dutch GPs experienced difficulties to adequately judge the for euthanasia obligatory criterion of unbearable suffering with no prospective improvement. After hav- ing read a case vignette which was based on the recent Dutch juridical case around euthanasia in a PWAD, only one out of five GPs agreed that an AED can replace an oral request in PWADs and that the family can initiate the euthanasia procedure. One-third of the GPs in our study had objections against sedation prior to performing euthanasia, even though this is allowed according to the currently being updated Dutch guideline on performance of euthanasia [24]. One out of five to one out of three GPs could not answer these questions with a clear yes or no.

In our fictive case vignette, the several elements of the first legal case where the physician was accused of murder, were integrated. At the moment the GPs completed the survey, this case was well-known by all Dutch physicians, as a lot of media attention was given to it. However, at that moment a judicial decision was not yet made. Our findings quantitatively confirm those from a Dutch interview study from 2015, in which many physicians considered euthanasia in PWAD problematic, both legally and personally [17]. In that interview study, physicians were reluctant to forgo adequate verbal communication with the patient, because they wished to verify the voluntariness of a patient's request, and the unbearableness of the actual suffering, and thus consider an AED of limited value in PWAD.

The Dutch law does not give restrictions towards euthanasia in PWAD if it is performed according to the obligatory due care criteria. We found in our study that the majority of GPs (54%) judged the acting of the doctor in the vignette case as not right. Recently, the supreme court in The Hague gave clearance and no punishment in the case on which our case vignette was inspired [20]. The argumentation of the Court is mainly based on the concept of 'precedent autonomy' and 'continuity of per- son', whereby the self-determination to be respected was made at the time the person was still competent. This argumentation is in line with the views of philosopher of law Ronald Dworkin. Dworkin emphasizes that critical interests –as coded in the AED- should take precedence over experiential interests (from flimsy games to poetry) as expressed by or observed from the patient [25]. According to legal philosopher Rozemond, this shows an overestimation of rational faculties of the human mind [26]. Rozemond doubts whether the previous competent self legally can prevail over the present, more or less incompetent self, commonly known as the "then-self-versus now-self " problem. In his reasoning it is a misconception that a loss of memory in dementia necessarily results in a diminished sense of self [27]. A more balanced perspective is suggested in which we factor in both the previously expressed wishes (respecting autonomy) and the current reality (respecting beneficence) [28].

In our study we found that two out of five GPs think that an AED cannot replace an oral request if communication with the concerned patient is impossible. Only one out of five think that it can replace it. As an AED now legally can replace an actual, oral euthanasia confirmation, a PWAD may not have the opportunity anymore to decide on his euthanasia request. Due to the progressive cognitive impairment, emotional – and/or behavioral problems in PWAD, regularly and carefully discussing and updating the person's wishes becomes extremely import. Specifically because consistency in choice and regular conformation of consistency is legally mandatory. An earlier study also showed that many GPs would like to have training to increase their knowledge around AEDs [12]. Up to now, the Royal Dutch Medical Association (KNMG) guideline for physicians gives no requirements for an AED, but is currently developing a new guide- line [29]. Consequently, at the moment it is uncertain whether an AED should be considered and thus made as a personal, conversational document, or that it should be a legal notarized pre-printed document, standardized according to the jurisprudence of the supreme court. When a PWD wants to discuss an AED, we recommend that GPs will take advantage of the opportunity, to also embark on the overarching advance care planning. By using the opportunity to provide realistic information about the dementia trajectory and its consequences, unrealistic fear for future suffering and loss of control may be relieved [30–32].

Although the Supreme Court ruling has confirmed the interpretation of the law, our study shows that GPs are very divided in their moral judgment regarding this law interpretation. The recent concerns of the United Nations-Human rights committee towards the Dutch euthanasia practice can be regarded as an opportunity to elaborate on the experiences of burden and the ethical dilemmas which GPs in the Netherlands are facing [33]. For example GPs could be supported by having opportunities for early ethical review. In line with this, an ethicist and former member of one of the regional euthanasia review committees recently publicly stated that in complex cases, like euthanasia in PWADs is, ethical and moral reflection is largely lacking [34]. She called for a "more proactive review" that is "being broader in scope" for complex cases by using a multidisciplinary approach [35]. This implies that there is also a need for a proactive, broader, multidisciplinary decision-making process for complex euthanasia requests of PWADs, for instance supported by moral case deliberation (MCD). A recent study showed that addressing harm in MCD aids health- care professionals in the task they are facing [36]. Giving GPs better access towards MCD would be a sensible pol- icy as it may counteract polarization within the profession and society. In our earlier study we also argued for creating awareness of the possibility to consult a spiritual care provider [13, 37]. These suggestions to introduce ethical review ex ante medical decisions on request for termination of life should be further explored, in order to address GPs' personal moral considerations and dealing with social pressure. Better support for physicians in an early phase may be beneficial in all countries dealing with the legalization of euthanasia.

Strengths and limitations

This quantitative survey is unique in focusing on Dutch GPs' views on euthanasia requests for PWAD. The Dutch jurisdiction on euthanasia and PWAD is interestingly unique, but limited to Dutch territory. The questions raised ethically reach much further. We had a high response rate from all regions of the Netherlands. The relatively high response rate emphasizes GPs' high involvement in this topic, as other surveys among Dutch GPs mostly had much lower response rates (around 30%) [38– 40]. The respondents are representative for the Dutch GP practice, as checked for age, gender and region [36].

A limitation is that the survey was no validated questionnaire. However, the basic questionnaire relied on two previous studies and a literature review, and was adapted after having received feedback from six experts.

Conclusion

In our exploration of the views of general practitioners confronted with an advance euthanasia request from a person with advanced dementia, the vast majority of the responding GPs experienced difficulties adequately judging the obligatory care criteria of the patients' unbearable suffering with no prospective improvement. Even though euthanasia on the basis of a previous AED is now possible by law for PWAD in the Netherlands, only a minority of GPs support this. Therefore, it can be emphasized that research and development of moral and ethical support throughout the decision making process is needed.

Abbreviations

AED: Advance euthanasia directive; GP: General Practitioner; KNMG: Royal Dutch Medical Association; MCD: Moral Case Deliberation; PW(A)D: Person with (Advanced) Dementia; PWDs: Persons with Dementia; SCEN: Support and Consultation on Euthanasia in the Netherlands.

Supplementary Information

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Authors' contributions

Study design authors number 1,2 and 5. Data analyse authors number 1,2 and 5. Manuscript written by author 1. All authors reviewed the manuscript. The author(s) read and approved the final manuscript.

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Availability of data and materials

The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Participation in this study was voluntary and data were processed anony- mously. Participants were not subject to treatment, nor were they required to behave in a particular way. Therefore, the Medical Review Ethics Com- mittee region Arnhem-Nijmegen concluded that this study was not subject to the Medical Research Involving Human Subjects Act (case number 2018-5003). All methods were performed in accordance with the relevant guidelines and regulations**.** In accordance with the Dutch law, Informed consent was not obtained as data processing was anonymous.

Consent for publication

Given by all recipients and authors.

Competing interests

None.

Author details

[1]General practice Ottenhoff, B. Ottenhoffstraat 18, 6561 CM Groesbeek, The Netherlands.
[2]Radboud University Medical Center, Postbox 9101, 6500 HB Nijmegen, The Netherlands.

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References

1. Clark D. Between hope and acceptance: the medicalisation of dying. BMJ. 2002;324(7342):905–7.

2. Munday T, Poon P. Geriatricians' attitudes towards voluntary assisted dying: a survey of Australian and new Zealand Society for Geriatric Medi- cine members. Australas J Ageing. 2020;39(1): e40–8.

3. Wet toetsing levensbeëindiging op verzoek en hulp bij zelfdoding (Law evaluation of life termination upon request and assisted suicide). 2018 [cited 2020 8 May]; Available from: https:// wetten.overheid.nl/BWBR0 012410/2018-08-01.

4. KNMG, The role of the physician in the voluntary termination of life. A KNMG (Royal Dutch Medical Association) position paper, KNMG, Editor. Utrecht: KNMG (Koninklijke Nederlandse Maatschappij voor Geneeskunde; 2011.

5. RTE. Year reports 2010-2018 of the regional evaluation commissions euthanasia (RTE). 2018 [cited 2020 8 May]; Available from: https://www.euthanasiecommissie.nl/de-toetsingscommissies/jaarverslagen.

6. KNMG. Euthanasie in cijfers (euthanasia in figures). [infographic] 2019 [cited 2020 8 May]; Available from: https://www.knmg.nl/advies-richtlijnen/dossiers/euthanasie.htm.

7. Landeweer M. Radeloze Joop (81): Soms loopt de urine langs haar enkels (Distraughted Joop: Sometimes her urine drops down her ankles). Rotterdam: Algemeen Dagblad (Dutch newspaper); 2016. Avail- able from: https://www.ad.nl/gezond/radeloze-joop-81-soms-loopt- urine-langs-haar-enkels~af8145d5/

8. Grooters, L. Drie inzichten uit de Leeuwenhoektour (Three insights from 'the Leeuwenhoek tour'). 2018 [cited 2020 8 May]; Available from: https:// www. human. nl/ in- de- leeuw enhoek/ lees/ inzic hten- tour. html.

9. Working together to tackle dementia. 2017 [cited 2020 8 May]; Available from: https:// www. gover nment. nl/ latest/ news/ 2017/ 05/ 16/ worki ng- toget her- inter natio nally- to-tackle- demen tia

10. Nederland, A. Factsheets cijfers en feiten over dementie. (fact sheets dementia figures and facts). 2019 [cited 2021 March 8]; Available from: https:// www. alzhe imer- neder land. nl/ facts heet- cijfe rs- en- feiten- over- demen tie.

11. Van Twillert, M. Meer mensen hebben schriftelijke wilsverklaring (a grow-ing number of people have a written advance directive). Medisch contact 2018 [cited 2020 8 May]; Available from: https:// www. medis chcon tact. nl/ nieuws/ laats te- nieuws/ artik el/ meer- mensen- hebben- schri fteli jke- wilsv erkla ring. htm.

12. Schuurmans J, et al. Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study. BMC Med Ethics. 2019;20(1):66.

13. Schuurmans J, et al. Dutch GPs' experience of burden by euthanasia requests from people with dementia: a quantitative survey. BJGP Open. 2021;5(1).

14. Schuurmans J, et al. Supporting general practitioners around euthanasia requests from people with dementia: nominal group meetings. BJGP. 2020;70(700):e833–e841

15. Kouwenhoven PSC, et al. Developments in euthanasia practice in the Netherlands: balancing professional responsibility and the patient's autonomy. Eur J Gen Pract. 2019;25(1):44–8.

16. de Nooijer K, et al. Written advance euthanasia directives in mentally incompetent patients with dementia: a systematic review of the litera-ture. Ned Tijdschr Geneeskd. 2017;161:D988.

17. Kouwenhoven PS, et al. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. BMC Med Ethics. 2015;16:7.

18. KNMG. Handreiking schriftelijk euthanasieverzoek (guideline written advanced euthanasia directive). 2015 [cited 20r21 March 8]; Available from: https:// www. rijks overh eid. nl/ docum enten/ broch ures/ 2015/ 12/ 17/ handr eiking- schri fteli jk- eutha nasie verzo ek-artse nvers ie.

19. Miller DG, Dresser R, Kim SYH. Advance euthanasia directives: a controver-sial case and its ethical implications. J Med Ethics. 2019;45(2):84–9.

20. Asscher ECA, van de Vathorst S. First prosecution of a Dutch doctor since the euthanasia act of 2002: what does the verdict mean? J Med Ethics. 2019;46(2):71–5.

21. Telegraph, T. Dutch euthanasia doctor cleared over death of dementia patient 2019 [cited 2019 October 31]; Available from: https:// www. teleg raph. co. uk/ news/ 2019/ 09/ 11/ dutch- eutha nasia- doctor- clear ed- death- demen tia- patie nt/.

22. Annual Report 2017 Dementia Cases in the Netherlands.
eutha nasie commi ssie. nl/ the- commi ttees/ docum ents/ publi catio ns/ annual- repor ts/ 2002/ annual- repor ts/ annual- repor ts.
2011 versus BODE and the COPD comorbidity index COTE.
Thorax. 2014;69(9):799–804.

23. Schuurmans J, et al. Supporting GPs around euthanasia
requests from people with dementia: a qualitative analysis of
Dutch nominal group meetings. Br J Gen Pract.
2020;70(700):e833–42. Med.

24. KNMG. Conceptrichtlijn 'Uitvoering euthanasie en hulp bij zelfdoding' open voor commentaar (concept guideline 'Euthanasia and assisted suicide' open for commentary). 2020 [cited 2021 June 6]; Available from: https:// www. knmp. nl/ actue el/ nieuws/ nieuws- 2020/

25. Dworkin RH. Life's dominion. An argument about abortion, euthanasia, and individual freedom. New York: Knopf; 1993.

26. De Rozemond K. rampzalige invloed van Ronald Dworkin op het Neder-landse euthanasierecht. Netherlands J Legal Philosophy. 2020;1:95–103.

27. Strikwerda-Brown C, et al. "All is not lost"-rethinking the nature of memory and the self in dementia. Ageing Res Rev. 2019;54:100932.

28. Gillick MR. Doing the right thing: a geriatrician's perspective on medi-cal care for the person with advanced dementia. J Law Med Ethics. 2012;40(1):51–6.

29. Association), K.R.D.M. KNMG-project euthanasie bij dementie (KNMG pro-ject euthanasia for persons with dementia). 2021; Available from: https:// www. knmg. nl/ actua liteit- opinie/ belei dspro gramm as/ passe nde- zorg- in- de-laats te- leven sfase/ knmg- proje ct-eutha nasie- bij- demen tie. htm.

30. Petty S, et al. Emotional distress with dementia: a systematic review using corpus-based analysis and meta-ethnography. Int J Geriatr Psychiatry. 2018;33(5):679–87.

31. Lloyd-Williams M, Mogan C, Dening KH. Identifying palliative care needs in people with dementia. Curr Opin Support Palliat Care. 2017;11(4):328–33.

32. Dixon J, Karagiannidou M, Knapp M. The effectiveness of advance care planning in improving end-of-life outcomes for people with dementia and their Carers: a systematic review and critical discussion. J Pain Symp-tom Manag. 2018;55(1):132–150 e1.

