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Regular Research Article

Euthanasia and Assisted Suicide of Persons With Dementia in the Netherlands

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ARTICLE INFO

Article history:
Received July, 22 2019
Revised August, 14 2019
Accepted August, 14 2019

Key Words:
Assisted suicide
euthanasia
clinical ethics
all cognitive disorders
dementia
decision-making capacity

ABSTRACT

Objective: *To describe the characteristics of persons with dementia receiving euthanasia/assisted suicide (EAS) and how the practice is regulated in the Netherlands.* ***Designs:*** *Qualitative directed content analysis of dementia EAS reports published by the Dutch euthanasia review committees between 2011 and October 5, 2018.* ***Results:*** *Seventy-five cases were reviewed: 59 concurrent requests and 16 advance requests. Fifty-three percent (40/75) were women, and 48% (36/75) had Alzheimer disease. Advance request EAS patients were younger, had dementia longer, and more frequently had personal experience with dementia. Some concurrent request EAS patients were quite impaired: 15% (9/59) were deemed incompetent by at least one physician; in 24% (14/59), patients' previous statements or current body language were used to assess competence. In 39% (29/75), patients' own physicians declined to perform EAS; in 43% (32/75), the physician performing EAS was new to them. Physicians disagreed about patients' eligibility in 21% (16/75). All advance request and 14 (25%) concurrent request patients had an advance euthanasia directive but the conditions of applicability often lacked specificity. In 5 of 16 advance request EAS and 2 of 56 concurrent request EAS cases, EAS procedure was modified (e.g., premedication). Twenty-five percent (4/16) of advance request cases did not meet legal due care criteria, in particular the "unbearable suffering" criterion.* ***Conclusions:*** *Advance and concurrent request EAS cases differ in age, duration of illness, and past experience. Advance request EAS cases were complicated by ambiguous directives, patients being unaware of the EAS procedure, and physicians' difficulty assessing "unbearable suffering." Notably, some concurrent request patients were quite impaired yet deemed competent by appeals to previous statements.* (Am J Geriatr Psychiatry 2019; ■■:■■–■■)

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Published by Elsevier Inc. on behalf of American Association for Geriatric Psychiatry.
https://doi.org/10.1016/j.jagp.2019.08.015

INTRODUCTION

Euthanasia or assisted suicide (EAS) is permitted in a small number of jurisdictions,[1] and in some, the practice includes an increasing number of persons with dementia.[2–4] Although EAS of persons with dementia (dementia EAS) constitutes a small percentage of all Dutch EAS cases, the number has more than tripled since 2011.[5,6] Most cases were reported as concurrent requests for EAS by patients deemed competent in the "early phases of dementia."[4] However, beginning in 2011, a small number of Dutch EAS requests based on written advance euthanasia directives have been granted.[4] Some of these advance request EAS cases have been widely discussed[4,7–10] and one case led to the first prosecution of a doctor since the 2002 law was enacted (Box).[5]

Much of the debate about dementia EAS focuses on challenges in determining decisional capacity, evaluating an advance euthanasia directive's applicability, assessing unbearable suffering, and implementing the EAS procedure in advance request cases.[2,11–16] Despite the controversy, there is a paucity of data about the practice of advance request EAS, and even less regarding concurrent request EAS. We therefore reviewed all of the Dutch regional euthanasia review committees' (RTE) (Box) published case reports of dementia EAS. These reports—intended by the RTE to be instructive[17]—contain patient-level detail and have been used to study other patient groups receiving EAS.[18] We report here the characteristics of persons with dementia who received EAS, how their physicians evaluated and implemented their requests, and how the RTE evaluated the physicians' practices.

Box. Brief background on EAS practice and regulation in the Netherlands

The practice of legally protected euthanasia or assisted suicide (EAS) has been in existence for several decades in the Netherlands, although formal legislation was not enacted until 2002 with the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.[1] Section 2(1)[1] provides medical "due care criteria" that must be met for EAS to be permitted and requires that the physician performing EAS:[11]

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; and
f) have exercised due medical care and attention in terminating the patient's life or assisting in his suicide.

