

The ethics of euthanasia in dementia: A qualitative content analysis of case summaries (2012–2020)

Antonie Stef Groenewoud PhD^{1,2}   | Ellen Leijten MSc³ |
Sterre van den Oever MSc³ | Julia van Sommeren MSc³ |
Theodoor Adriaan Boer PhD^{2,4,5}  

¹Radboud University Medical Center, Scientific Center for Quality of Healthcare (IQ Healthcare), Nijmegen, the Netherlands

²Protestant Theological University, Groningen, the Netherlands

³Radboud University Medical Center, Nijmegen, the Netherlands

⁴University of Sunderland, Sunderland, UK

⁵Health Council of the Netherlands, The Hague, the Netherlands

Correspondence

Antonie Stef Groenewoud, University Medical Center, P.O. Box 9101, 6500 HB Nijmegen, the Netherlands.

Email: stef.groenewoud@radboudumc.nl

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Abstract

Background: The practice of euthanasia in dementia has thus far been described both in terms of its empirical patient characteristics and its ethical questions. However, 40 new cases have been published since the last study.

Methods: A qualitative content analysis of all 111 Dutch case summaries of euthanasia in dementia patients between 2012 and 2020, selected from the total of 1117 cases published by the Regional Euthanasia Review Committees (RTE). Our initial analytical framework consists of six due care criteria and five ethical principles.

Results: 111 case summaries were analyzed, from which we distilled seven recurring ethical questions: (1) How voluntary is a request? (2) Can an incapacitated patient make well-considered requests? (3) What constitutes “unbearable suffering”? (4) What if the unbearableness of suffering solely consists of “the absence of any prospect of improvement”? (5) What if a euthanasia request is meant to prevent future suffering (now for then)? (6) How (well) can a patient with cognitive limitations be informed? (7) What are “reasonable alternatives” and what if patients decline available alternatives?

Conclusions: Beyond these questions, however, we also see some serious challenges for the future: (a) narrowing the gap between perceived and real nursing home quality, since many advance euthanasia directives refer to nursing homes as sources of unbearable suffering; (b) making information to incompetent patients and their relatives about end of life options more tailor made, since it is questionable whether patients with dementia currently understand all of the euthanasia procedure; (c) involving patients' own physician as long as possible in a euthanasia request. Training may help physicians to deal better with euthanasia requests by patients suffering from dementia; (d) longitudinal research is required that encompasses all dementia euthanasia cases, not only those selected by the RTE.

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KEYWORDS

dementia, end of life care, ethics, euthanasia, quality

INTRODUCTION

From 1985 to 2002 the Netherlands gradually legalized euthanasia (Text S1).¹ In the early 2000s, euthanasia in dementia was rare and only involved euthanasia in early stage dementia. In 2011, the first advanced-dementia-case was approved by the Regional Euthanasia Review Committees (RTE). The reported numbers amounted from five in 2005 to 170 in 2020 (Figure 1). This accounts for 1.3% of the Dutch dementia mortality in 2019.²

Empirical knowledge of euthanasia in dementia is expanding. Studies describe (i) empirical characteristics of patients and practices involved,^{3,4} (ii) competence issues and advance directives,^{5–9} (iii) the way RTEs apply legal criteria,^{10,11} (iv) the role of physicians and how euthanasia affects them.^{12–18}

Ethical questions have also been addressed, often at the level of individual cases. They revolve around (i) patient autonomy¹⁹ and voluntariness,^{20,21} (ii) suffering and the capriciousness of dementia,^{20,22,23} (iii) timing and problems with anticipatory choices,^{20,23} (iv) happiness, dignity and life's intrinsic value,^{19,20} (v) doctors' involvement,²⁰ (vi) the ethical importance of cultural and medical (e.g., palliative care) developments.^{22,24}

One study used a large number of cases for some ethical analysis of euthanasia in dementia.³ Our study is special in that it (1) reflects analysis on these cases by using an ethical analytical framework, whereas the existing study primarily describes characteristics of dementia patients in relation to the way euthanasia is regulated in the Netherlands, (2) provides a catalogue of texts that are analyzed fairly granular, and (3) it provides a larger database for the analysis of ethical issues by adding 40 more cases.

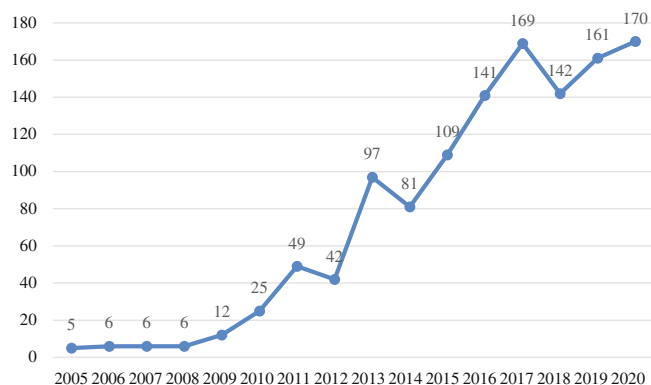


FIGURE 1 Number of euthanasia cases in dementia per year (2005–2020)

Key points

- We analyzed all published Dutch case reports on euthanasia in dementia (2012–2020).
- Among other ethical questions encompass “voluntariness of the request” and “now for then decisions.”

Why does this paper matter?

Since the last ethical analysis of Dutch cases of euthanasia in dementia, 40 new cases have been publicly disclosed. We include these new cases and use a bottom up, qualitative content analysis.

METHODS

We retrieved all 115 accessible cases of euthanasia in dementia from an open access database.²⁵ These cases are selected for publication by the RTE from the total of 1117 cases of euthanasia in dementia from 2012 through 2020 (Table 1).