33. United Nations, H.R.C. Concluding observations on the fifth periodic report of the Netherlands 2019 [cited 2021 March 8]; Available from: http:// docst ore. ohchr. org/ SelfS ervic es/ Files Handl er. ashx? enc= 6QkG1d% 2FPPR iCAqh Kb7yh srU3m lYiFH tCrYP BecWJ aXYxW 2vO2d aSC4q% 2BBvH NhI0Y Lma4m 6RVsc 0uaEER% 2B1Vx iDyrR zWXoZ hY7iK NWVkb oF4Sw mFU56 BWQrp mCMsj 3qeJ.

34. van Baarsen B. Een schriftelijke wilsverklaring is nog geen euthanasiev-erzoek. Misverstanden bij de interpretatie van wetsartikel 2 lid 2 Wtl (a written advance directive is not a euthanasia request; misconceptions in the interpretation of article 2, clause 2 of the termination of life on request and assisted suicide act, the Netherlands). Nederlands Juristen Blad. 2020;95(2):314–21.

35. van Baarsen B. De toetsing van euthanasie: zorgen om kwaliteit, argu-mentatie en normontwikkeling. Tijdschrift voor Gezondheidszorg Ethiek. 2018;28(3):79–87.

36. Spronk B, Widdershoven G, Alma H. Addressing harm in moral case deliberation: the views and experiences of facilitators. BMC Med Ethics. 2020;21(1):10.

37. Health, M.o. Kamerbrief over aanpak geestelijke verzorging (Parliamen-tary piece about spiritual care). 2018 [cited 2020 8 May]; Available from: https://www.rijksoverheid.nl/docum enten/kamerstukken/2018/10/08/kamerbrief-over-aanpak- geestelijke-verzorging-levensbegeleiding.

38. de Torres JP, et al. Prognostic evaluation of COPD patients: GOLD 2011 versus BODE and the COPD comorbidity index COTE. Thorax. 2014;69(9):799–804.

39. Hasselaar JG, et al. Dealing with delicate issues in continuous deep sedation. Varying practices among Dutch medical specialists, general practitioners, and nursing home physicians. Arch Intern Med. 2008;168(5):537–43.

40. Kouwenhoven PS, et al. Euthanasia or physician-assisted suicide? A survey from the Netherlands. Eur J Gen Pract. 2014;20(1):25–31.

CHAPTER 5B

EUTHANASIE BIJ VERGEVORDERDE DEMENTIE, MENINGEN VAN HUISARTSEN IN NEDERLAND.

DUTCH VERSION OF THE ORIGINAL PAPER, SHORTENED AND TRANSLATED IN DUTCH FOR THE GENERAL MEDICAL AUDIENCE OF ALL DUTCH PHYSICIANS. NED. TIJDSCHR. GENEESKD.;2022;166:D6647

DUTCH VERSION OF THE ORIGINAL PAPER, SHORTENEDAND TYRANSLATED IN DUTCH FOR THE GENERAL MEDICAL AUDIENCE OF ALL DUTCH PHYSICIANS: EUTHANASIE BIJ VERGEVORDERDE DEMENTIE, MENINGEN VAN HUISARTSEN IN NEDERLAND. NED. TIJDSCHR GENEESKD.;2022;166:D6647

Euthanasie bij vergevorderde dementie*
Meningen van huisartsen in Nederland

JAAP SCHUURMANS, CHANTALLE CROL, BOUDEWIJN CHABOT, MARCEL OLDE RIKKERT EN YVONNE ENGELS

Een euthanasieverzoek van patiënten met gevorderde dementie vraagt van huisartsen veel voorbereiding en is in de uitvoering vaak complex. Daarbij geeft de mogelijkheid van juridische of tuchtrechtelijke nasleep extra spanning. Een goede voorbereiding en uitvoe- ring van een dergelijke euthanasieprocedure vragen daarom gedegen kennis van en ervaring met de medische, communicatieve, juridische en ethische aspecten. In de praktijk ontstaan er toch vaak onzekerheden, dilemma's en twij- fels.

Met dit onderzoek wilden we te weten komen hoe huisartsen oordelen over hun kennis van en de omgang met de zorgvuldigheidseis van ondraaglijk en uitzichtloos lijden bij euthana- sieverzoeken van mensen met een vergevor- derde dementie. Ook onderzochten we wat hun persoonlijke opvattingen zijn ten aanzien van dergelijke euthanasieverzoeken.

Methode

Het onderzoek bestond uit een vragenlijst die wij eerder ontwikkelden en valideerden in een ander onderzoek. Op basis van randomisatie selecteerden wij 894 huisartsen uit de database van het Nederlands Instituut voor Onderzoek van de Gezondheidszorg (NIVEL); wij beschouwden deze groep huisartsen als een representatieve steekproef. Begin 2019 ver- stuurden we per post een vragenlijst met ant- woordenvelop aan de geselecteerde huisart- sen. Na 3 weken stuurden we een herinnering. Het beantwoorden van de 25 vragen besloeg plusminus 15 minuten. De hoofdbevindingen van dit onderzoek zijn eerder gepubliceerd.

In de huidige publicatie behandelen we het deel van de vragenlijst dat betrekking heeft op de zorgvuldigheidscriteria en de wilsverkla- ring. Verder bespreken we de reactie van de huisartsen op een fictieve casus (zie kader 'Casus'), die wij aan hen voorlegden. De huis- artsen kregen daarbij 4 vragen of stellingen die zij konden beantwoorden met 'ja', 'nee' of 'misschien'. Daarnaast konden zij hun ant- woord toelichten in een vrij tekstveld.

CASUS

Deze casus is een voorbeeld van een van de vragen uit het beschreven onderzoek. Deze situatie is fictief.

Dhr. Smit is 62 jaar en dement. Hij herkent zijn vrouw en kinderen niet meer, weigert te eten en trekt zich steeds meer terug. Het is niet meer mogelijk om met hem te praten over zijn behandeling. 10 maanden geleden heeft hij – toen nog wilsbekwaam – een schriftelijke euthanasieverklaring opgesteld, waarin hij wenst dat zijn leven beëindigd wordt wanneer hij dement is. De familie dringt erop aan de euthanasie nu te voltrekken op grond van zijn wilsverklaring en zijn uitzichtloos en ondraaglijk lijden. De huisarts acht de patiënt wilsonbekwaam, vindt het lijden invoelbaar en is ervan overtuigd dat zijn schriftelijke wilsverklaring een mondeling verzoek kan vervangen. De geconsulteerde SCEN-arts en consulent specialist ouderenzorg beamen dit. De euthanasie wordt uitgevoerd, voorafgegaan door orale toedie- ning van kalmerende medicatie om te voorkomen dat zich onvoorspelbaar gedrag, onrust of een schrikreactie voordoet waarbij hij weg zou kunnen lopen. De regionale toetsingscommissie nodigt de arts uit om toelichting te geven.

*Dit onderzoek werd eerder gepubliceerd in BMC Fam Pract (2021;22:232) met als titel ‘Euthanasia in advanced dementia; the view of the general practitioners in the Netherlands on a vignette case along the juridical and ethical dispute’. Afgedrukt met toestemming.
Gerelateerd artikel: Commentaar van Bert Keizer.

Tabel

	Totaal aantal antwoorden	Ja n (%)	Nee n (%)	Misschien N (%)
1. Vindt u het handelen van de arts in deze situatie juist?	388	178 (45.8)	210 (54.1)	–
2. Een schriftelijke wilsverklaring kan het mondeling verzoek vervangen als communicatie met de betrokkene onmogelijk is.	412	76 (18.4)	178 (43.2)	158 (38.3)
3. De familie kan als belangenbehartiger van betrokkene het initiatief nemen de euthenasieprocedure te beginnen.	414	95(22.9)	209 (50.4)	110 (26.5)
4. Voorafgaand aan de euthanasie mag kalmerende medicatie worden toegediend.	396	181 (45.7)	126 (31.8)	89 (22.4)

Resultaten

Van de 894 huisartsen retourneerden 422 (47%) onze vragenlijst. Een ruime meerderheid van de respondenten (82%) gaf aan dat zij bij een wilsonbekwame patiënt het criterium uitzichtloos en ondraaglijk lijden moeilijk kunnen beoordelen. Meer dan de helft van de huisartsen (58%) vond een wilsverklaring onvoldoende relevant wanneer de angst voor toekomstig lijden niet gelijk is aan het lijden op dat moment (tabel).

Meer dan de helft van de respondenten (54%) vond dat de arts in de casus niet juist had gehandeld. Bovendien twijfelden veel huisartsen (38%) of de schriftelijke wilsverklaring een mondeling verzoek wel kan vervangen bij ernstige communicatieve problemen door een vergevorderde dementie. De helft van de respondenten vond dat de familie niet automatisch het recht heeft om de euthanasieprocedure op te starten. Bij deze vraag werd het vaakst gebruikgemaakt van de mogelijkheid om extra toelichting te geven. Met name gaven de huisartsen de volgende opmerkingen: ‘dit kan alleen als ik betrokkene en familie goed ken’, ‘als betrokkene in een wilsverklaring opgesteld gedurende wilsbekwaamheid ook de familie heeft geautoriseerd’, ‘als de familie ook aanwezig is geweest bij eerder gevoerde gesprekken’, en ‘als er geen sprake is van belangenverstrengeling en er geen druk wordt uitge- oefend’.

Beschouwing

Uit ons onderzoek blijkt onder huisartsen grote variatie te bestaan in de houding ten aanzien van de uitvoering van euthanasie bij mensen met dementie in een vergevorderd stadium. Veel huisartsen blijken persoonlijke grenzen te stellen aan de uitvoering die niet overeenkomen met juridische en professionele kaders. Een eerdere interviewstudie onder specialisten ouderengeneeskunde en huisartsen en een onderzoek onder experts lieten zien dat huis- artsen veel druk ervaren bij de euthanasieprocedure, niet alleen vanuit de patiënt en de familie, maar ook vanuit de samenleving.

Ons onderzoek voegt aan de bestaande kennis toe dat een meerderheid van de huisartsen met name moeite heeft met het ‘elastische’ begrip ‘ondraaglijk lijden’ en dat meer dan de helft zich niet kan vinden in de prominente rol die wordt gegeven aan de wilsverklaring bij patiënten met dementie in een vergevorderd stadium. Momenteel worden euthanasieprocedures achteraf getoetst door de regionale commissies. De vraag is of bij complexe casuïstiek ook voorafgaand aan de euthanasie een vorm van toetsing of moreel beraad mogelijk en wenselijk is.

De verstrekkende reikwijdte van de wilsverklaring zoals deze in Nederland gestalte heeft gekregen, wordt inmiddels juridisch betwist op grond van mensenrechtenverdragen en het Verdrag voor de rechten van personen met een handicap. Volgens het VN-Comité voor de rechten van personen met een handicap mag de schriftelijke wilsverklaring niet worden gebruikt om het beslissingsrecht van patiënten over te dragen aan anderen. Dit verdrag is bedoeld om mensen met een handicap te hel- pen om zelf te beslissen. Op grond van het Verdrag inzake de rechten van personen met een handicap, waar ook mensen met gevorderde dementie onder vallen, zijn deze personen handelingsbekwaam in ‘alle aspecten van het leven’. Dat betekent dat zij ook het beslissings- recht hebben over de toediening van premedicatie. De huidige euthanasieprocedure mag daarom volgens een aantal juristen niet zonder toestemming worden uitgevoerd.

Een sterk punt van dit onderzoek is de hoge respons, waardoor er sprake is van een repre- sentatieve steekproef. Hierdoor is het aannemelijk dat de uitkomst van ons onderzoek de visie van de Nederlandse huisarts in het algemeen benadert. De hoge respons verklaren we doordat huisartsen stress ervaren rond dit onderwerp. Die stress werd nog vergroot doordat tijdens het onderzoek in de media veel aandacht werd besteed aan 'de koffie-euthanasiezaak'.

De belangrijkste beperkingen van de studie zijn dat we huisartsen naar hun mening hebben gevraagd en niet naar hun gedrag. Ook was de fictieve casus noodgedwongen veel minder gedetailleerd dan een echte praktijkcasus.

De onderzoeksresultaten zijn direct relevant voor de praktijk, omdat de KNMG en de Nederlandse wetgever inmiddels juist meer ruimte hebben gegeven aan euthanasie bij mensen met dementie. Nadere analyse van de grote praktijkvariatie en de afstand tussen de praktijk en de regelgeving is daarom belangrijk en urgent.

– Online artikel en reageren op ntvg.nl/D6647
– Huisartsenpraktijk Ottenhoff, Groesbeek: drs. J. Schuurmans, huisarts. Radboudumc, Nijmegen: Afd. Huisartsgeneeskunde: drs. C. Crol, haio. Afd. Geriatrie: prof.dr. M. Olde Rikkert, geriater. Afd. Anesthesiologie, Pijn en Palliatieve Geneeskunde: prof.dr. Y. Engels, gezondheidswetenschapper. Dr. B. Chabot, ouderenpsychiater niet praktiserend.
– Contact: J. Schuurmans (jschuurmans@praktijkottenhoff.nl) – Belangenconflict en financiële ondersteuning: er zijn mogelijke belangen gemeld bij dit artikel. ICMJE-formulieren met de belangenverklaring van de auteurs zijn online beschikbaar bij dit artikel.
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OORSPRONKELIJK ARTIKEL

Schuurmans J, et al. Euthanasia in advanced dementia; the view of the general practitioners in the Netherlands on a vignette case along the juridical and ethical dispute. BMC Fam Pract. 2021;22:232.

DUTCH VERSION OF THE ORIGINAL PAPER, SHORTENEDAND TYRANSLATED IN DUTCH FOR THE GENERAL MEDICAL AUDIENCE OF ALL DUTCH PHYSICIANS: EUTHANASIE BIJ VERGEVORDERDE DEMENTIE, MENINGEN VAN HUISARTSEN IN NEDERLAND. NED. TIJDSCHR GENEESKD.;2022;166:D6647

REDACTIONEEL

Lijden voorspel je niet

Yvo Smulders

Rachel is mijn oudste dochter. Nooit zo'n studiebol geweest. Via het mbo is ze in de intramurale verzorging van dementerende ouderen terechtgekomen. 'Je bent noodzakelijker dan ik, of ten minste gewilder', pleeg ik te zeggen wanneer ze zich beklaagt over haar carrière.