Section 2(2)[2] of the law states, "If a patient aged sixteen or over who is no longer capable of expressing his will, but before reaching this state was deemed capable of making a reasonable appraisal of his own interests, has made a written declaration requesting that his life be terminated, the physician may comply with this request. The due care criteria in subsection 1 apply mutatis mutandis."[11] Criteria a–d are sometimes called "substantive" or eligibility criteria; e and f are procedural criteria.[1]

Under the law, the Dutch regional euthanasia review committees (Regionale Toetsingscommissies Euthanasie (RTE)) review all EAS reports to determine whether the notifying physicians (physicians who performed EAS) acted in accordance with the statutory due care criteria laid out in the EAS legislation.[4] The RTE publishes a selection of their reports to "make clear what options the law gives physicians[,]" and to add to the "transparency and auditability" of EAS as it is practiced by physicians.[19]

Support and Consultation on Euthanasia in the Netherlands (SCEN) physicians are specially trained to assist colleagues in carrying out EAS. They often serve as the official independent physician consultant required by the Dutch EAS law but can also dispense less formal advice and assistance.[39]

The End-of-Life Clinic (Levenseindekliniek) was founded in 2012 and provides EAS evaluations for patients whose treating physician declined to perform EAS. Most patients who receive EAS at the End-of-Life Clinic are nonterminally ill.[40]

METHODS

The RTE received 834 dementia EAS notifications between 2011 and 2018.[3–6,17,19–21] Of these, we reviewed all 72 cases listed under the "dementia" search function on the RTE website as of October 5, 2018.[22] Three additional cases of dementia EAS (attributed to Alzheimer, Huntington's, and multiple cerebrovascular accidents) identified by the Canadian Council of Academies' Expert Panel Working Group were also included,[14] for a total of 75 cases. The RTE's designation of cases as concurrent or advance request was verified by contacting the RTE directly.

Before coding, we read all cases following machine translation into English. Twenty cases with complex histories were then translated into English by certified

medical translators through the National Institutes of Health Library's translation services. The remaining 55 cases were edited for accuracy by Dutch-speaking academics (RDV or MN).

Nine cases had abbreviated official RTE English translations (along with full-length Dutch reports), which served as validity checks of our full-length English translations.

The reports were analyzed using directed content analysis,[23] as described previously.[18] The coding scheme was developed iteratively, informed by the project's main research questions and focused on: 1) patient characteristics, 2) the EAS evaluation process by physicians, 3) the characteristics and roles of advance euthanasia directives, and 4) the RTE monitoring process. All cases were coded independently by DM and SK; any discrepancies were resolved by discussion and sometimes involved an additional reader (MN). The data were analyzed using STATA (version 15), consisting of frequencies, cross-tabulations, and exploratory post hoc tests of bivariate associations without hypothesis testing given their descriptive purpose.

RESULTS

Characteristics of Patients

Fifty-three percent (40/75) were women (Table 1). Alzheimer disease was the most common dementia diagnosis in both concurrent and advance request cases, and the sole dementia diagnosis in 48% (36/75). Concurrent request patients were 70 or older more frequently than advance request patients (86% [51/59] versus 44% [7/16], p = 0.001, Fisher's exact test). Among concurrent request patients, unspecified dementia was the second most common diagnosis (24% [14/59]). Advance request patients had dementia diagnoses longer before receiving EAS (5.3 [SD 3.2] years versus 2.3 [SD 1.8] years, p = 0.002, t-test) and were more likely to have prior personal experiences with dementia (usually in relatives) (81% [13/16] versus 44%, [26/59] p = 0.01, Fisher's exact test). For example, a man in his 50s with Alzheimer disease diagnosed 8 years prior had witnessed his mother deteriorate with Alzheimer but did not want EAS as long as he could enjoy his family, and opted to use an advance euthanasia directive (2016-18).

TABLE 1. Characteristics of Persons With Dementia Who Received EAS

	Concurrent Request N = 59		Advance Request N = 16	
	No.	%	No.	%
Women	29	49	11	69
Age[a]				
50–60	2	3	2	13
60–70	6	10	7	44
70–80	19	32	3	19
80–90	28	47	3	19
>90	4	7	1	6
Diagnosis				
Alzheimer	25	42	11	69
Lewy body dementia	6	10	0	0
Vascular dementia	4	7	2	13
Frontotemporal dementia	2	3	1	6
Mixed dementia	8	14	0	0
Huntington's Disease	0	0	1	6
Unspecified dementia	14	24	1	6
Years diagnosed (years [SD]) before EAS (n = 67)[b]	2.3 (1.8)		5.3 (3.2)	
Place of residence at time of EAS				
Nursing home or care facility	11	19	10	63
Home or unspecified	48	81	6	38
Fear of entering a nursing home or care facility	41	69	11	69
Fear of future suffering was part of current unbearable suffering	49	83	5	31
Past personal experience with dementia	26	44	13	81
Mentioned the patient as being a certain "kind of person"	29	49	8	50
Mentioned a fear of waiting too long for EAS	18	31	2	13
Able to initiate EAS evaluation				
Yes	56	95	3	19
No	2	3	11	69
Not clear	1	2	2	13

Notes: EAS: Euthanasia and assisted suicide; SD: standard deviation.
[a] Age groups reflect the categories used in the RTE reports.
[b] Unable to ascertain from the reports the time of diagnosis in eight concurrent request cases.