The RTE select cases that (1) “are relevant for the further development of (ethical) norms or for the societal debate,”²⁶ that (2) provide insights into the “spectrum of cases reviewed and to contribute to the understanding of complex or controversial cases among physicians and the general public,” plus (3) some cases that are “considered common.”²⁷ After excluding dementia cases in which the main cause of suffering was not dementia, 111 cases were left to analyze.

Our qualitative content analysis of the case summaries in ATLAS.ti (ATLAS.ti Scientific Software Development GmbH, version 8.4.20) started out in a first round with conventional content analysis. Using *open coding*²⁸ for eight randomly selected cases we developed an initial coding scheme containing the ethical aspects involved in the analyzed cases. Secondly, we iteratively developed a coding scheme based on the six legal criteria (Text S1). Third, we linked the findings to ethical questions and values widely shared in (bio)ethics and medicine.²⁹ This bottom-up coding approach yielded a conceptual framework (Figure 2).

In a second round, we coded all cases and recoded the first eight. Besides *open coding* we used *directed content analysis*.²⁸ In conformity with literature on qualitative research we only added new codes if data did not fit with existing codes.³⁰ To identify the prevalence of ethical issues we also applied *summative coding*.²⁸ Whereas

in the first round cases were coded by three researchers, the cases in the second round were coded by one researcher, with every tenth case coded by a colleague. Remaining discrepancies were discussed and if necessary new codes were added.

For background purposes we collected quantitative data about (a) patient characteristics, (b) the timeline, (c) the setting, and (d) the RTE's interpretation of the

legal criteria (Table 2, and Tables S1–S4).²⁷ For these case descriptions we chose variables used elsewhere.³

Ethical approval

All data is publicly accessible and fully anonymous and therefore no ethical review is needed.²⁷

TABLE 1 Number of published and reported cases of euthanasia in dementia (2012–2020)

Year	Dementia		
	Published	Reported	%
2012	5	42	11.90%
2013	14	97	14.43%
2014	13	81	16.05%
2015	9	109	8.26%
2016	12	141	8.51%
2017	12	169	7.10%
2018	19	146	13.01%
2019	10	162	6.17%
2020	21	170	12.35%
Total	115	1117	10.30%

RESULTS

Quantitative results

Sample characteristics are listed in Tables 2 and S1. Ethically relevant is the prevalence of psychological and spiritual suffering (99.1% and 84.7%), the refusal of palliative options by one in three patients, and the mental incompetence in 1 in 10 patients when the euthanasia was performed.

Timeline characteristics are presented in Table S2. Ethically relevant is the natural life expectancy of more than 6 months in most patients, the average time of almost 3 years between diagnosis and euthanasia, and an average of more than 3 years between the earliest mention of euthanasia and death. On average 3.62 months lie between the actual euthanasia request and death.