'Rachel, is het moeilijk om te zien of iemand die ernstig dement is lijdt?', vraag ik na het lezen van de drukproeven van D6647, blz. 8 en D6751, blz. 12. 'Nee hoor', zegt ze achteloos, 'alleen de dokters kunnen dat niet. Wij wel, wij zien ze dag en nacht.' Ik was verkocht. Perfect antwoord van mijn ongestudeerde liefste.

'We zijn op een dwaalspoor geraakt met de wilsverklaring'

In het onderzoek (D6647, blz. 8) staat, tot mijn opluchting, dat huisartsen veel moeite hebben met de juridische status van de schriftelijke anticiperende wilsverklaring. Ik voeg 'anticiperende' toe, omdat deze wilsverklaringen niet aangeven wat je wilt, maar wat je denkt te gaan willen wanneer het puntje bij het paaltje komt. In 2017 schreef ik al over gevoels- en wilsvoorspelling (ntvg.nl/B1389). Maakt u zich geen illusie, mensen kunnen dat niet; ik niet, u niet, uw vroeg dementerende moeder niet, niemand. Het voorspelde ondraaglijk lijden zou daarom niet moeten tellen. De wilsverklaring getuigt er slechts van dat iemand geen principiële bezwaren heeft tegen actieve levensbeëindiging. Ook handig om te weten, maar echt iets anders dan een agenda voor tijdig sterven.

Net als Bert Keizer denk ik dat het vaststellen van lijden bij ernstig demente mensen helemaal niet zo moeilijk is (D6751, blz. 12). Wat je daarvoor nodig hebt zijn ogen en oren die bedraad zijn met een gezonde, niet per se geleerde, geest. Net als bij Rachel. Je ziet lijden in het dagelijks leven, niet in je wekelijkse ronde als instellingsarts. Je kunt het er ook vast over eens worden, ook – of misschien zelfs vooral – zonder criteria of scorelijsten. Waardoor zijn we met de wilsverklaring zo op een dwaalspoor geraakt? Dat heeft te maken met de fundamentalistische heiligverklaring van autonomie en de juridisering van alles in het kielzog daarvan. Daardoor beëindigen we soms het leven van mensen die niet lijden, omdat ze ooit dachten dat wel te zullen doen.

Ik heb ook een wilsverklaring: ik wil alleen wat ik wil, niet wat ik vermoed te gaan willen. En als ik willoos word, dan wil ik dat mijn naasten zich over mij ontfermen.

DUTCH VERSION OF THE ORIGINAL PAPER, SHORTENEDAND TYRANSLATED IN DUTCH FOR THE GENERAL MEDICAL AUDIENCE OF ALL DUTCH PHYSICIANS: EUTHANASIE BIJ VERGEVORDERDE DEMENTIE, MENINGEN VAN HUISARTSEN IN NEDERLAND. NED. TIJDSCHR GENEESKD.;2022;166:D6647

COMMENTAAR

Euthanasie bij gevorderde dementie: het ongemak blijft

BERT KEIZER

Onder bepaalde voorwaarden is euthanasie mogelijk bij mensen met dementie die wilsonbekwaam zijn geworden op het moment van hun doodswens. De wilsverklaring speelt hierbij een belangrijke rol. Maar wat erin moet staan is onduidelijk. Het inschatten van ondraaglijk lijden bij gevorderde dementie wordt naar mijn mening ten onrechte als moeilijk ervaren. Tot mijn verrassing vindt een aanzienlijk percentage huisartsen dat bij de uitvoering de wil van de patiënt mag worden uitgeschakeld met ‘premedicatie’.

Een van de weinige constanten in de Nederlandse euthanasiepraktijk is de continue toevloed van nieuwe kandidaten. We gingen van terminaal ziek, naar chronisch ziek, naar psychiatrische beelden, toen naar beginnende dementie, toen stapeling van ouderdomsklachten en ten slotte naar gevorderde dementie. Bij deze laatste categorie patiënten is het niet zozeer het ziektestadium dat problemen veroorzaakt, als wel de wilsonbekwaamheid ten aanzien van hun doodswens. Het is immers zo dat iemand die gevorderd dement is, heel goed in staat kan zijn een samenhangende doodswens te uiten. Daar staat tegenover dat sommige mensen met beginnende dementie in dit opzicht het stuur al heel snel kwijt zijn.

‘Bij kinderen die niet praten kunnen we heel goed inschatten hoe ze zich voelen’

Schriftelijke wilsverklaring

In de euthanasiewet heeft altijd al gestaan dat de schriftelijke wilsverklaring het mondelinge verzoek kan vervangen. Juristen wezen er graag op. Artsen gingen het graag uit de weg. De reden is niet erg ingewikkeld. Als wilsonbekwaamheid geen probleem is dan mag je, met de wilsverklaring in de hand, het leven van een ziek mens beëindigen, ongeacht wat de man of vrouw in kwestie op dat moment wil.

Over de inhoud van de wilsverklaring wordt gretig, maar vruchteloos getobd. Vrijwel iedereen schrijft dat ene symptoom op dat er niet toe doet: ‘Als ik mijn vrouw, man, kinderen, broer, zus niet meer herken, dan wil ik euthanasie.’ Het doet er niet toe, omdat de meeste dementen niet lijden onder dit verlies. Ze denken dat de broeder hun vader is of zien hun dochter aan voor hun zus. Of ze zien niemand meer voor iemand aan. Die falende persoons herkenning is een vreselijke lijdensbron voor de omstanders, maar niet voor de demente rende. Het enige wat je in je wilsverklaring moet opschrijven is: ‘als ik doodongelukkig ben in mijn dementie’.

Ondraaglijk en uitzichtloos lijden

Een verrassende uitslag van het onderzoek van Schuurman en collega’s is dat 82% van de ondervraagden het moeilijk vindt om de criteria van ondraaglijk en uitzichtloos lijden in te schatten. Verrassend, omdat dementie duidelijk uitzichtloos is. En wat het lijden van wilsonbekwame dementen betreft, hoe moeilijk kan het zijn om dat te zien? De vrouw die dag en nacht wanhopig naar haar man loopt te zoeken. De man die angstig onder zijn bed probeert te kruipen, die gaat schreeuwen als je hem wil wassen, die nooit van zijn kamer af wil. De vrouw die urenlang op klagerige toon blijft roepen ‘Ik wil naar bed, ik wil naar bed, help me toch in bed’, terwijl ze in bed ligt.
Dat er geen verbale communicatie meer mogelijk is, betekent niet dat je iemands geestelijke toestand niet kunt inschatten. Bij kinderen die het niet goed of helemaal niet kunnen verwoorden, weten we heel goed in te schatten of ze ongelukkig zijn.

In het fictieve voorbeeld dat de onderzoekers gebruikten staat dat de heer Smit vrouw en kinderen niet meer herkent (daar heb je ’t weer), zich terugtrekt en niet eet. Vervolgens staat er dat de huisarts het lijden invoelbaar vindt. Vreemd, want er is geen lijden geschetst. Wat moeten we met meneer Smit als hij, voorgoed weg van vrouw en kinderen, teruggetrokken op zijn kamer, niet etend, de hele dag met zichtbaar plezier naar oude films zit te kijken? Kennelijk is hij niet ongelukkig.

Premedicatie

De uitvoering blijft bij wilsonbekwamen een probleem. Je doet die mensen iets aan, de dood namelijk, zonder dat zij dat beseffen. Om te voorkomen dat ze het wel beseffen, en dan op de loop gaan, zorg je dat ze dat niet kunnen door een sterk slaapmiddel te geven. Dit opzettelijk uitschakelen van de wil wordt aangeduid met het eufemisme ‘premedicatie’. Tot mijn verrassing vindt 45,7% van de huisartsen dit goed en vindt 22,4% dit ‘misschien’ wel goed.

‘Mensen met dementie lijden er zelf niet onder dat ze niemand herkennen’

Ik dacht tot voor kort: dit gaat echt niemand goed vinden. Maar het onderzoek van Schuurmans en collega’s toont aan dat een aanzienlijk percentage huisartsen hier wel in mee kan. Ik denk niet dat deze praktijk zal veranderen door een beroep op regels van het VN-comité voor de rechten van personen met een handicap. Het lijkt nogal gewrongen om deze regels op wilsonbekwame dementen toe te passen. De categorie waar het om gaat wordt daar beschreven als personen die handelingsbekwaam zijn in ‘alle aspecten van het leven’, iets wat beslist niet geldt voor de patiëntencategorie waarover we hier praten.

Dement, niet zonder meer wilsonbekwaam

Inmiddels blijf ik zitten met een uitspraak van de specialist ouderengeneeskunde die betrokken was bij ‘de koffie-euthanasie’. In het jaarrapport 2016 casus 85 vermeldt de Regionale Toetsingscommissie Euthanasie over haar handelen in de laatste minuten: ‘Patiënte was niet wilsbekwaam, haar uiting was op dat moment voor de arts niet relevant. Zelfs als patiënte op dat moment zou hebben gezegd: “Ik wil niet dood”, had de arts de levensbeëindiging verder uitgevoerd.’ Dit is niet consequent. Wilsonbekwaamheid moet altijd gerelateerd worden aan een bepaalde vraag of procedure. Ook de diep demente halfbewuste delirante patiënt is wilsbekwaam als het gaat om de vraag of hij of zij een brandende sigaret tegen zijn of haar huid wenst. Alleen een comateuze patiënt is zonder meer wilsonbekwaam. Het feit dat deze collega overweegt om een patiënt die zegt niet dood te willen toch de dood in te sturen op basis van de wilsverklaring, is de nauwelijks te verteren uitkomst van de euthanasiewet zoals die nu geïnterpreteerd wordt. Juristen zullen terecht zeggen: ‘Maar het stond er altijd al.’ Helaas lijkt het erop dat artsen er niet langer overheen willen lezen.

- Online artikel en reageren op ntvg.nl/D6751
- drs. B. Keizer, arts.
- Contact: B. Keizer (keizer47@gmail.com)
- Belangenconflict en financiële ondersteuning: geen gemeld. – Aanvaard op 30 maart 2022
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CHAPTER 6

GENERAL DISCUSSION

General Discussion

In this thesis, in which qualitative and quantitative methods were used, we explored how euthanasia requests of patients with dementia impact Dutch general practitioners (GPs)

Main Findings

Using in-depth interviews, we explored the impact of euthanasia requests from patients with dementia (PWD) on Dutch GPs and elderly care physicians. (Chapter 2)

In this first study we interviewed eleven physicians with a wide variety of experience with euthanasia requests from PWD. Difficulties they experienced were:

- High workload,
- Pressure from relatives of such patients,
- How to relate to society's negative view on dementia in combination with the 'right to die' view,
- Interpreting the euthanasia law and advance euthanasia directives (AEDs),
- Ethical considerations,
- Communication about this topic with PWD and relatives,
- And, if willing to perform euthanasia in a specific PWD, deciding on the right time to perform it.

Interviewees showed a larger variety of opinions than was found in a [similar] study more than a decade ago [1]. Most participants mentioned the negative view of Dutch society on dementia and the process of dying of PWDs, which was phrased by Allan Kellehear as 'shameful' dying: 'Dementia …. will deny most of us a good death or even a well-managed one' [2]. Furthermore, some participants argued that the societal influences they experienced also result from our culture's emphasis on autonomy and the view that euthanasia is synonymous with dignified dying. Kouwenhoven et al. also found this increased emphasis on the patient's wish for autonomy as the primary basis for euthanasia [3]. Indeed, in a recent large national survey, maintaining autonomy was in the top three end-of-life aims among the Dutch population [4].

Interviewees experienced both negative and positive emotions when confronted with a euthanasia request from a PWD. They mentioned feelings of insecurity, frustration, anger, moral distress, isolation and the feeling of being judged by society. Positive emotions they mentioned were being in control, satisfaction, relief and even heroism.

Participants use different forms of support when dealing with euthanasia requests from PWD. They mentioned using existing support services such as

SCEN (support and consultation during euthanasia procedures), consulting a palliative care team, or deliberating with colleagues. In addition, they experienced emotional support from their own family. Some of these forms of support were also cited in a study on complexities in euthanasia in general as perceived by Dutch physicians and relatives [5].

Based on the findings described in Chapter 2, we explored forms of support for GPs confronted with euthanasia requests from PWD by using the nominal group technique with a group of experts. (Chapter 3)

In terms of forms of support, four main themes were identified and prioritized:

- Support provided by health care professionals was considered most important - not only in a short, consultative way as available at the time of the study (by SCEN physicians and by the 'Expertise centrum Euthanasie'); GPs also expressed the wish for the opportunity to apply for a more long-term form of assistance. This is in line with a previous study, which recommended that physicians who deal with euthanasia requests be aware of their own needs. (6) A recent study that focused specifically on support for GPs and other physicians in recognizing sources of pressure recommended investment in support for the doctors and ways of guiding them towards adequate use of sources of support [7].
- Influencing the public opinion, as public opinion is biased and several aspects of euthanasia and dementia are widely misinterpreted, such as 'euthanasia is a right', 'dementia always means suffering' and 'a nursing home is terrible'.
- Educational activities (e.g., about dealing with AED, euthanasia legislation and the disease course of dementia). Due to the wide variety of reasons and aims people have for drafting an AED, the patient and physician should always discuss the AED in detail [8].
- Managing time and work pressure. Within this theme, four concrete suggestions were emphasized:
    - a Offering a buddy who would be available for the physician throughout the entire decision-making process
    - b Moral case deliberation. Although this is not yet very common, when a spiritual caregiver is asked to guide such a deliberation, this is now financed by the spiritual care division of the primary care programme of the ministry of health.
    - c One or more consultations with a spiritual caregiver for emotional and moral guidance [9].
    - d Developing and disseminating a brochure in layman's terms about the different aspects related to euthanasia in PWDs, including legislation clarification.