Fear of nursing home admission was common (69%) in both groups. Concurrent request cases more frequently mentioned that a fear of the future contributed to the patient's unbearable suffering (e.g., "The core of the [patient's] suffering was formed by the realization that she would eventually become dependent." 2012-29) (83% [49/59] versus 31% [5/16], p <0.001, Fisher's exact test). Approximately half of the reports mentioned personality characteristics of patients, such as "active" (2013-81), "very autonomous and independent" (2018-02), or "very intellectual" (2012-31).

EAS Refusals by Physicians

In 39% (29/75) of cases, EAS was performed after at least one doctor refused (Table 2). In five, more than one physician refused. Although 42% (15/36) of reasons had to do with particulars of the case (e.g., did not think due care criteria were met), 33% (12/36) reflected the doctors' own reasons including not providing EAS for some or all types of requests, personal/emotional reasons, or in one case (2014-63) having "euthanasia fatigue."

Physician Roles in the EAS Evaluation Process

The EAS physician (i.e., physician who performed EAS) was new to the patient in 43% (32/75; Table 2). The End-of-Life Clinic (Box) physicians accounted for 36% (27/75) of cases. The number and types of consultation and second opinion physicians involved in EAS evaluations were similar between concurrent and advance request cases. Advance request cases were more likely to involve second opinions from geriatricians (75% [12/16] versus 31% [18/59], p = 0.007, Fisher's exact test). EAS physicians, consultants, or second opinion physicians disagreed about the patients' eligibility for EAS in 31% (5/16) of advance request and 19% (11/59) of concurrent request cases, most frequently about whether a request was voluntary and well considered.

Evaluations of Concurrent Requests for EAS in Dementia

Disease severity and degree of physical and cognitive functioning in concurrent request patients varied. Physicians reported high degrees of functioning in some patients. In one case (2014-03), the patient was diagnosed with "mild dementia" 9 months prior by his primary physician while a geriatric psychiatrist noted "no significant deterioration" compared to a cognitive study 4 years prior, and "he was still able to put everything into words…" But other concurrent request patients had more significant impairments; one patient diagnosed with Alzheimer disease 8 years prior could no longer dress himself independently and did not understand the purpose of a consultant's visit 2.5 weeks before EAS (2015-66).

In 15% (9/59) of concurrent request cases, the patient was viewed as incompetent to request EAS by

TABLE 2. Physician Refusals of Patient EAS Requests and Characteristics of the EAS Evaluation and Implementation Process

	Concurrent Request N = 59		Advance Request N = 16	
	No.	%	No.	%
Initial request refused by patient's primary physician	23	39	6	38
Reasons for refusal[a]	29		7	
Case related		[b]		
Thought due care not met	4	14	2	29
Too complex	6	21	1	14
Did not know patient well enough	2	7	0	0
MD related				
Does not perform: EAS per se (3),nonterminal EAS (2), or dementia EAS (1)	6	21	1	14
Own reasons (3), emotional reasons (1), or "EAS fatigue" (1)	5	17	0	0
Unspecified	6	21	3	43
EAS MD is new to patient[c]	25	42	7	44
EAS physician				
Primary MD	34	58	9	56
GP but not primary MD	2	3	0	0
Nursing home MD	0	0	1	6
Other MD	2	3	0	0
End-of-Life Clinic involved	21	36	6	38
No. of official EAS consultants				
0	1	2	0	0
1	50	85	13	81
2	8	14	3	19
No. of SCEN consultants				
0	1	2	0	0
1	51	86	13	81
2	7	12	3	19
No. of physicians engaged in discussion of the case not counting the EAS physician				
1	16	27	3	19
2	25	42	8	50
3	13	22	3	19
4	3	5	1	6
5	2	3	1	6
Second opinions				
Geriatrician	18	31	12	75
Psychiatrist	22	37	2	13
Neurologist	3	5	1	6
GP or unspecified	2	3	3	19
Psychologist	2	3	0	0
End-of-Life clinic multidisciplinary meeting	1	2	0	0
Cases with disagreement among EAS physician, consultants, and second opinions	11	19	5	31
Issues of disagreement (can have more than one per patient)	14		6	
Voluntary and well considered	11		5	
Unbearable Suffering	2		1	
No prospect of improvement or no reasonable treatment	1		0	

(*continued*)

TABLE 2. (*continued*)

	Concurrent Request N = 59		Advance Request N = 16	
	No.	**%**	**No.**	**%**
Body language used as an important aspect of identifying a voluntary and well-considered request	7	12	11	69
Patient deemed incompetent by at least one MD involved	9	15	16	100
EAS MD used audio/video evidence	6	10	4	25
Involved an ambiguous or ambivalent request				
Ambivalent (puts request on hold at least once)	7	12	1	6
Ambiguous	6	10	8	50
Both	1	2	1	6
Patient awareness of EAS at time of implementation				
Aware	58	98	7	44
Unaware	0	0	5	31
Unclear if aware	1	2	4	25
Was the EAS implementation procedure altered?				
Unaltered	57	97	10	63
Altered	2	3	5	31
Unclear if altered	0	0	1	6
Case was deemed due care not met by review committee	3	5	4	25

Notes: EAS: Euthanasia and assisted suicide; SD: standard deviation; SCEN: Support and Consultation on Euthanasia in the Netherlands.