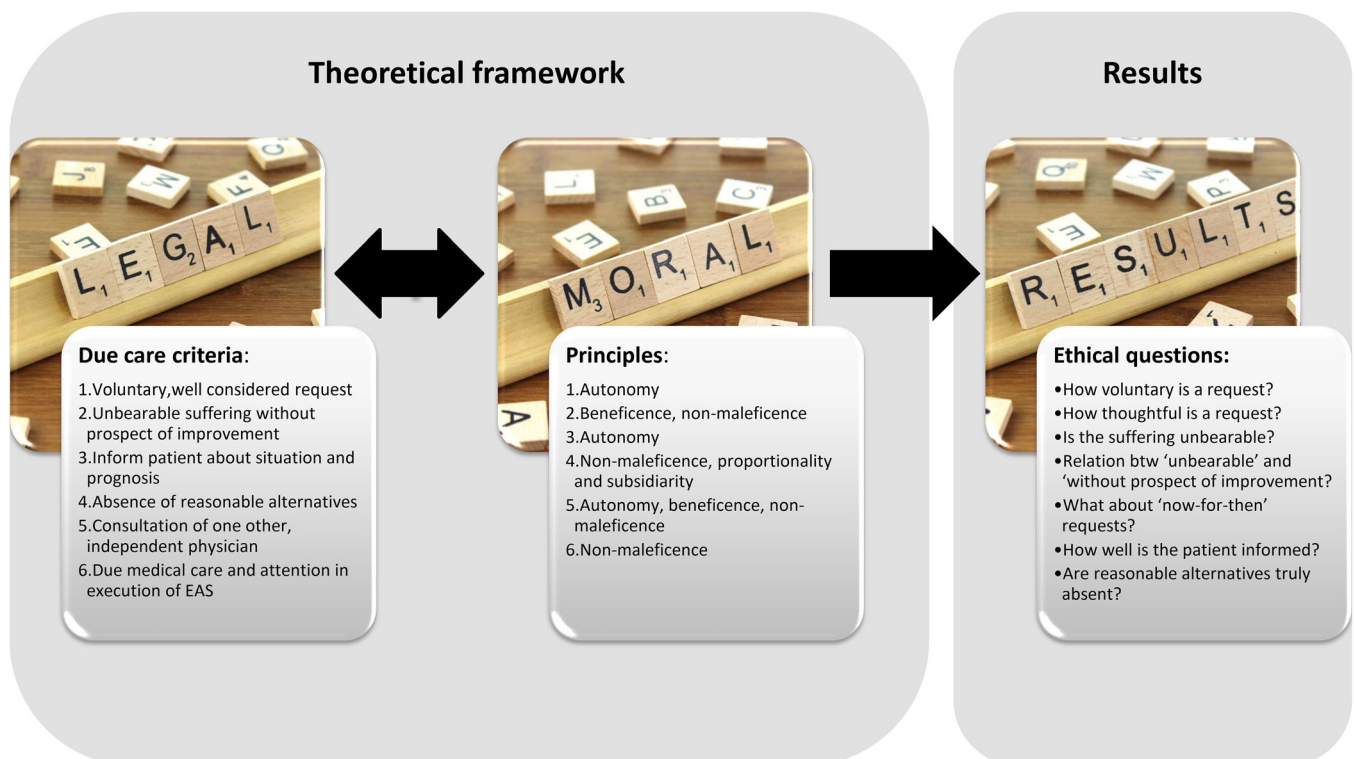


FIGURE 2 Theoretical framework

TABLE 2 Sample characteristics—patients and their suffering

Patient	Dementia (N = 111)	
	N	%
Gender		
Female	59	53.2
Male	52	46.8
Age		
18–40	0	0
40–50	0	0
50–60	4	3.6
60–70	18	16.2
70–80	33	29.7
80–90	47	42.3
90+	9	8.1
Primary diagnosis ^a		
Dementia, not specified	16	14.4
Alzheimer's disease	64	57.7
Vascular dementia	22	19.8
Frontotemporal/semantic dementia	7	6.3
Lewy body dementia	7	6.3
Other	3	2.7
Phase of dementia		
Beginning	18	16.2
Advanced	23	20.7
Unknown	70	63.1
Comorbidity		
Physical	40	36
Psychological	12	10.8
Cause of suffering		
Physical	40	36
Psychological	110	99.1
Social	50	45
Spiritual	94	84.7

^aIn some cases, patients have been diagnosed with two types of dementia.

Setting characteristics can be found in Table S3. Three out of four patients died at home, and one in five received assisted suicide, a number much higher than in other euthanasia contexts. Most patients discussed their first euthanasia intention with their GP, who in 39.6% of the cases declined assistance. Four out of 10 cases were carried out by GPs and one in 10 by geriatric specialists. In 40% the euthanizing physician was a Euthanasia Expertise Center physician with no prior patient-doctor relationship. Table S4 contains the topics most frequently debated by the RTE. In 5 out of 111 cases this led to a negative verdict.

Qualitative results

We group the identified ethical questions under seven headings (Figure 2, right part), and refer to [quotes] from the case summary reports to illustrate our findings. The full quotes list is found in Table 3.

How voluntary is a request?

In 12 of 111 cases (10.8%) a patient was not fully competent and the decision to terminate their life was based on fragmented expressions, circumstantial evidence, and written and/or oral directives. This carries some complexities. (1) In 10 of 111 cases (9%), information about the nature and severity of the suffering and about the actual request came wholly or partly from relatives [quotes 1–3].

In three cases, relatives refused palliation on behalf of their loved one, being afraid that the patient would not appear to be suffering enough to be eligible for euthanasia [quote 4].

About half of the incompetent patients could no longer confirm their death wish; the procedure was continued despite the presence of mixed signals [quote 5].

Sometimes a physician explained that although the patient did not confirm the request, they had not declined it either [quotes 6, 7]. A euthanasia case that became known as the “coffee-case” was first rejected by the RTE and later accepted by the High Court. In an advance directive, a 74-year-old dementia patient had indicated a euthanasia if she were to end up in a nursing home. When this scenario incurred and she had become incompetent, she gave varying signals: although most of the time she did not want to live, she also had moments of enjoyment. Despite being administered a sedative in her coffee, she resisted when the euthanasia was performed. The court ruled that the doctor had rightly based her action on the patient's advance directive.

In 14 cases (12.6%) the voluntariness of the caregivers and relatives is under pressure, either directly and orally or indirectly through aggressive behavior [quote 8]. In six cases (5.4%), patients were reported to consider suicide if their death wish was not granted [quote 9].

Can patients with limited competence make well-considered requests?

This is the topic most frequently discussed by the RTE: in 88 (79.3%) of the cases. Due to aphasia, disorientation in time, amnesia, and so forth, a patient may no longer be able to formulate a well-considered request [quotes