With the help of a survey, we quantified both the burden of the euthanasia practice for PWDs among Dutch GPs as well as the GPs' need for support. (Chapter 4)

Almost 500 GPs responded. Among the most burdensome issues mentioned were the emotional burden, pressure from relatives and patients, uncertainties about regarding mental competence assessment, and dealing with AEDs. The latter two came up significantly more often 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 previously when it concerned a PWD procedure or a euthanasia request. Most often, respondents mentioned needing more support from a SCEN physician, a geriatric consultation team, a palliative care consultation team or the expert centre for euthanasia.

About half of those who would not consider euthanasia for PWDs would always refer such a patient to a colleague or to the Dutch expert centre for euthanasia. Indeed, in 2017, of all euthanasia cases, 11.3% were performed by this national expert centre for euthanasia; when it concerned PWDs, this figure was 44.4% [10].

About half of the GPs estimated that they receive and discuss one or more AEDs per month, in which euthanasia is often brought up due to future prospects of dementia. 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.

The high percentage of GPs that experience euthanasia or euthanasia requests by PWDs as emotionally burdensome confirms findings from recent qualitative studies on this topic [11,12]. The high percentage of GPs that would like to be supported by a SCEN physician, a geriatric consultation team, a palliative care expert or the expert centre for euthanasia, is in accordance with the findings in Chapter 3 [13]. In this quantitative study, moral deliberation or spiritual counselling were hardly mentioned by the respondents, probably due to the unfamiliarity with such services.

The fact that respondents expressed a need for more support from a SCEN physician than they had experienced in the past is remarkable, considering that consulting a SCEN physician is obligatory in each euthanasia procedure. 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 [14] .

With the help of a case vignette, we quantitatively studied the views of GPs (Chapter 5)

As described in Chapter 4, a case vignette was shared as part of the survey. After having read this case vignette, which was based on the recent Dutch juridical case around euthanasia in a patient with advanced dementia (PWAD), only one out of five GPs agreed that an AED can replace an oral request in PWADs and that the family can initiate the euthanasia procedure. One-third of the GPs in our study had objections to sedation prior to performing euthanasia, even though this is allowed according to the Dutch guideline on the performance of euthanasia [15].

Several elements of the first legal case, where the physician was accused of murder, were integrated into our fictitious case vignette. This case was well-known by all Dutch physicians, as a lot of media attention had been given to it. Our findings quantitatively confirm those from a 2015 Dutch interview study, in which many physicians considered euthanasia in PWAD problematic, both legally and personally [16]. In that interview study, physicians were reluctant to forgo adequate verbal communication with the patient, because they wished to verify the voluntariness of a patient's request, and the unbearableness of the actual suffering, and thus considered an AED of limited value in PWAD.

The Dutch law does not give restrictions on euthanasia in PWAD if it is performed according to the obligatory due care criteria. In our study the majority of GPs (54%) judged the doctor's action in the vignette case as not right. Recently, the supreme court in The Hague gave clearance and no punishment in the actual case on which our case vignette was based [17]. The argumentation of the Court is mainly based on the concept of 'precedent autonomy' and 'continuity of person', whereby the self-determination to be respected was made at the time the person in question was still competent. This argumentation is in line with the views of philosopher of law, Ronald Dworkin. Dworkin emphasizes that critical interests – expressed or observed by the patient, and as coded in the AED – should take precedence over experiential interests [18]. However, according to legal philosopher Rozemond, this shows an overestimation of rational faculties of the human mind [19]. Rozemond doubts whether the previously competent self can legally prevail over the present, more or less incompetent self, which is commonly referred to as the "then-self-versus now-self" problem.

When stating that the family can initiate the start of a euthanasia procedure representing the interests of the patient in question (in case this patient is no longer able to confirm such a previously documented wish), nearly a quarter of the GPs agreed, half of them disagreed, and a quarter of them answered 'maybe'. In the open text box, GPs added explanations like: 'this is only an option if I know the family and patient well'; 'if the patient has authorized this family member earlier when he or she was still mentally capable', or 'if the family participated in earlier conversations about euthanasia and if there is no pressure from relatives or conflict of interest'. Finally, two out of five GPs thought an AED cannot replace an oral request if communication with the patient in question is impossible. Only one out of five think that it can replace it.

Consequences of our studies in a broader view

Globally, in 2016, it was already estimated that there were 36 million people living with dementia and that it would rise to 66 million by 2030 [20]. The World Health Organisation (WHO) also recognises that people with dementia continue to receive inadequate support and care towards the end of their lives [21]. Although PWADs have complex physical and psychological needs, the disease is not always recognised as terminal by health and social care practitioners. (22) While the importance of palliative care for people with dementia is recognised globally, a coordinated palliative care philosophy, including ACP, is lacking [23-25]. The WHO describes ACP as a discussion about preferences for future care between an individual and their next of kin and a care provider in anticipation of deterioration in the person's condition [26]. Therefore, each chapter of this thesis shows the importance of timely ACP for these vulnerable persons, albeit with a focus on different but related aspects. ACP is seen by the International Court of Human Rights as a legal, binding document that records decisions made while a person has the capacity to make decisions regarding the treatment and care that he/she should be given in the event of becoming incapacitated. Several international conventions approve not only the right to give consent, but also the right to withdraw consent [27,28]. People with early dementia and an AED might come to adapt and shift their views regarding what constitutes a good quality of life as the disease progresses. Besides, some older people may choose to avoid discussing the potential needs or their preferences for future treatment and how these should be addressed. Several studies already highlighted the complex challenges that we, as a society, face in providing a supportive approach to people with dementia nearing the end of their lives [29,30]. The supported decision-making regime of Article 12 of the Convention on the Rights of Persons with Disabilities (CRPD) requires that in case of mental incapacity, people still have legal capacity and decision-making rights when it comes to euthanasia [31].

Worldwide, euthanasia has been legalized in the Netherlands, Belgium, Luxembourg, Canada, the states of Victoria and Western Australia in Australia, New Zealand and Spain. Physician-assisted suicide (PAS) is legal in Switzerland and in eight states of the USA. In Switzerland assisted suicide is also available for non-Swiss residents. Recently, in 2021, Germany decriminalized assisted suicide, and in France, the government recently invited a panel of 150 members of the public to begin discussing whether or not to adopt legislation-assisted dying. Debates about the legalization of euthanasia or PAS are ongoing in many more countries and there are surveys showing increased support for euthanasia and PAS from different countries across the world [32,33]. The Dutch law regarding euthanasia and advanced dementia is, in this respect, not only medical and ethical but also juridical, which makes it a unique and thus scientifically and societally interesting case.

The studies in this thesis show the impact of Dutch law on GPs within a society where euthanasia is regarded as lawful in the case of advanced dementia. Although the Supreme Court ruling has confirmed a physician's interpretation of the law, our studies show that GPs are very divided in their moral judgement regarding this interpretation. A recently published analysis of 111 case studies in dementia in the Netherlands (between 2012 and 2020) confirms our findings that many more ethical questions arise in practice: the researchers arrived at seven questions [that will be handled in this paper] [34]. Interestingly, there is considerable unexplained variation in euthanasia prevalence between Dutch regions [35].

Finally, several difficult ethical questions regarding the model of proxy decision making remain underexposed, such as: what are the limitations of using interpreters when it concerns sensitive decision-making regarding euthanasia in PWADs?

Methodological considerations

Our first study (Chapter 2) involved both GPs and elderly care physicians, the groups of professionals most frequently confronted with euthanasia requests by PWD. We explored the impact of euthanasia requests from PWDs on Dutch GPs and elderly care physicians using in-depth interviews. Although we included physicians with a wide variety of opinions and experience on this topic and tried to provide a broad perspective, the majority of participants had signed the critical statement about euthanasia in persons with advanced dementia [36]. This might have caused a selection bias, of which we were aware but which was not a great problem here as we aimed for purposive sampling to include physicians with opposite opinions. Nevertheless, although saturation was reached, interviewing just a small number of physicians on such a sensitive issue and the selection bias may have caused us to miss essential information.

We chose the nominal group technique (NGT) for the study in Chapter 3, as it is a structured and evaluative method for obtaining group consensus and is often used to generate, clarify and prioritize ideas and /or solutions around a specific topic within a small-group discussion [37,38]. The inclusion of a multidisciplinary group of experts, including healthcare professionals (e.g., elderly care physicians, GPs), legal experts, an ethicist and researchers, is one of the main strengths of this study. The fact that they all had a professional background related to this topic provided a broad perspective.

However, this study also had some limitations. Even though we invited several politicians, no politician participated. Besides, group dynamics and the absence of anonymity might have influenced the responses and discussions [39]. The last phase of the NGT process consisted of prioritising the generated forms of support. Some experts felt reluctance when prioritising improvements for euthanasia practice, due to the different aspects of the generated solutions. While the study aimed to find different types of support needed by GPs in dealing with the moral dilemmas of euthanasia in PWD, the small number of participating GPs warrants further research in a larger cohort of Dutch GPs.

Our questionnaire study (Chapters 4 and 5) 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 emphasises GPs' high involvement in this topic, as other surveys among Dutch GPs mostly had much lower response rates (around 30%) [40,41]. Although the respondents were representative for the Dutch GP population regarding age, gender and region, response bias was possible [42].

Another limitation is that the survey was not a validated questionnaire. However, the basic questionnaire relied on two previous studies and a literature review, and we adapted it after having received feedback from six experts. Besides, we asked GPs for their opinion and not for their behaviour. Next, the fictitious case was, for practical reasons, much less detailed than a real practical case.

Finally, all our studies involved Dutch GPs, and the Netherlands is a country where GPs have a patient list, are gatekeepers for secondary care and where a euthanasia law exists.

Implications and recommendations for policy, clinical practice, education and research

Recommendations for policy

Chapters 2 and 3 make clear that in Dutch society there is an increasing focus on euthanasia 'as a right'. Consequently, performing euthanasia is often seen as a doctor's duty. For that reason, it is the duty of GPs to communicate clearly with their patients and their family on this topic. More importantly, this has policy implications in a much broader sense on public information from the professional organisation itself.

All chapters indirectly endorse the importance of ACP. Reimbursement to enable and support the GPs to have sufficient time to fully discuss end-of-life issues, including euthanasia, is highly necessary, especially for vulnerable people. The possibility to consult SCEN physicians and possibly even to ask the regional committees for evaluation prior to enacting euthanasia should be considered to allow improvement of quality of care and lower the burden of work and related work stress for GPs in this respect.

GPs experience a lack of legal, moral and medical clarity regarding AEDs in the Royal Dutch Medical Association (KNMG) euthanasia guidelines of 2015. The 2021 update again gives hardly any information about the content requirements of an AED. We recommend the KNMG to give more thought to the juridical implications of such a document in the broader international juridical view.

Recommendations for clinical practice

Physicians express their concern regarding the tendency to cross their own personal boundaries. They are in need of emotional support, moral guidance and care. We recommend that intervision groups should be used to evaluate the burdening experiences in euthanasia related palliative care.
In Chapter 3, experts expressed not only the need for support provided by other professionals in a short consultative way, but also the possibility of a more long-term form of assistance. Examples they mentioned were a buddy who is available for the physician throughout the entire euthanasia decision-making process, or support by taking part in regular meetings of GPs and nurses on proactive palliative care.

Recommendations for education and training

During the in-depth interviews documented in Chapter 2, a ‘culture of non-disclosure’ of the dementia diagnosis was found. This needs attention, as GPs still find it challenging to initiate ACP while the number of requests will continue to grow. In several studies, training with actors simulating patients appeared effective [30,43]. Therefore, it is of the utmost importance to bring communication with patients with dementia and their family to the centre of attention in the GP curriculum and post-academic training. In addition, training and education in the disease course of dementia, on AEDs and on communication with PWD is needed.

Recommendations for future research

It would be interesting to conduct an international comparison of our qualitative research findings on end-of-life care provided by GPs for persons with dementia, as cultural, medical and legislation differences may result in diverse end of life care questions in dementia care.
The questionable practice of giving premedication before giving a lethal injection in patients with advanced dementia has been adopted by nearly half of the Dutch GPs as an acceptable practice, but requires careful scientific evaluation with methods fitting these special situations.
Pressure from relatives concerning dealing with euthanasia requests as specifically coming forward in Chapters 2 and 3 needs much more ethical reflection on the role of “interpreters” (the model of proxy decision making)

regarding AEDs and euthanasia in patients with advanced dementia. This needs further exploration, specifically with qualitative methods.
Although the Supreme Court ruling has attempted to make the interpretation of the law clear, Chapter 5 shows that GPs vary in their moral judgement regarding this law interpretation. There is an urgent need to create much more space for ethical review before the euthanasia performance instead of just after it has taken place.

Expiry dates of AEDs are very much dependent on monitoring differences in the patient’s context and existential view on life quality, as these can shift. There is a need for further research, specifically in PWDs, to gain insights into basic neuro-scientific, biological, psychological and philosophical views on our ‘consciousness regarding end-of-life issues’ and their translation into the juridical and medical implications on ‘capacity of decision making’. These are major challenges that need further exploration, continuous ethical reflection and discussion.

References

1. de Boer ME, Droes RM, Jonker C, Eefsting JA, Hertogh CM. Advance directives for euthanasia in dementia: how do they affect resident care in Dutch nursing homes? Experiences of physicians and relatives. J Am Geriatr Soc. 2011;59(6):989-96.

2. Kellehear A. A Social History of Dying. Cambridge: Cambridge University Press; 2007.

3. de Boer A, de Klerk M. Informele zorg in Nederland. Een literatuurstudie naar mantelzorg en vrijwilligerswerk in de zorg. Den Haag: Sociaal en Cultureel Planbureau; 2013.

4. van der Velden A, Engels Y, Nanninga M, Francke A, Fritsma J, Boddaert M, et al. What Matters Most for the Dutch Public in Palliative Care: A Survey2018. e107 p.

5. Snijdewind MC, van Tol DG, Onwuteaka-Philipsen BD, Willems DL. Complexities in euthanasia or physician-assisted suicide as perceived by Dutch physicians and patients' relatives. J Pain Symptom Manage. 2014;48(6):1125-34.

6. van Marwijk H, Haverkate I, van Royen P, The AM. Impact of euthanasia on primary care physicians in the Netherlands. Palliat Med. 2007;21(7):609-14.

7. Kouwenhoven PSC, van Thiel GJMW, van der Heide A, Rietjens JAC, van Delden JJM. Developments in euthanasia practice in the Netherlands: Balancing professional responsibility and the patient's autonomy. The European journal of general practice. 2019;25(1):44-8.