[a] More than 29 reasons for refusal because some cases involved refusals by 2 doctors or doctors gave more than 1 reason.

[b] Percentages reported as percent of reasons given by physicians.

[c] In 88% (28 of 32) of cases where the physician was new to the patient, the initial physician refused. In the remaining four, an additional physician was needed to assist in a couple's euthanasia (2014-27b), the patient recently changed physicians (2016-85; 2015-66), and the patient approached the End-of-Life Clinic directly (2016-82).

a physician at some point, either by their own physician or in the evaluation process (Table 2). In some of these cases, the patient's past conversations were used to confirm competence to request EAS. In 2018-21, the consultant said the "patient was no longer competent" but met the due care criteria because "it is reasonable to assume that the euthanasia wish of the patient has not changed." The consultant appealed to the patient's previous conversations with his family doctor and wife in support. In other cases, consultants appeared to declare the patient incompetent, but later clarified their views (e.g., 2015-66). In 2014-33, one consultant reported that the "patient was not competent at [the time of her evaluation] but she had been until recently. Her desire for euthanasia had been so consistent lately that the reduced competence should not be a stumbling block..." and later said to the RTE that "...the patient was not fully competent, but she certainly was with regard to her request."

Patient body language played a role in the evaluation of 12% (7/59) of concurrent request cases: "The consultant had decided that [the] patient's request was voluntary and repeated not so much because of the verbal expression of a euthanasia request, but because of her body language" (2014-66). In another concurrent request case, the EAS physician thought that the patient could consistently communicate verbally and nonverbally the "essence" of her wish until her death: "Every time she requested euthanasia, she would remove her wedding ring and her watch" (2013-96).

Twelve percent (7/59) of concurrent request cases involved ambiguous requests that required physicians to interpret phrases, gestures, or both: "the patient requested the physician to actually implement the termination of life in the terms 'last bus ride' and 'end time'" (2018-21); "She sometimes just babbled...but then she suddenly could say something...[s]he indicated her wish to die...although indirectly and sometimes cryptically" (2016-39); "The patient made it clear in body language and in word repeatedly that she wanted to be helped with going to a different life, using the word euthanasia regularly" (2014-33); "[the] patient answered with 'ready is ready' when [the consultant] had asked her whether she wanted to die. From the context it was clear to the consultant that this remark was a request to let her die" (2014-66).

Fourteen percent (8/59) of concurrent request cases involved patients putting requests on hold temporarily at least once. Some temporarily withdrew multiple times (e.g., 2016-23), and some withdrew requests at the time of implementation (e.g., 2018-11 in which the patient received EAS 3 months later).

Characteristics and Uses of Advance Euthanasia Directives

Forty percent (30/75) of patients had an advance euthanasia directive (Table 3). In 75% (12/16) of advance request cases, a physician was involved with its preparation, including evaluating patient decision-making capacity or discussing trigger criteria (i.e., conditions under which a patient would desire EAS). Eighty percent (24/30) of reports mentioned at least one such criterion; admission to a nursing home/institution was the most common (43% [13/30]). Other EAS triggers included, "inability to recognize people" (2015-37), "losing her dignity" (2018-41), being "completely dependent" (2016-38), "being sad"

TABLE 3. Characteristics and Uses of Advance Euthanasia Directives (n = 30)

	Concurrent Request N = 14		Advance Request N = 16	
	No.	%	No.	%
An MD involved with advance euthanasia directive preparation	1	7	12	75
Triggers mentioned[a]	9	64	15[b]	94
At least 1 update to advance euthanasia directive	8	57	9	56
Role advance euthanasia directive played for EAS MD's evaluation				
The basis for voluntary and well-considered request	0	0	16	100
Played a significant role but was not basis	6	43	0	0
Played some role but not as basis	3	21	0	0
Played no role	5	36	0	0
Role advance euthanasia directive played for RTE's review of case				
The basis for voluntary and well considered request	0	0	16	100
Played a significant role but was not basis	5	36	0	0
Played some role but not as basis	1	7	0	0
Played no role	8	57	0	0

Notes: EAS: Euthanasia and assisted suicide; RTE: Regional Euthanasia Review Committee.

[a] Triggers are conditions specified in the advance euthanasia directive that would "trigger" an evaluation and discussion about EAS for that patient if she were incompetent.