TABLE 3 Quotes supporting and illustrating our findings

No.	Case	Quote
1	2018-29	<i>At the start of these conversations, the patient was no longer able to speak intelligibly. In particular, the doctor spoke to family, practitioners and nursing and care staff about the patient's suffering and life termination.</i>
2	2019-119	<i>The psychiatrist, like the initial doctor, learned of the suffering mainly through the relatives and caregivers.</i>
3	2017-103	<i>The doctor was informed by the children and one of the patient's carers and observed the patient. [...] She has again been extensively informed by relatives and caregivers. With regard to the advance directive, the doctor noted that in this declaration the patient is brief with regard to explaining the suffering that she does not want. The doctor thinks the context is clear from relatives' statements with whom the patient has extensively discussed her wish at an earlier stage.</i>
4	2019-79	<i>When asked, the doctor replied that the patient's the wife [...] feared that the patient in the nursing home would be sedated to such an extent that his suffering would no longer be clearly visible. The wife was only reluctant, because she was afraid that his advance directive would not be honored.</i>
5	2019-79	<i>Although the patient again indicated that he was doing well and that he did not want to die, the doctor decided to continue the euthanasia process and visited the patient again after more than a week.</i>
6	2019-79	<i>The doctor tried to talk to the patient about euthanasia in the nursing home, but there was no response. However, the patient never said that he did not want euthanasia.</i>
7	2019-119	<i>The doctor made several (fruitless) attempts to contact the patient to investigate whether the patient could indicate verbally or non-verbally that he no longer wanted euthanasia. It has become clear from the file that such statements have not been made. In view of the foregoing, the doctor was able to conclude that performing the euthanasia was in accordance with the patient's advance directive and not contradictory to the patient's statements.</i>
8	2017-103	<i>The patient frequently resisted the daily routines, such as when she was changed because of her incontinence for urine and faeces. [...] She repeatedly became angry. That was a major problem in her care: patient hit, spilled, kicked, grabbed and wouldn't let go.</i>
9	2016-85	<i>She said she wanted to die and suggested hanging herself at the door ("but it's too low").</i>
10	2014-35	<i>The medical file showed that at the end, partly due to a lack of time awareness caused by her illness, the patient was no longer able to verbally express and substantiate her request.</i>
11	2016-39	<i>The patient had phatic disorders due to her vascular dementia. Because of the aphasia, the patient was not or only partly able to verbalize her thoughts, certainly when she experienced tension.</i>
12	2014-66	<i>With the words "I am all done with it," the patient had convinced the consultant that it was ready for her.</i>
13	2018-21	<i>Some week before her death, the patient made a final euthanasia request with the words "last bus ride" and "closing time." According to the doctor, this was a voluntary and well-considered request.</i>
14	2013-80	<i>With regard to the intolerable suffering, the second consultant noted that the patient was unable to answer whether she knew what situation she could end up in in case of advanced dementia.</i>
15	2017-14	<i>The doctor consulted both an independent geriatric specialist and a geriatric psychiatrist [...] about the patient's mental capacity. The first considered the patient incapable of making decisions in complex cases, but the psychiatrist was of the opinion that the patient was mentally competent with regard to the euthanasia request.</i>
16	2018-34	<i>The patient's suffering consisted of the awareness of his declining cognitive ability. The patient was able to do almost nothing and was increasingly apathetic. He had been unable to cook for years and only ate and drank when reminded.</i>
17	2018-34	<i>[Still, this] patient was able to make his request clear. The doctor considered the patient competent with regard to his request. According to the doctor, this was a voluntary and well-considered request.</i>
18	2018-29	<i>Seven years before his death, patient had drawn an advance directive listing the conditions under which he would choose not to continue living. This would be if:</i> <i>a. He would no longer have control over his life, because he would have lost all understanding of time and place.</i> <i>b. Others would [...] decide for him what to do and when.</i> <i>c. He would have become totally dependent on other people.</i> <i>d. He would no longer recognise his loved ones.</i> <i>e. He would no longer be able to verbally express himself.</i>
19	2016-39	<i>For the physician [it was very] valuable to understand the background of the patient's request by interpreting her biography, written down by her children, and learn what unbearable suffering meant for this patient.</i>

TABLE 3 (Continued)

No.	Case	Quote
20	2012-29	<i>Given the patient's personality the doctor could sympathize with her request.</i>
21	2014-03	<i>The patient's unbearable suffering was certainly influenced by how he was as a person, with his sense of decorum. [...]Others can still live with this disorder. However, for this man, with his background and knowledge of the dementia process, the suffering was unbearable.</i>
22	2014-03	<i>It was clear that he hated his mental decline very much. According to the consultant, it made the patient desperate. People no would longer came to seek his advice. The patient was also no longer able to read scientific documents. Although mental decline comes with this illness, the patient was embarrassed by it. He hated it and avoided seeing people.</i>
23	2020-129	<i>He became care dependent and lost all interest in what had previously determined his quality of life, such as reading newspapers, playing chess, doing puzzles, practicing sports, or watching documentaries. He resented his stay in the psychogeriatric ward for being unable to have (meaningful) conversations with other residents and for being confronted with his foreland.</i>
24	2016-94	<i>The patient, who had acted very independently all her life, experienced her suffering as unbearable.</i>
25	2020-118	<i>When I find myself in a situation in which I suffer hopelessly, in which there is no reasonable prospect of returning to a dignified state of living, and in which further decline is at hand, I request my doctor to administer or provide me the means that will end my life. It is true that the patient had not specified what she meant by a 'dignified state of life' and 'decline,' but it is certain that she could no longer communicate meaningfully, needed help with everyday things, no longer had a grip on her thinking and acting and that she occasionally suffered from stool incontinence, loss of decorum and not recognizing her children.</i>
26	2016-85	<i>For the greater part of the day, between lunchtime and about 5 AM, the patient showed restless behavior and looked deeply unhappy. Only when her family was present did she feel better. The patient found life acceptable as long as her husband and adult child were with there to join her on long walks. However, these walks were impossible, partly due to the husband's condition. Patient's husband visited her every day for two hours in the nursing home. Patient enjoyed his company but as soon as he was out of sight, she became restless and sad. The husband could only leave [...] with the help of the nursing staff, who distracted the patient by taking her to the toilet, for example.</i>
27	2017-103	<i>According to [the consultant, the patient's] anger, resistance or defense could be seen as 'without substance' in this advanced dementia. They need not be interpreted as indications of suffering. The consultant indicated that in contrast to these emotions, there also were experiences of (occasionally intense) pleasure. These should be better accounted for in the assessment.</i>
28	2016-85	<i>Nevertheless, taking all together, the Committee concludes that the doctor can reasonably have reached the conclusion that the patient on the whole experienced her suffering as unbearable. [The] Committee does not assume that it is necessary for the patient to suffer unbearably every minute of the day.</i>
29	2016-59	<i>[T]he patient could explain clearly that her euthanasia wish was not based on fear of the nursing home, but was motivated by her hopelessness.</i>
30	2012-29	<i>The patient was still functioning quite well, but found the idea of having to give up more and more unbearable.</i>
31	2020-04	<i>For her cognitive decline as a result of her dementia there are no known treatment options. The nature of this disease implies that the suffering lacks any prospect of improvement.</i>
32	2020-88	<i>The Committee stresses that the hopelessness of the suffering, given the nature of the disease, is uncontested and requires no further justification.</i>
33	2013-80	<i>The first consultant concluded that the patient's suffering given the lack of effective therapy for dementia was without any prospect of improvement.</i>
34	2017-103	<i>The Committee requested [the doctor to explain how] he had examined whether the patient suffered without any prospect of improvement, and on the basis of which the doctor had concluded that there was no reasonable alternative solution.</i>
35	2019-60	<i>After visiting the patient, the first consultant wondered whether the patient's request was not partly motivated by depression, and whether there were no remaining treatment options for the patient, and recommended a visit to [a] clinical geriatrician.</i>