8. van Wijmen MP, Pasman HR, Widdershoven GA, Onwuteaka-Philipsen BD. Motivations, aims and communication around advance directives: a mixed-methods study into the perspective of their owners and the influence of a current illness. Patient Educ Couns. 2014;95(3):393-9.

9. Instellingen DUSa. Palliatieve terminale zorg en geestelijke verzorging 2023 [Available from: https://www.dus-i.nl/subsidies/palliatieve-terminale-zorg.

10. KNMG. Euthanasie in cijfers (Euthanasia in figures) [Infographic]. Utrecht: KNMG 2019 [Available from: https://www.knmg.nl/advies-richtlijnen/dossiers/euthanasie.htm.

11. Schuurmans J, Bouwmeester R, Crombach L, Van Rijssel T, Wingens L, Georgieva K, et al. Euthanasia in Dementia Cases; what are experiences and needs of Dutch physicians? A qualitative interview study. [Accepted for publication in BMC Medical Ethics]. In press 2019.

12. de Boer ME, Depla M, den Breejen M, Slottje P, Onwuteaka-Philipsen BD, Hertogh C. Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners. Journal of medical ethics. 2019.

13. Schuurmans J, Vos S, Vissers P, Tilburgs B, Engels Y. Supporting GPs around euthanasia requests from people with dementia: a qualitative analysis of Dutch nominal group meetings. Br J Gen Pract. 2020;70(700):e833-e42.

14. Deandrea S, Montanari M, Moja L, Apolone G. Prevalence of undertreatment in cancer pain. A review of published literature. Ann Oncol. 2008;19(12):1985-91.

15. KNMG. Conceptrichtlijn ‘Uitvoering euthanasie en hulp bij zelfdoding’ open voor commentaar (Concept guideline 'Euthanasia and assisted suicide' open for commentary) Utrecht: KNMG; 2020 [Available from: https://www.knmp.nl/actueel/nieuws/nieuws-2020/conceptrichtlijn-2018uitvoering-euthanasie-en-hulp-bij-zelfdoding2019-open-voor-commentaar.

16. Kouwenhoven PS, Raijmakers NJ, van Delden JJ, Rietjens JA, van Tol DG, van de Vathorst S, et al. Opinions about euthanasia and advanced dementia: a qualitative study among Dutch physicians and members of the general public. BMC Med Ethics. 2015;16:7.

17. Asscher ECA, van de Vathorst S. First prosecution of a Dutch doctor since the Euthanasia Act of 2002: what does the verdict mean? Journal of medical ethics. 2019.

18. Dworkin RH. Life's dominion. An argument about abortion, euthanasia, and individual freedom. New York: Knopf; 1993.

19. Rozemond K. De rampzalige invloed van Ronald Dworkin op het Nederlandse euthanasierecht. Netherlands Journal of Legal Philosophy. 2020;1.

20. International AsD. Overcoming the stigma of dementia. 2012.

21. Organisation WH. Dementia a public health priority Geneva, Switzerland: WHO; 2012.

22. Evans CG, C. End of Life Care for Older People with Dementia Living in a Care Home. Journal of Integrated Care. 2008;16(6):15-26.

23. Gott M, Ibrahim, A.M., Binstock, R.H. The disadvantaged dying: ageing, ageism and palliative care provision for older people in the UK. M Gott, & C Ingleton (Eds). 2011; Living with ageing and dying

24. Houttekier D, Cohen J, Bilsen J, Addington-Hall J, Onwuteaka-Philipsen BD, Deliens L. Place of death of older persons with dementia. A study in five European countries. J Am Geriatr Soc. 2010;58(4):751-6.

25. van der Steen JT. Dying with dementia: what we know after more than a decade of research. J Alzheimers Dis. 2010;22(1):37-55.

26. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. Lancet Oncol. 2017;18(9):E543-E51.

27. Rozemond N. Het zelfgekozen levenseinde: Een pleidooi voor het recht van mensen om over hun eigen levenseinde te beschikken. . Leusden: ISVW Uitgevers.; 2021. 220 p.

28. Rozemond N. Euthanasie bij mensen met dementie volgens het supported decision-making regime van artikel 12 van het Verdrag inzake de Rechten van Personen met een Handicap. Handicap & Recht. 2021;6(1):10-6.

29. Busser ST, Rens J, Thoonsen B, Engels Y, Wichmann AB. The GP's perceived role and use of language concerning the existential dimension of palliative patients: a Dutch interview study. BMC Prim Care. 2022;23(1):182.

30. Tilburgs B, Koopmans R, Vernooij-Dassen M, Adang E, Schers H, Teerenstra S, et al. Educating Dutch General Practitioners in Dementia Advance Care Planning: A Cluster Randomized Controlled Trial. J Am Med Dir Assoc. 2020;21(6):837-42 e4.

31. United Nations DoEaSAD. Convention on the Rights of Persons with Disabilities (CRPD) [Available from: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-12-equal-recognition-before-the-law.html.

32. Mroz S, Dierickx S, Deliens L, Cohen J, Chambaere K. Assisted dying around the world: a status quaestionis. Ann Palliat Med. 2021;10(3):3540-53.

33. Roehr B. Assisted dying around the world. BMJ. 2021;374: n2200.

34. Groenewoud AS, Leijten E, van den Oever S, van Sommeren J, Boer TA. The ethics of euthanasia in dementia: A qualitative content analysis of case summaries (2012-2020). J Am Geriatr Soc. 2022;70(6):1704-16.

35. Groenewoud AS, Atsma F, Arvin M, Westert GP, Boer TA. Euthanasia in the Netherlands: a claims data cross-sectional study of geographical variation. BMJ Support Palliat Care. 2021.

36. B. Chabot PvL, J. Schuurmans. Niet Stiekem bij Dementie 2019 [Available from: http://www.nietstiekembijdementie.nl/.

37. McMillan SS KF, Sav A, Kendall E, King MA, Whitty JA, Wheeler AJ. Using the nominal group technique: how to analyse across multiple groups. Health Services and Outcomes Research Methodology. 2014;14, 92–108.

38. van Riet Paap J, Vissers K, Iliffe S, Radbruch L, Hjermstad MJ, Chattat R, et al. Strategies to implement evidence into practice to improve palliative care: recommendations of a nominal group approach with expert opinion leaders. BMC palliative care. 2015;14:47.

39. Aspinal F, Hughes R, Dunckley M, Addington-Hall J. What is important to measure in the last months and weeks of life?: A modified nominal group study. Int J Nurs Stud. 2006;43(4):393-403.

40. United Nations HRC. Concluding observations on the fifth periodic report of the Netherlands United Nations; 2019 [Available from: http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhsrU3mlYiFHtCrYPBecWJaXYxW2vO2daSC4q%2BBvHNhl0YLma4m6RVsc0uaEER%2B1VxiDyrRzWXoZhY7iKNWVkboF4SwmFU56BWQrpmCMsj3qeJ

41. van Baarsen B. De toetsing van euthanasie: zorgen om kwaliteit, argumentatie en normontwikkeling. Tijdschrift voor Gezondheidszorg en Ethiek. 2018;28(3):79-87.

42. Spronk B, Widdershoven G, Alma H. Addressing harm in moral case deliberation: the views and experiences of facilitators. BMC Med Ethics. 2020;21(1):10.

43. van Meurs J, Wichmann AB, van Mierlo P, van Dongen R, van de Geer J, Vissers K, et al. Identifying, exploring and integrating the spiritual dimension in proactive care planning: A mixed methods evaluation of a communication training intervention for multidisciplinary palliative care teams. Palliat Med. 2022;36(10):1493-503.

CHAPTER 7A

SUMMARY / SAMENVATTING

Summary

In the introduction of this thesis - Chapter 1 - a global current picture and future expectations are shared regarding dementia and the role of primary care. It outlines the developments surrounding euthanasia legislation in the Netherlands. This thesis will focus on requests for euthanasia by patients with advanced dementia and what this means for their general practitioners. It is divided into four chapters where four individual researched questions focus on different aspects regarding euthanasia for patients with advanced dementia, exploring the thought processes, its limitations and the need for support to benefit general practitioners.

In Chapter 2, we present the results from our in-depth interview study. Euthanasia in dementia places an ethically and emotionally heavy burden on elderly care physicians and GPs in the Netherlands. The majority of the participants wished for more clarification of their professional guidelines. Existing useful support mechanisms, such as moral deliberation and support from chaplains are available for elderly care physicians. The awareness of, and access to, such support for GPs needs further exploration. Apart from the legal perspective, the interpretation of 'unbearable suffering' and 'competence' for people unable to express themselves needs more debate from psychological and ethical perspectives.

In Chapter 3, we present further research to identify ways of supporting physicians confronted with requests for euthanasia in PWD. As part of our research, we performed a qualitative consensus study using the nominal group technique (NGT). Four themes of forms of support were identified and prioritized, namely: (1) support provided by healthcare professionals, which was considered most important, (2) influencing the public opinion, (3) educational activities, and (4) managing time and work pressure. Four concrete examples were emphasized: the possibility of a buddy who is available for the physician throughout the entire decision-making process, moral case deliberation, a spiritual care provider for emotional-moral guidance for the confronted physician and a brochure in layman's terms about the different aspects related to euthanasia in PWD including legislation clarification.

In Chapter 4 we set out how we tried to gain quantitative insights into the problems and needs of physicians confronted with euthanasia requests in general and in PWD, with the help of a survey. Almost 500 GPs responded. 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.

In Chapter 5, we carried out a further exploration of the answers on the survey, with a focus on the views of GPs confronted with an advance euthanasia request from a person with advanced dementia. The vast majority of the responding GPs experienced difficulties adequately judging the obligatory care criteria of the patients' unbearable suffering with no prospective improvement. Even though euthanasia, on the basis of a previous AED, is now possible by law for persons with advanced dementia in the Netherlands, only a minority of GPs support this.

In Chapter 6, I discussed the main findings, made methodological considerations and provided recommendations for policy, practice, education and training and future research.

Samenvatting

In het eerste hoofdstuk, wordt uitleg gegeven aan de opbouw van dit proefschrift. Het concentreert zich voornamelijk op vraagstukken rondom euthanasie bij patiënten met dementie en wat dat betekent voor hun huisartsen. Uit ons onderzoek blijkt onder huisartsen grote variatie te bestaan in de attitude t.a.v. uitvoering van euthanasie bij mensen met een vergevorderde dementie. Veel huisartsen blijken persoonlijke grenzen te stellen aan de uitvoering die niet overeenkomen met juridische en professionele kaders.

In hoofdstuk twee, wordt gerapporteerd over een interviewstudie bij specialisten ouderengeneeskunde en huisartsen over de impact die de euthanasievraag door een patiënt met demente op de behandelend arts (huisarts of specialist ouderengeneeskunde) heeft. De meerderheid van de artsen gaf aan meer duidelijkheid te wensen in de professionele richtlijnen. Opvallend is dat specialisten ouderengeneeskunde bij dit soort complexe besluitvormingsprocessen gebruik maken van moreel beraad, vaak ondersteund door een geestelijk verzorger. Onder huisartsen zou de mogelijke onbekendheid en beschikbaarheid van deze ondersteuning onderwerp van nader onderzoek moeten zijn. Los van de juridische-medische interpretatie zou ondraaglijk lijden en wils(on)bekwaamheid verder psychologisch en ethisch verder onderzoek behoeven.

In hoofdstuk drie, presenteren we ons vervolgonderzoek naar ondersteuning voor huisartsen die bij patiënten met dementie geconfronteerd worden met de vraag naar euthanasie. Middels een tweetal nominal group bijeenkomsten met diverse deskundigen werden een viertal vormen van ondersteuning benoemd; (1) ondersteuning door zorgprofessionals, (2) maatschappelijke opvattingen over euthanasie trachten te beïnvloeden, (3) onderwijs- en trainingsactiviteiten en (4) omgang met tijd- en werkdruk. Diverse concrete voorbeelden werden genoemd zoals het beschikbaar stellen van een buddy gedurende het gehele proces van bespreking en aanvraag tot eventuele uitvoer van euthanasie bij patiënten met dementie. Maar ook het faciliteren van moreel ethisch beraad. Het verbeteren van toegankelijkheid tot ondersteuning van een geestelijk verzorger. Publiekelijke verduidelijking in heldere en eenvoudige taal omtrent de mogelijkheden en onmogelijkheden omtrent het verzoek tot euthanasie bij dementie.

In hoofdstuk vier, wordt ons vragenlijstonderzoek onder een representatieve groep van bijna 500 Nederlandse huisartsen gepresenteerd. Dit onderzoek toont aan dat veel huisartsen emotionele belasting en onzekerheid ervaren rondom het verzoek tot euthanasie bij patiënten met dementie, met name bij de beoordeling van de wilsbekwaamheid, de vooraf opgestelde wilsverklaringen, en druk van naasten en familie. Ook wordt door een groot aantal huisartsen aangegeven behoefte te hebben aan meer professionele ondersteuning en verbetering van praktische en kennisvaardigheden rondom dit thema.

In hoofdstuk vijf, gaan we in op een specifiek onderdeel van deze vragenlijst aangaande vragen over de zorgvuldigheidscriteria en de wilsverklaring bij mensen met dementie met een euthanasieverzoek. We legden tevens een fictieve casus voor, met mogelijkheid van reflectie in een vrije tekstveld. Veel huisartsen vonden dat een schriftelijke wilsverklaring een mondeling verzoek niet kan vervangen bij ernstige communicatieproblemen door vergevorderde dementie. De helft van de respondenten vond dat de familie, als wettelijk vertegenwoordiger van de patiënt, niet automatisch het recht heeft de euthanasieprocedure op te starten. Bij deze vraag werd het meest gebruik gemaakt van de mogelijkheid om extra toelichting te geven. Met name gaven de huisartsen de volgende opmerkingen: “dit kan alleen als ik betrokkene en familie goed ken”, “als betrokkene in een wilsverklaring opgesteld gedurende wilsbekwaamheid ook de familie heeft geautoriseerd”, “als de familie ook aanwezig is geweest bij eerder gevoerde gesprekken”, en als “er geen sprake is van belangenverstrengeling en er geen druk wordt uitgeoefend”. Uit ons onderzoek blijkt onder huisartsen grote variatie te bestaan in de attitude t.a.v. de uitvoering van euthanasie bij mensen met vergevorderde dementie. Veel huisartsen blijken persoonlijke grenzen te stellen aan de uitvoering die niet overeenkomt met juridische en professionele kaders.