[b] One advance request case (2017-14) did not specify triggers in report.

(2016-39), or feeling "permanently unhappy" (2016-62). An update after initial creation of the advance euthanasia directive was described in 57% (17/30).

By definition, advance euthanasia directives were the basis for a voluntary and well-considered request in advance request cases. However, physicians or the RTE appealed to advance euthanasia directives when assessing the voluntary and well-considered request criterion in 15% (9/59) of concurrent request cases as well. In a case the RTE designated as a concurrent request, the consultant was unable to determine whether the patient was competent, and was therefore of the opinion that "Article 2, Section 2" (i.e., section of the Dutch EAS law specifying advance requests) applied. However, the EAS physician "felt that [the] patient until the very end was indeed capable of making a decision about her request despite the fact that [the] patient did not satisfy Appelbaum's criteria," with the RTE agreeing that "[t]he physician's opinion that [the] patient still knew what she asked, was confirmed by [the] patient's statement of intent and living will" (2016-39). In another concurrent request case, the consultant believed "[t]he patient was not competent because she could no longer fully oversee the consequences of her wishes and actions. Despite the incapacity... the consistent wish of the patient was still in line with her personality and background" (2013-96). The consultant concluded that the due care requirements were met partly because of "the patient's competence at the time of the preparation of the written directive and the recording of the video, and the 'maintenance' of the request..." He later said to the RTE that "the patient had been competent regarding her request, but that she was incompetent in all other areas."

EAS Implementation Procedure

Some EAS implementation procedures were modified (e.g., administering premedication) and are described in Table 4. In advance request cases without modifications, patients were sometimes unaware that EAS was to be performed (e.g., "The patient was not conscious that euthanasia was being performed" 2012-8) or their awareness was unclear (e.g., "It was not totally clear whether [the] patient...was aware of what was about to happen" 2016-38).

Reviews by the Regional Euthanasia Review Committee (RTE)

The RTE asked physicians for additional information (in writing or interviews), about the EAS evaluation and implementation in advance request cases more frequently than in concurrent request cases (75% [12/16] versus 41% [24/59], $p = 0.02$, Fisher's exact test). The RTE judged that due care criteria were not met in 3 concurrent and 4 advance request cases (Table 5). All four advance request cases failed at least one eligibility criteria; concurrent request cases failed only the procedural criteria.

TABLE 4. EAS in Persons With Dementia Where Alterations to EAS Implementation Procedure Were Reported

Case ID	Patient Description	Modification	Modification Summary
Concurrent requests (n = 2)			
2013-96	A woman 80–90 years old, diagnosed with Alzheimer 3 years prior, with nocturnal restlessness, aggressive moods, and complete dependence.	Premedication given	According to the doctor, the patient "...confirmed her request prior to the procedure. She was aware that the medication would be administered. The doctor had first put the patient to sleep by administering Dormicum [midazolam]. Then he had an infusion and injected the euthanatics."
2016-39	A woman 70–80 years old, diagnosed with Alzheimer 5 years prior with history of strokes, aphasia, and behavioral disorders.	Premedication given	The physician handed a drink containing premedication "...which the patient herself drank." The physician thought "[s]he seemed aware of what was about to happen" because the patient asked "'Can we now not continue?'" when there was initial difficulty with inserting the infusion line.
Advance requests (n = 5)			
2014-02	A woman 80–90 years old, with mobility problems, seizures, and aphasia stemming from two strokes within the last 2 years.	Premedication given	The EAS physician prescribed premedication "...in connection with a possibl[e] unpredicted reaction to the insertion of the infusion line." The premedication was given to the patient on the morning of EAS by "[t]he child with whom the patient was staying..." When the EAS physician arrived to perform EAS "... the patient was sleeping/drowsy in bed. At 10:30 a.m. an infusion line was inserted... [t]he patient reacted to the stick, but she remained quiet and was not aggressive."
2016-18	A man 50–60 years old, diagnosed with Alzheimer 8 years prior. Admitted to a nursing home 2 months prior because of aggressive behavior.	Patient not informed of EAS	According to the physician, "[d]uring his stay at the nursing home (and already long before that) it was no longer possible to have a conversation with [the] patient." However, the physician reported that she"...spoke regularly with [the] patient's wife and father during his admission to the nursing home." According to the doctor: "At the moment the euthanasia was performed, [the] patient did not know it. He was not informed because of fear of aggression."
2016-85	A woman, 70–80 years old diagnosed with Alzheimer 4 years prior.	Premedication given surreptitiously	"The physician performed euthanasia by first administering 15mg of Dormicum dissolved in coffee (as premedication) and then after 45 minutes another 10mg of Dormicum by subcutaneous injection... later the physician administered [the euthanatics]. In her report the physician noted that the patient awoke when the thiopental was being injected and put up physical resistance." The EAS physician "...explained that she had administered the Dormicum dissolved in coffee because the patient was not taking any medication and she would probably have refused had she been asked to take the Dormicum herself."
2018-29	A man 60–70 years old diagnosed with Alzheimer 8 years prior. He could no longer speak or recognize his relatives.	Infusion line (as a backup) not started prior to oral administration of euthanatics	According to the EAS physician, "[i]t was not possible to apply an infusion to [the] patient when he was conscious because of his great fear of every touch." However the doctor explained to the RTE that, "[i]t was known that the patient drank everything he was given[,]" and "[e]veryone had the utmost confidence that the patient would drink the barbiturate drink without problems."
2018-41	A woman 60–70 years old diagnosed 6 years prior with Alzheimer was unable to recognize anyone and was completely dependent on the care of others.	Premedication given	According to the report, "[t]he patient took a sleeping tablet (7.5 mg dormicum) in the morning provided by the nursing staff. Then she felt tired, lay down in bed, and fell asleep..." According to the report, the use of premedication "...was motivated by the fact that the patient often had unpredictable behavior...[t]he physician could not exclude that the patient would respond unpredictably to the insertion of the infusion needle due to her condition.... [s]he could have taken the infusion needle from her arm and injured herself." The RTE was "of the opinion that administering premedication...under these specific circumstances falls under good medical practice."