(Continues)

TABLE 3 (Continued)

No.	Case	Quote
36	2020-55	<i>[His] wife emphasized that the patient's parents had suffered from Alzheimer's, and that the patient had experienced their process of deterioration as terrible. The patient had always been adamant to prevent this from happening to himself.</i>
37	2017-06	<i>Patient, who had worked with dementia patients for over thirty years, did not want to deteriorate further and end up in the way she had so often seen in patients.</i>
38	2015-107	<i>One of her parents had become demented and ended up in a nursing home, where she often sat crying. Patient had always indicated that she found this degrading and inhumane and that she herself never wanted to end up in such a situation of care dependence and grief, and never wanted to be admitted to a nursing home.</i>
39	2015-66	<i>He wondered what meaning in life there is left if you forget everything.</i>
40	2012-23	<i>Patient, who wanted to part with dignity and not as a demented person in a diaper, experienced his suffering as unbearable.</i>
41	2018-34	<i>The confrontation with his old (demented) neighbor, who no longer recognized him, was a great shock to him. He didn't want to be a 'crumpled' person.</i>
42	2019-79	<i>Although the doctor, given the patient's advance directive, saw that he was in a situation that he had indicated he did not want to be in, the doctor also established that the patient had no awareness of the disease and felt comfortable in the situation in which he was in.</i>
43	2014-69	<i>In addition to her deterioration, the patient's suffering mainly consisted of fear of ending up in a situation in which euthanasia was no longer possible.</i>
44	2016-82	<i>The doctor has considered postponing the euthanasia. [On the other hand,] he did not want to risk being late. The chaos in the patient's head was increasing. He could have opted not to perform euthanasia at all, but then he would have abandoned the patient.</i>
45	2017-95	<i>[T]he psychiatrist warned that the patient's condition was deteriorating so rapidly that her mental competence would be threatened before too long. The euthanasia process should therefore, in his opinion, be initiated in the relatively short term.</i>
46	2020-106	<i>Furthermore, it could be inferred from the documents that the doctor had sufficiently informed the patient about the situation in which he found himself and about his prospects.</i>
47	2018-41	<i>It can be inferred from the documents that the doctor and the specialists have sufficiently informed the patient about the situation in which she found herself and about her prospects.</i>
48	2020-26	<i>The GP, two attending geriatricians and the [euthanizing] doctor adequately informed the patient about the prospects of Alzheimer's during the disease process. The deafness had existed since the patient's childhood. The Committee concludes from the doctor's account that the patient until the very end understood what was said to him, despite that he was hindered in his communication.</i>
49	2018-41	<i>The patient was no longer able to express what was bothering her. She no longer understood what others were saying to her and could not provide a reply.</i>
50	2015-107	<i>When talking about the future, the consultant told the patient that dementia – a word that the patient knew – is expected to get only worse: it is a brain disease with no prospect of improvement. At that moment the patient said of her own accord, "enough is enough" and, "I don't want any more."</i>
51	2013-80	<i>She realized the consequences of taking in [the deadly] drink and realized that she would deteriorate to death if she was admitted to a nursing home.</i>
52	2017-92	<i>The knowledge that he would eventually have to move to a nursing home was unbearable for him.</i>
53	2012-29	<i>The patient would refuse admission to a nursing home under any circumstances.</i>
54	2016-59	<i>Permanent admission to a nursing home was a nightmare for the patient because of previous negative experiences with her mother who had spent her last years in a nursing home due to dementia. [Her own short stay] in the nursing home had strengthened her view that she would refuse to live permanently in a care institution.</i>
55	2012-23	<i>Patient, whose mother [had] suffered from dementia and [been] nursed in a nursing home, dreaded his own future. He did not want, like his mother, to end up in a nursing home and not realize that he was alive.</i>
56	2013-96	<i>In front of her relatives, her doctor, and other caregivers patient has always refused admission to a nursing home. Someone she knew had had the same disease, sitting lifeless in a chair waiting for her end. She did not want to end up like that.</i>

TABLE 3 (Continued)

No.	Case	Quote
57	2015-107	<i>Patient refused day care, the involvement of a dementia case manager, and check-ups by the geriatrician.</i>
58	2013-96	<i>Patient was not open to guidance from a PG team.</i>
59	2012-29	<i>[P]alliative alternatives such as medication, providing structure, and admission to a nursing home were discussed with the patient. The consultant suggested monitoring the disease process after the diagnosis, which she explicitly rejected. None of these were reasonable alternatives, since what was 'unbearable' to her was determined by her history and by the fear of having to continue living in the certain prospect of progressive mental and physical decline with further loss of independence, dignity, and self-esteem.</i>
60	2015-107	<i>Invoking help from others was for both the patient and her husband no reasonable option. Thus far, they had managed to 'keep out' the help that was offered.</i>
61	2012-29	<i>The Committee concludes that the doctor cannot be blamed for not offering this patient to monitor the process on a monthly basis. This option would be unnegotiable to the patient as her deep fear for the future was an important component of the current unbearable suffering.</i>
62	2019-79	<i>The first consultant suggested to try again an send the patient to day treatment in a nursing home. This could provide more clarity and offer some respite to his relative at home, for whom the care was clearly too heavy.</i>
63	2013-80	<i>According to the first consultant, expanding care could positively influence the patient's suffering.</i>
64	2017-103	<i>The Committee [rules] that the doctor could not come to the conviction that there was no reasonable other solution for the situation [of] the patient. [...] The patient had been admitted to a small-scale residential care facility, not a nursing facility specialised in caring for patients with advanced dementia. The patient's pathology exceeded the level of the care home and justified a transfer to an institution that would meet the patient's specific needs. [If the patient would have been transferred,] some improvement in her situation might have been achieved. The Committee is aware that [...] Alzheimer's cannot be cured. But [before one can conclude that the suffering is hopeless, it should have been assessed] that there is no reasonable solution other than euthanasia to stop the suffering. (Article 2 lid 1 sub d WTL).</i>