In hoofdstuk zes, bediscussieer ik de belangrijkste onderzoekresultaten en wordt de onderzoeksmethodologie besproken. Tot slot worden aanbevelingen gedaan naar de politiek, de professionele praktijk, het onderwijs en onderzoek.

CHAPTER 7B

DATA MANAGEMENT

Data management

This thesis is based on the results of human studies, which were conducted in accordance with the principles of the Declaration of Helsinki. The medical ethics Committee on Research Involving Human Subjects the Netherlands East considered each study as not subject to the Medical Research Involving Human Subjects Act and gave approval to start the studies.

The studies in this thesis were performed without external funding.

For the qualitative studies in chapters 2, 3, 6 and 7 audio-taped data were used. Audio recordings were transcripted and stored and analyzed in ATLAS-ti, licensed under Radboudumc. For chapters 2 and 3, data are stored at the departments h-disc Researchzin/2018. Data of chapters 6 and 7 are stored at the department's h-disc Ecovid-20 YE.

The survey for the quantitative data (as described in chapters 4 and 5) were send to general practitioners and after completion send back on paper. Paper data were stored at Anes_research_archief / Researchzin/2018. Hard copies of the studies are archived at UTS VERKROOST Nijmegen BV ; Bijsterhuizen 11-31 6546 AR Nijmegen.
Data were entered in Castor and after closing the data set uploaded in SPSS and stored at the departments h-disc Researchzin/2018.

Privacy of the participants in all studies is warranted by use of encrypted and individual subject codes. To keep confidentiality, all data were stored anonymously.

All data are only accessible by project members and the research management of the department of anaesthesiology, and will be saved for 15 years after closure of the study.

Datasets analysed during the studies are available from the corresponding author on reasonable request. Requests can be made via Onderzoek.anes@radboudumc.nl.

CHAPTER 7C

Dankwoord

Dankwoord

Allereerst gaat mijn dank uit naar mijn ouders die ik nooit toe liet bij diploma uitreikingen, maar nu dan wel want dit voelt toch anders en ze hebben mij en mijn broers (Wytze, Jan) en zussen (Margreet, Akke en Hanneke) veel liefde en steun gegeven. Mijn moeder heeft met haar Master Engels taalkundig steun gegeven.

De afgelopen jaren heb ik als huisarts en onderzoeker veel steun ondervonden van mijn geliefden: de kinderen Eva en Jan Brecht, de kleinkinderen, mijn ex echtgenote Saskia en mijn vastberaden vriendin Fatima.

Alle mede auteurs, vaak destijds nog student van diverse studierichtingen dank ik voor hun enthousiasme en hulp op vele wijzen.

Yvonne Engels wil ik danken voor het aanreiken van de mogelijkheid om verdiepende studies te doen. We hebben elkaar al lang voor haar hoogleraarschap leren kennen en ik ben blij met al haar kennis en ervaring en enorm vertrouwen. Zonder haar lag dit boekje er niet.
Marcel Olde Rikkert, je intrigeerde me al tussen de honderden eerste jaar studenten. Je bent voor mij een autoriteit binnen de Geneeskunde en een voorvechter van wat Geneeskunst genoemd wordt op zowel de inhoud als de uitvoering en ik ben trots dat je samen met Yvonne mijn promotor wilt zijn.

Dank aan alle andere leden van het Doctoral Examination Board, in het bijzonder de leescommisie onder voorzitterschap van Maria van den Muijsenbergh.

Dank aan de vele huisartsen en co assistenten en deskundigen met andere achtergrond zoals verpleegkundigen geestelijk verzorgers, psychologen sociologen en onderzoekers die meeliepen binnen de praktijk of op afstand betrokken waren en zijn.

Speciale dank aan Radboud Honours Academy, de studenten die in het kader van een extra master programma hieraan deelnamen en aan de onderzoeken hebben bijgedragen en de mede auteurs.

Mijn Engelse vriend Tim Padley heb ik in nagedachtenis als ondersteuner inhoudelijke en taalkundig, zijn vrouw Nicki heeft me inhoudelijk en taalkundig dit jaar erg geholpen. Ik mis Tim, zijn sigaren en ons contact waarin we elkaar met humor konden spiegelen over ons werk.

Bert Ummelen ik mis je als vriend, mede auteur en discussie slijpsteen.

Ben Koopmans je bent de huisarts zoals ik die graag aan mijn sterf bed heb, maar die kans krijg je nog niet.

Dank gaat uit naar alle team leden van het palliatief consultatie team Nijmegen en omgeving, het huisartseninstituut Nijmegen de mede bestuursleden van de Landelijke Huisartsen Opleiders Vereniging en de mede redacteuren van E Pal (palliaweb.nl).

Boudewijn Chabot dank voor je vertrouwen, je betrokkenheid, je kennis, en analyses rondom het levenseinde op verzoek. We leerden elkaar pas echt kennen bij mijn eerste confrontatie met euthanasie op het grensvlak van al of niet wilsbekwaamheid bij en patiënte met dementie.

Ik heb velen niet bij naam genoemd, maar ben ieder zeer dankbaar die bijgedragen heeft om tot dit eind resultaat te komen. Mag ik ervanuit gaan dat hierdoor geen onderlinge band geschaad zal zijn?

CHAPTER 7D

A PERSONAL ODYSSEY BASED ON THIS RESEARCH

A personal odyssey based on this research

Not wanting to avoid the personal aspect but also not wanting to write a biography, I have given myself some freedom in this reflective epilogue.

After some wanderings as an assistant surgeon in Groningen and Tilburg and a job at the Integral Cancer Centre in Enschede, I specialised in pain management theory. This was followed by an in-depth study of palliative care and general medicine, first in England and later in the Netherlands. Both during my work at St Luke's Hospice in Plymouth and during my work in acute geriatrics I gained much depth in practicing medicine. This certainly had something to do with the fact that I worked on the borderline between life and death without a conspiracy of silence. At the same time, I observed how support among professionals can be shaped by open reflection discussions and/or moral deliberations. And, of course, good team leadership to make this possible.

Back in the Netherlands in 1995, I worked for almost a year in a nursing home and worked during the weekends as a locum GP. During this year I put up a lot of interest towards the first palliative care initiatives in the Netherlands: nursing home and hospice Antonius Ijsselmonde of Frans Baar in Rotterdam, hospice Kuria of Corry van Tol-Verhagen and Wouter Zuurmond in Amsterdam and hospice Rozenheuvel in Arnhem of Ben Zylicz. During a visit to a European palliative conference in Barcelona, I met medical oncologist and palliative care specialist Stans Verhagen. A man who, in addition to intelligence and knowledge, also had had many profound life experience. As an independently practising GP in Groesbeek, starting the 1st of January 1996, I put many ideals into the organisation of palliative and elderly care. I participated in establishing the regional palliative care consultation team by the Integral Cancer Centre East. We also worked on national guidelines and publications issued by the National Association of Integral Cancer Centres. I contributed to the first training of palliative care physicians supported by the Dutch General Practitioners Association and grounded the Dutch Palliative Care Physicians Foundation. At that time the discussion about euthanasia was still very black and white: palliative care as a body of thought fitted very well within the Dutch legislation, but there was a substantial lack of knowledge, especially among doctors, about basic knowledge concerning pain management and other medical interventions and possibilities to combat other unpleasant symptoms. In 2004, on my initiative and in collaboration with Stans Verhagen, we published the first Dutch guideline distinguishing palliative sedation from euthanasia. With my general practice team, I increased our efforts to proactively set up an elder care programme. We also introduced a method to evaluate home deaths in our practice, as a continuous quality improvement method to improve future care for the elderly. In doing so, we demonstrated our ability to support an above-average number of people dying at home.

In addition to my work as a GP and palliative care consultant, I initiated two projects with an editor and journalist friend, Bert Ummelen. The first was the founding of the internet magazine Holosbulletin.nl, in which my current supervisors Yvonne Engels and Marcel Olde Rikkert were involved as editors. From July 2016 till September 2019 we released 21 editions. This magazine was merged with E-pal after the death of Bert Ummelen. We aimed to break through the rigid way of thinking of separate specialities; geriatrics, geriatric specialists, and palliative teams. GPs are characterised by transcending generalist thinking where diagnostic thoughts occur in parallel with a symptom review. Secondly, we wanted to better inform individual patients, their families and next of kin about what care looks like ideally in the palliative phase. We achieved this by publishing the booklet 'What NOW? Guide for those Facing Incurable Diseases.' The lack of a primary care service for moral and ethical reflection that institutions do have, which I would ideally have liked to see in the complex case presented as an example, has inspired me to continue with scientific research and creating awareness in national media. In my general practice, we have been using a spiritual counsellor for many years now. We see it as a proven tool for organising moral and ethical reflection, as a support for patients and their families, and as a support for individual staff members.

In my proloque, I outline an exceptional experience. Namely, the provision of euthanasia at the interface of the patient's legal capacity or lack of ability to make such a decision. The KNMG's professional guideline on euthanasia in dementia was silently amended in 2015. The coffee euthanasia case was given an oppressive character by the editorial and editorial comment of de Volkskrant on 6 January 2017, partly due to the NVVE, whose director Robert Schurink stated, "People sign such a living will with complete conviction, but as soon as they pass the point of legal competence, doctors suddenly no longer want to do so." The opinion article in de Volkskrant, by Boudewijn Chabot, was co-signed by many prominent ethicists, geriatricians and GPs. That was reason enough to mobilise more stakeholders, and we started the action 'not sneaky with dementia' initiated in an interview in Trouw and supported by a website. Within a week, we managed to raise enough money, through the support of more than 450 donating doctors (everyone donated 100 euros), to be able to place three full page advertisements in the newspapers Trouw, NRC and Volkskrant. The remaining funds were donated to Anne Mei The's research group. In the advert, we deliberately chose to make it of a solid moral and condemnation nature and thus provoking a lot of debate in the media at home and abroad, in the professional press, and within politics. This resulted in parliamentary questions, followed by an official hearing of field experts in the Dutch Parliament.

We received an overwhelming number of responding emails from doctors, especially from GPs and elderly care physicians, in which they shared their experiences and feelings: how they were weighed down by both social pressure and pressure exerted by individual patients and/or their relatives. This aroused my curiosity, and thanks to Yvonne Engels, in recent years, the opportunity presented itself to delve deeper into the matter through academic research, training and this dissertation. This is not based on moral judgements, but on a genuine and increasingly keen curiosity about what is happening in this field, socially, legally and within the medical profession.

During the surveys and writing the Covid pandemic came up. I originally thought of a second part of the thesis. The second part would focus on the consequences of this regarding advanced care planning and the ethical backgrounds regarding hospital references towards General Practitioners. The connection between the subjects needed explicit explanation, so this part is left out. The overarching theme of my research is medicine when it confronts death. It is still Medicine’s implicit mission to defeat death when a doctor meets a patient with life threating disease. How to deal with these imminent decisions when death is near.

CHAPTER 7E

CURRICULUM VITEA

Curriculum Vitae

Personalia

Naam en voornaam:	Schuurmans, Jaap
Adres:	Burg. Ottenhofstraat 16, 6561 CM Groesbeek
Geboorteplaats en geboorte datum:	Geleen, 17 maart 1961
Nationaliteit:	Nederlandse
Burgerlijke staat:	Ongehuwd, twee kinderen. Partner Fatima Abdesslem

Opleiding

- 1979 en 1981 Eindexamen Havo en VWO, Rijksscholengemeenschap te Epe
- 1986 Doctoraal examen Geneeskunde aan Rijksuniversiteit Groningen
- 1989 Arts examen 23 februari na co- assistentschappen in Stichting Deventer ziekenhuizen
- 1989 Bedrijfseconomie voor non profit organisaties, Rijksuniversiteit Groningen (examen)
- 1991 Epidemiologie, Erasmus universiteit Rotterdam (examen)
- 1992 Inleidende milieukunde, Open Universiteit (examen)
- 1994 Huisartsenexamen Universiteit Exeter, Engeland. GMC registratie Engeland 3623338. 1994 Huisartsen BIG registratie Nederland no 29023831501
- 2000 Geregistreerd als opleider t.b.v. opleiding tot huisarts (voor onbepaalde termijn)
- 2004 CHBB registratie als palliatief specialist.
- 2008 Post Academische 1 jarige Opleiding Existentiële Psychotherapie te Nijmegen (dr. Kalmthout en drs. Huygevoort)
- 2011 CHBB registratie als Erkend Kwaliteitsconsulent, in 2016 t/m 2022
- 2013 en 2014 Inleiding in de Filosofie aan de Open Universiteit deel I en II (examens)
- 2015 Ethiek, Open Universiteit.(examen)
- 2015 Inleiding Cultuurgeschiedenis, deel I en II Open Universiteit (examens)
- 2016 Argumentatieleer., Open Universiteit (examen)
- 2017 Geschiedenis van de middeleeuwen, Open Universiteit (examen)
- 2019 Promovendus onderzoeker bij Radboud UMC beoogde promotie 2023

Werkervaring

- 1989 Assistent chirurgie niet in opleiding, Academisch ziekenhuis Groningen
- 1989-1990 Assistent chirurgie niet in opleiding, Maria ziekenhuis Tilburg
- 1990-1992 Coördinator eerste lijn; initiëren en uitvoeren projecten op het gebied van kanker voor het Integraal Kankercentrum Enschede
- 1992-1993 Assistentschappen in palliatieve geneeskunde, acute geriatrie en -oncologie, Derriford Hospital te Plymouth (UK).
- 1994 Huisartsenopleiding gedurende een jaar te Plymouth (UK).
- 1995 Een jaar werkzaam in het Verpleeghuis te Raalte (revalidatie psychogeriatrie - en somatische revalidatie afdeling)
- 1996-heden Fulltime praktijk houdend huisarts, van een “universitaire praktijk” en “NHG geaccrediteerde praktijk” te Groesbeek, 3100 patiënten. Het team bestaat uit een huisarts in dienstverband gedurende drie dagen in de week, twee praktijkondersteuners (totaal 1.5 FTE op gebied van diabetes, CVRM astma, COPD, ouderenzorg en GGZ) en vier assistentes (3 FTE), een co assistent en een huisarts in opleiding (zowel eerste- als derde jaars).