Notes: RTE: Regional Euthanasia Review Committee; EAS: Euthanasia and assisted suicide.

TABLE 5. EAS in Persons With Dementia Deemed to Not Meet Due Care Criteria

Case ID	Patient Description	Criteria Not Met	Summary
Concurrent requests (n = 3)			
2012-31	A woman 80–90 years old diagnosed within the last 2 years with hip pain and limited vision.	Consultation	The EAS physician had no experience performing EAS and reached out to an experienced SCEN physician who was present for the physician's evaluation of the patient and during the EAS implementation. The RTE noted, ". . .the consultant became a co-practitioner, because she took over a considerable part of patient's guidance during the euthanasia process." Although the RTE noted the EAS physician acted in good faith, there was "insufficient distance between [the] consultant and physician. . ."
2016-23	A man 80–90 years old diagnosed with Alzheimer 2 years prior.	Medical care	The physician gave the patient a drug not listed in the Royal Dutch Medical Association's Guidelines for the practice of EAS and at too low of a dose, later requiring the administration of additional EAS agents.
2018-04	A man 70–80 years diagnosed with Alzheimer 2 years prior with disorientation, unrest, and fear.	Consultation	The patient's original GP refused "for his own reasons." The patient then met with the End of life Clinic ". . .for an introductory meeting[,]'" and simultaneously sought out another physician who took over the EAS process. The EAS physician used the End-of-Life Clinic report from the "introductory meeting" as a consultation report without an additional consultant. RTE noted an independent consultant was "more pressing in this case, because the doctor only knew the patient for a short time. . ."
Advance requests (n = 4)			
2012-08	A woman 50–60 years old diagnosed with Huntington's disease 10 years prior also had dementia.	Voluntary and well considered; Unbearable suffering; No reasonable alternative	RTE said the physician could not solely rely on existing advance euthanasia directive because there was ". . .no clear, consistent pattern regarding the patient's wishes about euthanasia over the years." RTE thought there was "little factual material" to support the physician's conclusions about unbearable suffering and that a ". . .nursing home admission might have been a real option..." for the patient.
2014-02	A woman 80–90 years old, with mobility problems, seizures, and aphasia stemming from two strokes within the last 2 years.	Unbearable suffering	RTE noted, "The mere fact that the patient permanently had to leave her own environment and be admitted to a nursing home is insufficient to assume that the suffering is unbearable. The physician moreover did not present any other circumstance (not even the consultant's findings) to support his contention that the patient suffered unbearably. . ."
2016-85	A woman 70–80 years old diagnosed with Alzheimer 4 years prior.	Voluntary and well considered; Medical care	Because "two mutually exclusive interpretations" of the dementia clause were possible the RTE had doubts about the advance euthanasia directive's applicability. Regarding the implementation: ". . .when the patient did respond negatively, the physician wrongly failed to consider whether this could be interpreted as an important sign that she did not want a cannula and a needle to be inserted." In the RTE's view, ". . .the physician should have halted the euthanasia procedure in order to reconsider the current situation instead of proceeding." Regarding the fact that the patient had to be restrained, the RTE wrote, ". . .when performing euthanasia, coercion – and anything that might suggest coercion – must be avoided."
2017-103	A woman 60–70 years old diagnosed with Alzheimer 7 years prior was admitted to a retirement home 3 years before EAS with increased dependence and anxiety/mood disorders.	Voluntary and well considered; Unbearable suffering; No reasonable alternative	The patient handed an advance euthanasia directive to her primary physician 6 years prior and made an oral request for EAS at the same time. The physician refused. After this, "[b]roaching the subject again was not considered, because the general practitioner's refusal had been so adamant." Four years prior to EAS it was noted the patient "did not express any end-of-life request to her family members either. . .." The RTE "considered the content of the advance directive to be insufficient. . .to conclude that it expressed the patient's wishes. . ." partly because the ". . .patient did not reaffirm the advance directive. . ." Regarding unbearable suffering, doctors