10, 11]. Some patients issued multi-interpretable statements [quotes 12, 13], others lacked insight in the disease and its progression [quote 14]. If, as was the case in 18 cases (16.2%), there was disagreement between physicians [quote 15], a euthanizing physician and the RTE have two options. One is to assume that a patient with limited competence may still be competent with regard to their death wish [quotes 16, 17]. In total, 87 out of 111 patients (78.4%) were deemed competent enough to make a decision about euthanasia. The other option is to act primarily on an advance directive, oftentimes interpreted by relatives.

What constitutes “unbearable suffering”?

The definition of “unbearable suffering” varies due to the multifaceted character of dementia. It is often described in terms of having lost sense of time and place, being totally care-dependent, with others having to make decisions for them, being unable to recognize their loved ones, or being unable to verbally express themselves [quote 18]. Much more than in terminal illnesses, the suffering in dementia differs per patient. In most cases, physicians cautiously weigh a patient's personality, biography and background when assessing their suffering

[quotes 19–21]. Suffering thus means different things for different patients [quotes 22–24]. In one case, an advance directive was unspecific and used impersonal, almost standardized texts, and it had to be interpreted by the physicians and the RTE [quote 25].

The incessant character of the suffering plays an important role in qualifying it as unbearable. In some reports suffering was present 24 hours per day with no positive moments left. Elsewhere, the occasional moments of happiness did not outweigh the distress [quote 26]. Recurring moments of happiness led one consultant to conclude that the suffering was not unbearable [quote 27]. Similar situations were described in 11 other cases (9.9%). On the whole, however, the RTE do not require the agony to be incessant [quote 28].

What if the unbearable suffering solely consists of “the absence of any prospect of improvement”?

Although the law requires that the suffering must be unbearable and without prospect of improvement, some suffering that in itself may be bearable becomes unbearable in the absence of any prospect of improvement. In 48 cases (43.2%), patients suffer from such a lack of

perspective. In 18 of these cases, this lack of prospect appears to be the main cause of suffering [quotes 29, 30].

The criterion “suffering without prospect of improvement” is discussed relatively seldom. It is perhaps because dementia is incurable and progressive that many physicians and RTE assume that such prospect is absent [quotes 31–33]. But not always is it assumed that there is no prospect of improvement [quotes 34, 35].

A euthanasia request to prevent future suffering (now-for-then)?

A euthanasia request may be motivated by a wish to forgo future suffering rather than by suffering in the present.³¹ Many patients base their expectations on earlier experiences in people close to them [quotes 36–38]. These “ghosts from the past,” alongside narratives shared in the media and elsewhere, often made such a deep impression that the prospect of ending up in a similar situation causes unbearable suffering in the present. The basis for future suffering seems to be the absence of dignity as the patient considers it now, rather than real experiences of suffering in the future. Patients fear losing control, ceasing to be the person they are, losing their dignity, or the prospect of having to move to a nursing home [quotes 39–41]. Mainly two strategies are found to prevent this scenario to happen. One is to list the conditions one wants to forgo, as in the advance directive found in quote 25. Over 70% of the patients license their doctor and/or relatives to make a euthanasia decision in the case of mental incompetence. Not all physicians are convinced that such “now-for-then” preferences will hold under all circumstances [quote 42].

A second strategy is to have euthanasia in an earlier stage of dementia. Patients are afraid to become incompetent and unable to make a euthanasia request [quote 43]. In eight cases (7.2%) physicians indicate that they experience time pressure to perform euthanasia due to the deteriorating mental competence of a patient. For many doctors performing euthanasia in an incompetent patient is too problematic [quote 44]. Some consultants warn patients or colleagues to make haste for the same reasons [quote 45].

How (well) can a cognitively limited patient be informed?

Amidst the complexities connected to the unpredictable course of dementia and the limited cognitive abilities of many dementia patients, the criterion of being “well informed about one’s situation and prognosis” receives little attention in the case summaries. If mentioned at all, a maximum of one or two sentences are spent, always with a

positive judgment, making use of default formulations [quotes 46, 47]. Only exceptionally specific attention is given to the information given to the patient [quote 48].

All patients in our sample experienced some form of cognitive decline. In 49.5% of the cases specific attention was paid to communication problems [quote 49]. In that case, the RTE judged that the patient had been sufficiently informed about her situation, although it remains unclear how this was achieved.

Where care dependency and (partial) incompetence come together, it comes very precise how information is formulated and communicated. Sometimes physicians can hardly avoid the use of value laden terminology [quotes 50, 51].

What are “reasonable alternatives,” and what if patients decline them?