Nevenwerkzaamheden

- 1997- 2012 Lid van de medische beroepsgroep van Amnesty International, tweemaal in het jaar verrichtte ik onder auspiciën van de Nederlandse medische beroepsgroep een juridisch medisch onderzoeksrapportage, welke een rol speelt in de juridische asiel procedure.
- 1996-1998 Consulent Palliatieve zorg bij Intergraal Kankercentrum Enschede
- 1999- nu Consulent Palliatieve zorg OPZ Nijmegen in dienst van het Integraal Kankercentrum Oost, tegenwoordig IKNL. Regionaal wordt door de OPZ artsen een 24 uur bereikbaarheid verzorgt. Werkzaamheden bestaan uit telefonische en bed side consultaties (gemiddeld 600 consultaties op jaarbasis) zowel binnen de eerste - als tweede lijn. Het multidisciplinair team bestaat uit een geestelijk verzorger, psycholoog, verpleegkundige, ethicus, oncoloog en huisarts/ verpleeghuisarts.
- Gedurende 2009, 2010 en 2011 ben ik als onderzoeker verbonden geweest aan het UMC St Radboud en als waarnemend consulent bij het IKO te Nijmegen, sedert januari 2012 weer in vaste dienst. Er zijn met regelmaat intervisie bijeenkomsten.
- Oprichter en sedertdien voorzitter van de Nederlandse Associatie Palliatief arts Consulenten (NAPC) t/m 2008. In dit kader zijn columns geschreven in Nederlands Tijdschrift voor Palliatieve Zorg (niet opgenomen in publicatie lijst) waar elk kwartaal door NAPC verslag werd gedaan van ontwikkelingen. NAPC is opgegaan in PalHAG, Huisartsen Advies Groep Palliatieve zorg als onderdeel van het Nederlands Huisartsen Genootschap.

Docentschap ervaringen

Gedurende de afgelopen jaren heb ik ervaring opgebouwd zowel in de organisatie als in de presentatie van het geven van cursussen, onderwijs, lezingen en dag symposia. Zowel voor kleine als voor grote groepen. Enkele voorbeelden; College Palliatieve zorg voor 4^{e} jaar Geneeskunde studenten. Ik was als docentbegeleider betrokken bij de organisatie en onderwijs va de eerste NHG kadercursus palliatieve zorg, voor de NAPC en recentelijk in 2021 voor het LHOV organiseerde ik dag symposia. Binnen de huisartsenopleiding heb ik betrokkenheid gehad in sporadisch onderwijs en in het verzorgen van een cursus in de tweedaagse nascholing voor huisartsenopleiders. Ik heb lezingen gehouden voor de NVVE, medisch contact congres, het 5 jarig bestaan van de levenseinde kliniek en voor cursus ethiek in de zorgsector. Tevens heb ik aan hoorzittingen meegedaan in parlement België en Nederland. Van 2018 t/m 2020 heb ik als mede docent tweemaal masterstudenten begeleid in hun werkzaamheden voor Radboud UMC Health Academy

Bestuurlijke ervaringen

Voorzitter en oprichter eerste landelijke vereniging voor artsen werkzaam binnen de palliatieve zorg (5 jaar)
Bestuurslid Landelijke Huisartsen Opleiders Vereniging, met ingang van 2018 tot nu

Wetenschappelijke ervaringen

Naast het zelf doen van diverse typen van wetenschappelijk onderzoek en het publiceren daarvan, heb ik diverse master studenten begeleid in het doen van wetenschappelijk onderzoek en hun publicatie. Een aantal keren heb ik artikelen gereviseerd voor Engelstalige 'Peer review' tijdschriften.

Publicaties Nederlands

- Literatuurstudie pijn bij kanker, J. Schuurmans. NVBPijnbulletin nr3, 12^{e} jaargang, 1992
- Pijnanamnese lijst voor wijkverpleegkundigen; de extramurale pijnvragenlijst, J. Schuurmans, A. Wulferink, H. de Boer. Nederlands Vlaams wetenschappelijk tijdschrift voor verpleegkundigen. 8^{e} jaargang nr1,1993
- Pijn bij kanker, opvattingen van verpleegkundigen. J. Schuurmans, A wulferink, H. de Boer. Tijdschrift voor Verpleegkundigen nr3, 1993

- Cytostaticumpaspoort voor de patient, J. Schuurmans en N.J. Dam. Medisch Contact nr22 48e jaargang, 1993
- De verpleegkundige pijnrapportage bij kankerpatienten, J. Schuurmans, A. Wulferink. Oncologica, tijdschrift van de vereniging voor oncologie verpleegkundigen, 1993
- Ervaringen in een Engelse hospice, J. Schuurmans. NVB Pijnbulletin 13e jaargang nr4 1993
- Een patiënt met pijn, J. Schuurmans, J. van Roosendaal. Tijdschrift voor verpleegkundigen nr5, 1994.
- Pijn en pijnbestrijding, J. Schuurmans. Tijdschrift voor Huisartsengeneeskunde, jaargang 13, nr. 9, september 1996
- Palliatieve zorg bij dyspneu, J. Schuurmans. Tijdschrift voor Huisartsengeneeskunde, jaargang 16, nr.1, januari 1999
- Psychostimulantia in de thuisbehandeling van de patiënt met een ernstige ziekte, MJT Gerhardus en J. Schuurmans. Nederlands Tijdschrift voor Palliatieve Zorg. 2e jaargang nr.1, 2001
- Parenterale pijnmedicatie, J Schuurmans. Optimale pijnbestrijding bij kanker; nieuwe inzichten. PAOG Heyendael 20 december 2001. ISBN 90 373 06 08x
- Palliatieve zorg . Ingezonden brief. Huisarts en Wetenschap 46(5) mei 2003.
- If you can't make a picnic out of life…, impressie EAPC congres een bijdrage voor Pallium juli/augustus 2003.
- Gevaarlijk terrein, grijs gebied tussen euthanasie en palliatieve sedatie minimaliseren, J. Schuurmans c.s. Medisch Contact 59 nr. 45, 5 november 2004.
- Rouwverwerking bij artsen, H.M. Veldhuis en J. Schuurmans. Nederlands Tijdschrift voor Palliatieve Zorg , 5e jaargang nummer 3, 2004.
- Zingevingvragen in een huisartsenpraktijk, Humanistiek nr.42, 11e jaargang oktober 2010.
- Een zoektocht naar hoe wij ons kunnen verhouden tot weerloos geluk, Humanistieknr.47, 12e jaargang december 2011.
- Het belang van geestelijk verzorger in de eerste lijn, Tijdschrift Geestelijke Verzorging jr 14, 2011, nr. 64
- Bestaansconsulenten binnen eerste lijn behandelteams, abstract en orale presentatie op 8e Vlaams- Nederlands onderzoeksforum palliatieve zorg 23 maart 2012, Rotterdam.
- De dood als exit optie is niet normaal, artikel voor politiek tijdschrift Socialisme en Democratie juni 2012
- Bestaansconsulenten binnen eerstelijns behandelteams: een verborgen vraag en mogelijkheden voor een nieuw aanbod. De Theologie gevierendeeld, annalen van het Thijmgenootschap jaargang 101, 2013 Valkhof Pers.
- De levensbeschouwelijke professional in transitie, Handelingen 2014, nummer 3.
- Euthanasie steeds vaker als exit-optie, Pallium jaargang 17, nummer 1, 2015
- Voorzorg, Pallium jaargang 17, nummer 2, juli 2015
- Nogmaals Tuitjenhorn. Vakblad voor praktijk houdende huisarts, jaar 2 #4-2015
- Spreekuur Huisartsgeneeskunde nr. 7 2015. Kan de huisarts aan de wens van de patiënt voldoen thuis te willen overlijden?
- Ons Trauma, Pallium jaargang 17, nummer 5, november 2015
- Zorg voor stervenden onder de loep. Medisch Contact nr 20 19 mei 2016
- Ontkoker de zorg voor kwetsbare ouderen. Medisch Contact 33-34, 18 augustus 2016
- Euthanasie bij vergevorderde dementie, meningen van huisartsen in Nederland. Ned. Tijdschr. Geneeskd.;2022;166:D6647

Publicities English

- EAPC congres 2006 Venetië; The Charon index; clarification index differentiating palliative sedation from euthanasia and from unspecified hastening of death in end of life decisions.
- EAPC congres 2007 Boedapest; Clarification on decision making in the end of life care; a comparison between different European countries.
- Euthanasia requests in dementia cases; what are experiences and needs of Dutch physicians? A qualitative interview study. BMC Medical ethics 2029 20;66
- Supporting GPs around euthanasia requests from people with dementia. British Journal of General Practice, November 2020
- Dutch GP's experience of burden by euthanasia requests from people with dementia; a quantitative survey. BJGP Open 2020, DOI;10.3399
- Euthanasia in advanced dementia; the view of the general practitioners in the Netherlands on a vignette case along the juridical and ethical dispute, BMC Family Practice 2021 22;232
- The COVID-19 pandemic; A tipping point for advance care planning? Experiences of general practitioners. Palliative Medicine 1-11. 2021
- Making complex decisions in uncertain times; experiences of Dutch GPs as gatekeepers regarding hospital referrals during COVID-19, a qualitative study. BMC Medical Ethics 12, 2021

Opinie artikelen

- Why Britain is still tops for training GPs, J. Schuurmans . Pulse letters April 23, 1994
- Hoe meer artsen van pijnstilling weten, hoe minder euthanasie, J. Schuurmans. Trouw Podium 12 april 1995
- De kunst om waardig te sterven, J. Schuurmans. Dagblad Trouw, de Verdieping 7 november 2000. Opgenomen in 'Als de dood voor het lijden', Trouw dossier NL nr.11 Rainbow pocketboeken juli 2001, ISBN 90 417 0264 4
- Prinsjesdag. Rubriek brieven Medisch Contact, 55^{e} jaargang nr. 42, 20 oktober 2000
- De kunst van het sterven, euthanasie houdt geneeskunde in de wurggreep, J. Schuurmans. Medisch Contact, 55^{e} jaargang nr47, 24 november 2000
- Omslag in denken artsen over 'goede dood', J. Schuurmans. De Gelderlander 16 november 2001
- Emotionele chantage van artsen is uit den boze, J. Schuurmans. Rubriek brieven. Trouw 21 november 2001
- Uitspraak bakent bevoegdheid arts tot euthanasie af, J. Schuurmans. De Gelderlander Opinie pagina 8 december 2001
- Cultuuromslag onder artsen? J. Schuurmans en R.S. van Coevorden. Rubriek brieven Medisch Contact 57^{e} jaargang nr1, 4 januari 2002.
- België moet leren van Nederlandse fouten. De Standaard, 18 januari 2002.
- Elk ziekenhuis moet palliatief team krijgen. De Gelderlander, 4 maart 2003
- Verlichting van het lijden is doel van terminale sedatie. De Gelderlander, 28 juni 2003
- Artsen moeten helder handelen bij levenseinde. NRC, 5 augustus 2004
- SCEN gilde ook voor steun bij palliatie, ingezonden brief Medisch Contact 60 nr 14, 8 april 2005.
- Huisarts wil blijven voor zijn patiënten, Trouw, 24 mei 2005
- Huisarts vraagt zijn 'ereloon', De Gelderlander, 25 mei 2005
- Verklaring nodig van mensenrechten in de zorg, De Gelderlander 18 november 2006
- Vertrapt op de vrije markt, Medisch contact 2 februari 2007, 62 nr.5
- Aandacht voor kwaliteit leven bespaart kosten, Trouw, 20 juli 2010
- Huisarts zal met minder geld zakelijker moeten worden, Trouw, 6 oktober 2011
- De dood is niet van de dokter, ingezonden brief Medisch Contact 67 nr.4, 27 januari 2012
- Wilsverklaring gaat vooraf aan de euthanasiepraktijk, NRC 2 november 2012
- Registratie wilsverklaring in de huisartsenpraktijk, Lijn 1 jaargang 11,nr.2, juli 2013

- Meer zinloze ingrepen door overlevingscijfers, Trouw, 17 september 2013
- We moeten huisarts Nico Tromp herdenken, deze Allerzielen, NRC 2/3 november 2013
- Accepteer de vergankelijkheid, euthanasie is niet het ijkpunt, NRC 27 oktober 2014
- Laat leven boven de 70 vanzelfsprekend blijven, Trouw 1 november 2014
- Consulent helpt arts bij euthanasie over de brug, Trouw 18 februari 2015
- Kies ons! Elders overlijdt u sneller. NRC 20 augustus 2015
- Palliatief? Nee zorg zoals zorg moet zijn, Trouw 30 september 2015
- Zorgkosten omlaag? Geef palliatieve zorg de ruimte! NRC 16 augustus 2016
- Beste zorg; geen behandeling meer. Trouw 8 oktober 2016
- Dood nooit weerloze die het niet beseft, meerdere auteurs Volkskrant 21 januari 2017
- Goed levenseinde kan ook zonder euthanasie, Algemeen Dagblad 19 december 2017
- Wilsverklaring wekt irreële verwachtingen, Algemeen Dagblad 19 januari 2018
- Kijk met de arts mee bij palliatieve sedatie, Nederlands Dagblad 8 oktober 2018
- Huisarts moet gesprek aangaan over levenseind, Algemeen Dagblad 17 oktober 2018
- Ga het gesprek aan over de laatste fase van het leven, De stentor 17 november 2018
- Crisis verraadt lacune ouderenzorg, Nederlands dagblad 17 november 2020
- Help de vertrouwde huisarts verzuipt, Trouw 25 juni 2022