(*continued*)

TABLE 5. (*continued*)

Case ID	Patient Description	Criteria Not Met	Summary
			involved "held opposing views" in their assessments. The RTE watched videos from this case and concluded that they "...did not provide unequivocal guidance supporting the physician's assessment that the patient was suffering unbearably." RTE also noted that the patient's care requirements "...exceeded the level of the care home and made it perfectly reasonable to insist that she be transferred to a specialised institution that was equipped to provide the high level of care required."

Notes: RTE: Regional Euthanasia Review Committee; EAS: Euthanasia and assisted suicide.

DISCUSSION

Much of the controversy in dementia EAS has focused on advance requests.[5] There have been studies of physicians,[24–27] discussions of publicized cases,[8,9,28] and committees formed to address dilemmas involved in the practice.[29] However, little is known at the patient level about dementia EAS whether by advance or concurrent request (e.g., patient characteristics, the evaluation process, and the RTE review of cases). Our study of all published dementia EAS cases from the online RTE database fills this gap, with several key findings.

One finding is that advance request patients, who receive EAS based on written advance euthanasia directives, are indeed different from concurrent request patients: they were younger, had more personal experience with dementia, and although they feared future deterioration as in concurrent request cases, advance request patients were willing to live to reach more advanced stages of their disease. It may be that the older concurrent request patients who had greater fear of the future also felt they had less to lose.

Despite these differences between advance and concurrent request cases, a key finding is that although conceptually and legally there is a sharp boundary between advance and concurrent requests for EAS, in practice the boundary is not so clear. For example, in case 2017-14, even though the RTE designated it as advance request EAS, it said the physician "...could reasonably conclude that [the] patient was capable of making a decision about her request" (i.e., concurrent request EAS). Relatedly, the RTE sometimes uses the terms "early" and "advanced" dementia as almost synonymous with concurrent and advance request cases,[4,11] but concurrent request patients can have significant impairments. The advanced condition of some concurrent request patients likely explains why some were viewed as incompetent by at least one physician and why physicians sometimes used advance euthanasia directives or cited body language to aid in determining competence. One or more of these elements were present in 18 of 59 (31%) distinct concurrent request cases.

These observations reflect the fact that some Dutch physicians and the RTE apply the competence requirement in a novel way. The RTE urges "particular caution" in assessing decisional competence,[11] and in theory competence requires that one have the functional abilities "...to understand relevant information ... consider any alternatives and assess the implications of his decision."[11] But in practice, the RTE accepts that patients can be competent even when they are "unable to present supporting arguments" for their request.[11] In such cases, the RTE recommends that "the utterances the patient is still able to make at that point can be assessed in conjunction with earlier oral or written directives, and the patient's behaviour or signals."[11]

Thus, the assessment of capacity in dementia EAS is not the usual application of the functional model of decision-making capacity. Instead, it appears to be either a functional model applied with a low threshold (the ability to express a consistent choice, relying even on utterances and behaviors) or a model that prioritizes a kind of authenticity criterion (focusing on whether the patient's previously stated wishes are still in effect, despite current severe impairments). Either way, a significant degree of functional impairment (e.g., not meeting the "Appelbaum criteria" 2016-39) and incompetence in all other decision-

making domains (e.g., 2013-96) is compatible with being seen as competent to request EAS.

Such a view of competence also explains the discrepancy between the RTE's view that persons in "early stages" of dementia are generally competent to request EAS[11] and the research literature that shows consistently that persons even in early stages of dementia are, based on a functional model of capacity, very often or usually incompetent to consent to treatment,[30] to research,[31] or to write an advance treatment directive.[32]

This departure from a strictly functional framework to a decision-content focused "authenticity" approach is a potentially problematic finding that deserves more ethical scrutiny. In the literature on competence and surrogate consent, the term "authenticity" arises in two ways. One sense refers to the ability to reflectively endorse, identify with, or reject a value or preference. Some have rejected this construal of "authenticity" arguing that it creates a capacity standard that is too demanding.[33] The sense of authenticity employed in Dutch concurrent request EAS cases seems to be in its second sense, namely, authenticity that is normally sought in surrogate decision-making *after* a person has lost decision-making capacity.[34] Thus, evidence (e.g., previously stated wishes) that is typically used to guide surrogate decision-making is used to assess competence, a potentially confusing practice that may account for why some physicians appear to state that a patient is not competent in one sense (by functional criteria) but is competent in another sense (based on previous statements).