Although dementia is an incurable disease, several options exist to ease the suffering.^{32–35} One option is admission to a nursing home. In the analyzed cases, however, this features as the most contested alternative. In 38.7% of the cases, patients stated that they find admission to a nursing home unacceptable; for many of them, this (prospect) equals “unbearable suffering” [quotes 38, 52, 53]. Sometimes “ghosts from the past” cause someone to turn down what seems to be a reasonable alternative at first sight [quotes 54–56]. Besides admission to a nursing home, other palliative options are also declined, as we found in six patients (5.4%) [quotes 57–59]. Thus, even if alternative options were sometimes available, the criterion “no reasonable alternative” was judged to be met. The declined alternatives were deemed not to be reasonable for *this* patient. Sometimes a patient’s refusal was part of a behavioral pattern [quote 60]. In many cases a patient’s refusal to accept institutional care was accepted as “no reasonable alternatives” by the physician and the RTE.

In some cases, the patient did not refuse care but neither did the physician bring up alternative options [quote 61]. In other cases, a consultant made suggestions to alleviate the suffering [quotes 62, 63], but the attending physician still decided to proceed with the euthanasia procedure. In one case the RTE ruled that the patient should have been offered admission to an institution specialized in care for dementia patients [quote 64].

DISCUSSION

Strengths and limitations

In our study we analyzed 111 case descriptions of euthanasia in dementia published between 2012 and 2020.

These descriptions form the only publicly accessible empirical data on this topic in the Netherlands and worldwide. In comparison to prior research our study includes 40 extra cases and uses a bottom-up, open coding, content-analysis approach. One limitation is that the RTE offer only a selection of cases: those that are seen as “ground breaking” and “complex” (Table 1).²⁷ Precise selection criteria are unclear and seem to have changed over time. Moreover, the documents used are abbreviated representations of complex cases, made suitable for publication on an open access website and selected for predominantly educational purposes. They contain “plain language” with little medical, social and historical context-descriptions.^{3,27} Since much standardized wording was used, we coded non-standard texts with special attention.

Interpretation

Some of the questions emerging from our data, such as problems connected to the voluntariness of a request, also recur in the literature. Some argued that although “*dementia infiltrates the very centre of autonomy and voluntariness of a person,*” the vast majority of patients are competent enough to decide about their own death.²⁰ But what holds for many, does not hold for all: a considerable part of the published cases involve patients with gaps in their understanding, competence, and communicative abilities. Moreover, as has been described by others,³⁶ voluntariness may become problematic if proxy-decision makers (with their own subjective values and fears) are involved.³⁷ The opposite may also be true: pressure of a patient and their loved ones may inhibit a well-considered and voluntary decision on the part of the physician.¹⁴ This becomes especially pressing when declining a euthanasia request may lead to a patient killing themselves.³⁷

We found that in 16.2% of the cases there was discussion among the involved physicians about the patient’s mental competence. That no agreement is required (Dutch law requires a consultation, no unanimity) may solve the issue legally but not ethically⁶: How can we ethically justify the far-reaching decision to kill a patient without being fully convinced that this is in accordance with their well-considered wish? Some have criticized the RTE for substituting the so-called “functional model of capacity” (which is still part of their Code of Practice³⁸ and encompasses the capacities of communicating, understanding, seeing through, and reasoning⁵), with the more interpretative “authenticity criterion” that is also applied to the more ambiguous requests.³ Over the years, the RTE increasingly stress the value of Advance Euthanasia Directives (AED)^{5,6,9,10,36} which reflect a patient’s

will while still fully competent. Based upon our results and in line with other publications^{3,6,39} we would argue for a more demanding threshold for the mental competence. Besides, more can be done to improve the availability of advance directives that are tailor made for dementia patients. Such directives would need to be brief and accessible, yet detailed enough to anticipate on the possible changes in cognition and on the changes in the caring needs as the illness progresses.⁴⁰

Our third, fourth and fifth ethical question all concern the unbearableness of suffering in dementia patients: its subjectivity, the absence of prospects of improvement, and now-for-then suffering. Our findings on the unbearableness of suffering criterion strongly resonate with those of Mangino et al., who found that 25% of advance request cases did not meet legal due care criteria, in particular the “unbearable suffering” criterion.³ One could of course argue that our finding that “unbearable suffering” is a very subjective criterion, rather than being problematic, matches the frequently propagated concept of “patient centred care.”⁴¹ On the other hand, we know that suffering has many sources, commonly social and relational ones. This is also reflected by relational approaches in care for persons suffering from dementia, approaches that rely on a much less individual understanding of suffering.^{42–44} Some authors take a middle position as they suggest that the unbearableness of suffering and the patient’s request is not merely a matter of autonomy and subjectivity, but that it should be valued using a “whole person” or a “personalist” approach.¹⁹ At the other end of the spectrum, authors have criticized the Dutch euthanasia system for its subjective character, as it allows physicians to act on personal judgments about philosophically controversial dilemmas, rather than on a more objective evaluation.⁶ We found quotes that stated that “not being in contact with other people” and “not being able to do anything anymore” does not suit the patient. We doubt however, if one could say that suffering from cognitive decline “suits” one person better than another.