Interviews

- Palliatieve zorg vereist een andere manier van denken, Perpetuum Mobile jaargang 2, nr 10, oktober 1997
- De keerzijde van de euthanasiewet. Dagblad de Gelderlander 15 november 2001
- Huisarts wil soort ‘mensenrechten’ in de zorg. De Gelderlander 8 februari 2002
- Huisarts heeft afwachtende houding laten varen, pleidooi voor een pro-actieve houding ten aanzien van psychosociale zorg. IKO nieuws jaargang 22, nummer 1, mei 2002
- Geef ieder ziekenhuis een palliatieve vliegende keep. Nederlands Dagblad 22 maart 2003
- Een waardig levenseinde, meer aandacht voor palliatieve zorg. De Huisarts, maart 2004 nr 3.
- Nog steeds een stiefkindje, Reformatorisch Dagblad, 28 februari 2009
- Levenseinde op maat, Joost Visser Medisch Contact 2012
- Sterven in eigen regie, ooggetuigen (ook Engelse versie; Self-Directed dying, eyewitnesses). Uitgave door Boudewijn Chabot 2013.
- Velen sterven het liefst thuis, Edwin Kreulen. Trouw 30 augustus 2014.
- Over sedatie praat huisarts niet bij de lunch, Edwin Kreulen, Trouw bijlage de Verdieping, 4 oktober 2014.
- Meneer, heeft u de wilsverklaring al ingevuld?, Inge Klijn, Relevant, tijdschrift van de NVVE, nummer 4, oktober 2014.
- Een pleidooi voor palliatieve zorg, Ad Rem Remonstrants maandblad, nr. 1 januari 2015
- Blijven zeuren over euthanasie, Reformatorisch dagblad, 9 februari 2015
- Er wordt nogal getrokken aan de huisarts, Trouw De Verdieping 8 juni 2018
- Dutch euthanasia doctor cleared over death of dementia patient, 11 September 2019
- Should assisted dying be legal? The lessons learnt in the Netherlands, Senay Boztas. The Sunday Times. October 25, 2020
- Dutch doctors allowed to sedate dementia patients before euthanasia injections, Daily Telegraph 21 November 2020
- Euthanasie met wilsverklaring bij dementie; slechts een op de vijf huisartsen vindt dit kunnen, Maarten van de Wier. Trouw 2022

7E

Columns

Columnist geweest op www.palliatievezorg.nl en Kwartaal bijdrage columns gedurende 5 jaar voor het Nederlands-Vlaams Tijdschrift voor Palliatieve Zorg 2003 t/m 2008

Boeken

- Palliatieve zorg: Richtlijnen voor de praktijk, uitgegeven door de Vereniging van Integrale Kankercentra 2006 (Mede auteur oa van de richtlijn euthanasie en commentator van diverse richtlijnen) Uitgave 2010, mede auteur richtlijn euthanasie.
- “Leerboek Palliatieve zorg” Casus 17 De patient, de naasten en de huisarts. Uitgave Bohn Stafleu v. Lochem 2010
- Wat nu? Gids voor wie te maken krijgt met ongeneeslijke ziekte. Bohn Stafleu van Loghum 2014. ISBN 978-90-368-0761-6
- HNG leerboek palliatieve zorg 2017 en 2023. Tweetal hoofdstukken; Palliatieve sedatie thuis en Anorexie. Nieuwe druk met de herschreven hoofdstukken zal verschijnen in 2023
- Uitweg, een waardig levenseinde in eigen hand, Boudewijn Chabot. Bijdragen hoofdstuk 2 stoppen met eten en drinken. Nijgh & Van Ditmar 13^{e} druk 2017. Bijdrage hoofdstuk 10 Wilsverklaring in vijftiende herziene druk augustus 2022

Internetbulletin

Holosbulletin.nl. nu opgegaan in E-PAL Vanaf 2016 t/m 2020 een internet bulletin. Mede oprichter en redacteur. Een elk kwartaal verschijnend blad gericht op artsen om belang van integratie van ouderenzorg en palliatieve zorg onder de aandacht te brengen middels relevante publicaties, reviews en opinie. Het is na het overlijden van mijn vriend Bert Ummelen in 2021opgegaan in E-PAL waar ik momenteel mede redacteur van ben.

Recensies geschreven door mij

- Het Palliatief Formularium, Nederlands Tijdschrift voor Palliatieve Zorg 5^{e} jaargang 2004. De stilte van het licht, schoonheid en onbehagen in de kunst. Joost Zwagerman, Verlangen naar stilte, rubriek media en cultuur Medisch Contact 29 oktober 2015.
- Huisarts en levenseinde. Onderzoek van Andries Baart. Rubriek media en cultuur Medisch Contact 13 april 2017.
- Existentie en zingeving, tweetal boeken van Yalom en Kalmthout. Rubriek media&cultuur Medisch Contact 30 november 2017
- Leven en sterven met dementie, Herman van Hoogdalem en Constance de Vries. Rubriek media&cultuur Medisch Contact 30 november 2018
- Factoren die het welzijn bepalen van leden interdisciplinaire hospiceteam. Nummer 2 jaargang 24, april 2022
- Euthanasie bij iemand met dementie, Nummer 4 Pallium jaargang 24 augustus 2022

Recensies

- Film Chabot toont hulp euthanasie, NRC 19 en 20 juni 2013
- Geen euthanasie, toch hulp Medisch Contact 20 juni 2013
- Wat nu?, in boekenrubriek “in beeld” van Relevant, tijdschrift van de NVVE, nummer 4, oktober 2014.
- Boekbespreking Wat nu? Zorg rondom het levenseinde in Medisch Contact, 27 november 2014
- Boekbespreking Wat nu? Palliatieve levensweg, Pallium februari 2015.
- Boekbespreking Wat nu? “Omgaan met terminale ziekte”. Huisarts en Wetenschap 58, mei 2015.

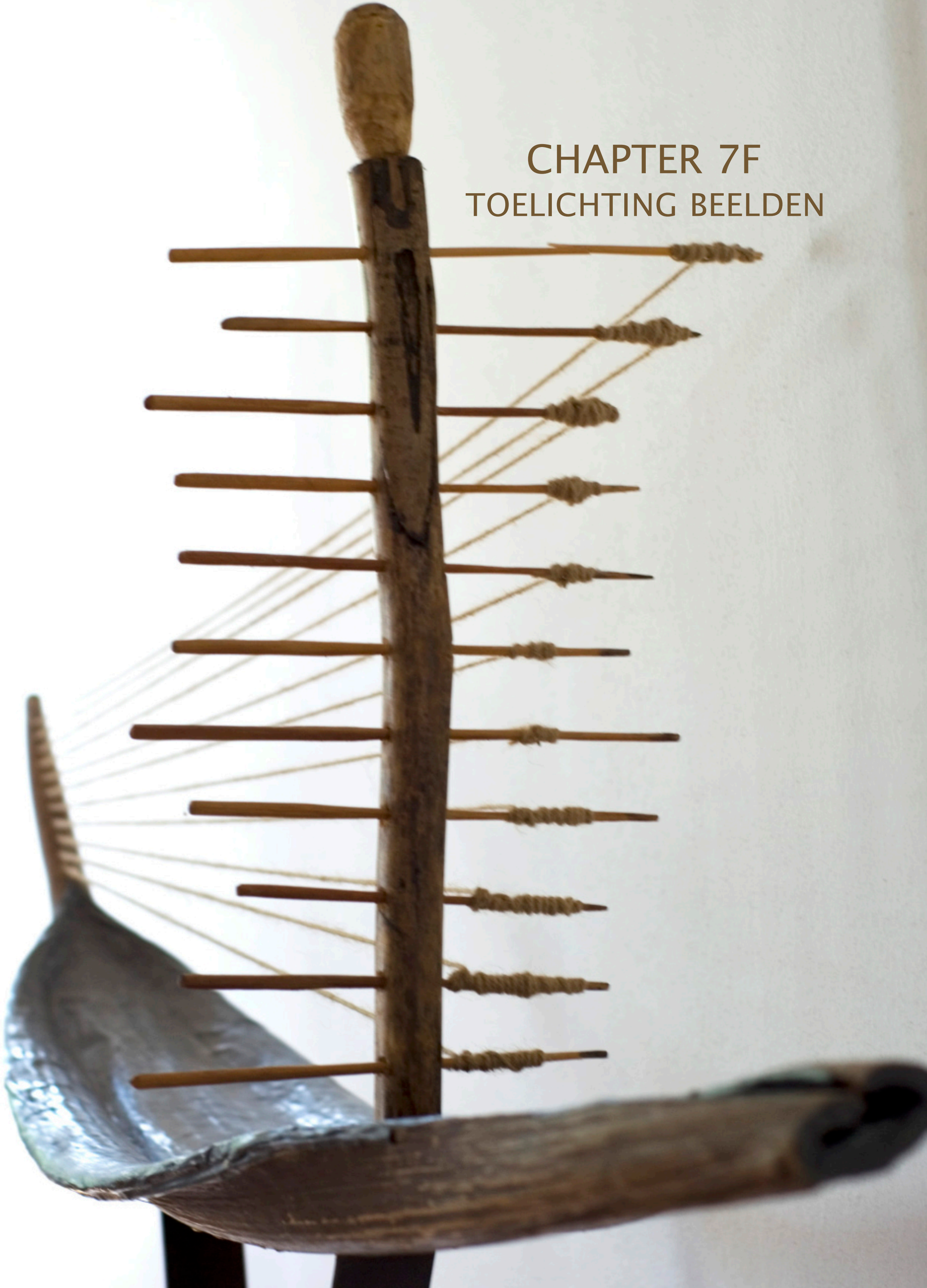
- Huisarts wil steun bij euthanasieverzoek bij dementie, Nienke Fleuren NTvG, nummer 15, 16 april 2021.
- Bespreking Holos bulletin, Medisch Contact media&cultuur nr 35 2016
  Lijden voorspel je niet, redactioneel commentaar Yvo Smulders NTvG jaargang 166, nummer 18, 6 mei 2022
- Ondraaglijk lijden door dementie? Commentaar door Bert Keizer Ned. Tijdschr. Geneeskd. 2022;166;D6751

Kunst; interview, publicaties en exposities

- ‘1.1 Fragmentarische levenswijze’, gedichten, J. Schuurmans . ‘Af en toe malaria’, stichting Zakaj 1984 ISBN 90/9000805-5
- Tuin expositie tijdens kunstroute Groesbeek in 2004 , 2006 en 2011
- Expositie in Galerie Pictura te Aijen in mei 2005 gezamenlijk met de schilder J. de Bekker
- Expositie tijdens European Palliative Care Congres te Boedapest in juni 2007
- Arts en Kunst, Medisch Ondernemen jaargang 4, nummer 4, september 2007
- Drietal grafbeelden te Soest, Maastricht en Groesbeek
- Expositie in galerie de Cellebreur te Maastricht in september 2008
- Illustraties van mijn beelden in het boek “Overlevingskunst”, Christa Anbeek 2010 ISBN 978 90 259 5979 1. Diverse herdrukken.
- Illustratie van beeld in tijdschrift Humanistieknr.47, 12^{e} jaargang december 2011.
- Beeld tableau in hal van Hervormde kerk te Groesbeek, 2012
- Illustraties van mijn beelden in derde kwartaalnummer Tijdschrift Geestelijke Verzorging jaargang 15, nr.66 2012
- Illustratie van beeld in AdRem, Remonstrants Maandblad jaargang 23 nr.7 juli/augustus 2012
- Expositie kerk te Molenhoek november en december 2012
- DVD illustratie omslag; Sterven in eigen regie, ooggetuigen. 2013 (Nederlandse, Duitse Engelse en Amerikaanse versie)
- Expositie Domus Medica te Utrecht, geheel voorjaar 2013
- Expositie Hervormde kerk te Groesbeek zomer 2013
- Palliatieve zorg als inspiratiebron van kunst. Lijn 1 (UMC St Radboud) jaargang 11 nr. 3 oktober 2013
- Expositie september 2014 Galerie RoBA in St. Hubert.
- Illustraties van mijn beelden in het boek “Wat nu? Gids voor wie te maken krijgt met ongeneeslijke ziekte”. Bohn Stafleu van Loghum 2014. ISBN 978-90-368-0761-6
- Mede exposant in museum De Wieger te Deurne, gehele zomer 2016
- Expositie binnentuin ziekenhuis Doetinchem zomer 2017
- Expositie Persingen 28 en 29 oktober 2017
- Vaste Expositie in galerie en beeldentuin Mestriner te Noorbeek en binnen de Ned. Hervormde kerk te Groesbeek vanaf 2008-heden
- Website www.redladder.nl

Sport

Zeilen, fietsen, lopen en eenmaal de Jungfrau Marathon in 2013



CHAPTER 7F

TOELICHTING BEELDEN

Toelichting beelden

Jaap Schuurmans, noemt zich medicus/ sculptor en is werkzaam als huisarts te Groesbeek en als palliatief arts in dienst van het Integraal Kankercentrumte Nijmegen. Beeldhouwlessen gevolgd bij de beeldend kunstenaar Peter-Willem Dekkers te Milsbeek vanaf 1996 tot 2003 en siersmeden in creatief centrum Lindenberg te Nijmegen.

Materiaal

Belgisch hardsteen en leisteen beiden organisch materiaal van verharde zeebodem en fossielen, hout, lood, de kleur van het grauwe water, en geoxideerd koper en Corte staal.

Thematiek

Het menselijk lichaam vooral het hoofd en de handen en de symboliek van schepen. Voor mijn boten en hun bemanning zijn mijn inspiratie de zoektochten van een ieder in zijn leven. De zoektochten van ontdekkingsreizigers, maar ook de bootvluchtelingen en asielzoekers die hun weg zoeken over zee. Ook de pelgrimages zoals verbeeld op middeleeuwse afbeeldingen waar schepen en hun bemanningsleden geheel buiten de anatomische verhoudingen worden geportretteerd, waardoor de ziel meer tot uiting komt. Inspiratie voor de gezichten van de bemanningsleden komt uit de illustraties van de Spaanse vroeg middeleeuwse handschriften, met Noord Afrikaanse en christelijke invloeden, bekend onder de verzamelnaam “Beatus”. Immigranten overstekers en de symboliek van het stroomgebied van de Styx is nauw verbonden met mijn ervaringen binnen de palliatieve zorg. De Egyptenaren aanbaden de zongod met zijn tocht langs de hemel en onderaards op een boot ook de stroom van een rivier volgend. En dan tenslotte de inspiratie uit de Griekse mythologie de zwerftochten van Odysseus en de Cycladencultuur die bloeide tussen 3200 en 2000 voor Christus. Deze kenmerkt zich door beeldjes met eenvoudige, gestileerde vormen.