Our results also show that advance euthanasia directives often included trigger criteria that could make their implementation difficult, such as "losing her dignity." This may reflect the fact that only a minority of advance euthanasia directives involved physicians at the preparation stage, consistent with other Dutch data on physician involvement in advance euthanasia directive preparation.[35] However, it was notable that most advance euthanasia directives used in advance request cases (75%) had physician involvement at the preparation stage, suggesting that EAS evaluators are more likely to adhere to an advance euthanasia directive if it has been discussed with a physician prior to its implementation. Nevertheless, greater physician involvement is needed to ensure that patients are competent to draft advance euthanasia directives and that trigger criteria are specific and realistic.[14]

Even when a clearer trigger criterion (e.g., admission to a nursing home) is met, advance euthanasia directives only speak to the voluntary and well-considered criterion and the physicians must still assess the patient's unbearable suffering.[11] In case 2014-02, the RTE notes that the mere fact of a nursing home admission is insufficient to meet the unbearable suffering criterion. That the doctors struggled with this criterion (e.g., doctors holding "opposing views" in 2017-103) is consistent with studies that report Dutch physicians find it difficult to determine whether an incompetent person experiences her dementia as unbearable and hopeless suffering.[24,27] Perhaps this explains why three of the four advance request EAS due care not met cases did not meet the unbearable suffering due care criterion.

Another key finding relates to the use of premedication and other modifications to the implementation procedure, particularly in advance request cases. The RTE notes some advanced dementia patients may be unaware that EAS is being performed and respond negatively to the implementation process "...giving the appearance of resistance."[11] This may be why almost a third of advance request cases involved procedural modifications—e.g., using premedication to prevent "unpredictable behavior" in a patient who "could have...injured herself"(2018-41). Although there is no particular legal guidance on this issue, the RTE condones the use of premedication, noting that it "must be assessed in each specific case, taking into account the particular circumstances of that case..."[11] The RTE emphasizes that physicians should keep "meticulous records" of any alterations so they can be assessed[11] yet some physicians may not do this (e.g., 2016-38),[9] a reminder that the retrospective oversight system relies on self-reports by physicians involved in the EAS process.

Moreover, it is not clear how using premedication in impaired patients fits with the RTE's requirement that physicians "be alert to any behaviour and utterances that indicate objection to termination of life,"[11] or with a Dutch disciplinary board's suggestion that physicians should talk to incapacitated patients about the intended euthanasia and use of premedication before implementing EAS.[36] Some commentators criticize the use of premedication because it intentionally deprives the patient of the ability to resist EAS.[7,28] Others point out that talking with an incapacitated patient about using premedication is unlikely to serve

a reasonable purpose.[37] Indeed, procedural modifications and use of premedication remain controversial in dementia EAS and warrant more ethical analysis.[38]

LIMITATIONS

There are several limitations to our study. First, although we used professional medical translations or translations vetted by Dutch-speaking academics, there may be translation-related limitations. Second, the RTE does not publish all dementia EAS cases, limiting generalizability. Additionally, only completed EAS cases were studied. Despite these factors, we note that the RTEs intend the published cases to serve educational, precedent setting functions,[20] and these published reports are the only contemporaneous accounts of dementia EAS with patient-level detail available to inform this important practice. Third, qualitative coding requires judgment in interpretation. Sometimes this was due to case reports not being written in clinical language. Fourth, our use of statistical tests was post hoc using a small sample and should be interpreted with caution.

CONCLUSIONS

Although some controversial cases of EAS involving persons with dementia—especially when based on advance requests—have been discussed extensively[4,7–10], relatively little is known about the practice of dementia EAS in general, especially regarding concurrent requests. Our study shows that concurrent request patients are older, less likely to have had experience with dementia, and more likely to state as present suffering their anticipation of future deterioration. It also appears that key points of debate regarding advance requests[11–16]—including difficulties interpreting advance euthanasia directives, assessing unbearable suffering, and implementing the EAS procedure—are indeed problems that arise in advance request EAS. Our most novel finding is that the dividing line between advance and concurrent request cases in Dutch dementia EAS practice is not clear and is not where one might expect if a strictly functional model of decision-making capacity were used. These findings may be of special interest for those jurisdictions debating whether to permit EAS for persons with dementia.[2,14]

The authors thank Rebecca Dresser and Matthew Morgado for helpful comments on an earlier draft.

The authors report no disclosures.

This research was supported in part by the Intramural Research Program of the NIH Clinical Center. The ideas and opinions expressed are the authors'; they do not represent any position or policy of the National Institute of Health, the Department of Health and Human Services, or the U.S. Government.

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