In some cases, the unbearableness fully consisted in the absence of prospects of improvement. Other authors have stated that the suffering is caused by the knowledge that dementia is a progressive disease, the effects of which will get worse.²⁰ It has also been mentioned that part of the suffering of dementia is “*the pointlessness of letting nature take its course; why go on and slowly disintegrate? Why not bring a halt to the merciless process? From the moment, the diagnosis is given one can be sure that it will never get better, only worse.*”²⁰ In fact, in most cases hopelessness seems to be taken for granted. However, the fact that in one case (quote 64) the RTE ruled that attempts to improve the patient’s situation should have

been made, shows that dementia does not imply this absence by definition, and that alternatives, for example to comfort patients³²⁻³⁵ may be explored more meticulously in the future. Also, the Royal Dutch Medical Association (KNMG) stated in their recently published “Guideline Medical Decisions at the End of Life,” that the mere fact that a person has (advanced) dementia is insufficient grounds for euthanasia and that the physician should always investigate whether there are other ways to eliminate, or alleviate, the suffering.⁴⁵ This resonates with our seventh finding: in many cases possible alternatives (palliative care, admission to a nursing home) were deemed “not reasonable” and were declined by patients or relatives. We believe that discussions about the unbearable nature of suffering and about possible alternatives would benefit from taking into consideration current developments in palliative care and advance care planning (ACP), many of which are truly promising.²²

Our finding that a euthanasia request is often based on “now-for-then” judgments about future suffering has been debated in literature before. Some have argued that the trend to allow euthanasia on the basis of advance directives leads to a different assessment of criteria such as patient competence, unbearable suffering, and hopelessness.³ Current discussions range from the claim that accepting fear of future decline as a form of unbearable suffering leads to a slippery slope, to claims that euthanasia in dementia is “now (when a patient is still mentally competent) or never.”²⁰ According to some it is impossible to ascertain whether seemingly happy dementia patients are happy indeed, and whether seemingly unhappy patients are indeed unhappy.⁸ Some argue that it is dubitable if people in an advanced stage of dementia really experience the sort of suffering they feared and estimated when they issued an advance directive.^{6,9} This may partly be caused by psychological adaptation,^{9,46} and is described in the literature on chronic illness as “response shift.”⁴⁷ As knowledge about these mechanisms increases—and as has been done in chronic care—more may be done to support early stage dementia patients to better cope with and anticipate on things to come.

To be able to make a well-considered euthanasia request, patients should be properly informed about their situation and prognosis. Although this is one of the legal due care criteria, no mention to any discussion about patient information is found in the 111 case reports we analyzed. This could indicate that most physicians diligently inform their patients about their mental decline and about the pros and the cons of, and the alternatives to euthanasia. However, Mangino et al. found that in advance request cases, patients were sometimes (31%) unaware that euthanasia was to be performed.³ Even if this unawareness would be due to the advanced disease, one could wonder how this relates to the criterion of

“being well informed.” Philosophical literature on the topic states that informed consent is not a static concept: only if tailored to the individual patient can we speak of “genuine consent.”⁴⁸⁻⁵¹ If someone has a reduced mental capacity (as in dementia), and especially if a procedure is highly invasive (as in euthanasia), the requirements of informed consent rise accordingly. Therefore, with the concept of genuine consent in mind, and given the limited allusions in the case summaries to how information was provided, we suggest that the informed consent procedure deserves more attention in euthanasia in dementia.

Conclusion and recommendations

We believe this study provides insights into the practice of euthanasia in dementia by addressing the seven most frequently occurring ethical discussions. Beyond these questions we see the following points that deserve future attention.

First, we mention patients’ rejection of palliative alternatives and their deeply rooted fear of nursing homes. A well-known adage in health care marketing and policy is: “perception is reality.” Investments are needed in a better (perceived) climate of hospitality and quality in long term care facilities. A better match between perception and reality enables people to make better-considered end-of-life choices.

Second, we recommend that in the future more attention be paid to provide incompetent patients and their families with tailor made information about pathology and prognosis in order to reach “genuine consent.” Patients need access to all relevant information, at a level they can understand.⁵⁰

Third, the practice of euthanasia in dementia will be importantly influenced by the future (broad or narrow) interpretation of the “coffee case” mentioned above. Initially, it seemed that (a) “advance requests” have gained in importance over “concurrent requests” and (b) the uses of sedatives as a premedication will also increase.⁵² On the other hand, the Dutch Public Prosecutor has recently pleaded for a more narrow reading of the High Court’s ruling.⁵³ Also, the Royal Dutch Medical Association (KNMG) in their recently published “Guideline Medical Decisions at the End of Life,” states that the use of sedatives is certainly not default in patients with dementia who receive euthanasia and who may become anxious or agitated. In all cases, including incompetent patients, the premise is that administering any premedication should be discussed with the patient.⁴⁵

Fourth, we found that in many cases (38.5%) not the patient’s own physician, but the Euthanasia Expertise Center is involved, often due to feelings of unease in the patient’s attending physician. We recommend that more

be done, such as training programs or peer group intervention, to keep the patient's own doctor involved as long as possible. After all, euthanasia is a last resort for a very complex problem that is inherently best understood, empathized with, and addressed by one's own physician.

Finally, more, and preferably longitudinal research is needed into more cases than those selected by the RTE: either *all* reported dementia cases, or a representative selection of cases. This could shed a more comprehensive and objective light on euthanasia in dementia in the Netherlands.

CONFLICT OF INTEREST

All of the authors declare absence of any conflict of interest.

AUTHOR CONTRIBUTIONS

All authors meet the requirements for authorship, have seen and approved the final version of this manuscript, and are aware of and agree to this submission to JAGS.

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ORCID

Antonie Stef Groenewoud  <https://orcid.org/0000-0001-5919-4856>

Theodoor Adriaan Boer  <https://orcid.org/0000-0002-0026-7974>

TWITTER

Antonie Stef Groenewoud  @stefgroenewoud

Theodoor Adriaan Boer  @theoboer

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

Text S1: Brief background on euthanasia practice and regulation in the Netherlands

Table S1: Sample characteristics (additional)

Table S2: Sample characteristics—the process of euthanasia in dementia

Table S3: Sample characteristics—the setting of euthanasia in dementia. *More than one reason for decline can be present in one case. **More than one consultant of each specialty can be involved in one case. ***More than one physician or family member can be involved in one case.

Table S4: Sample characteristics – discussion about due care criteria. *More than one due care criterion can be discussed in one case.

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