Advance request in euthanasia and assisted suicide of patients with severe dementia.

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Background/Introduction/Aim

Worldwide, euthanasia or assistant suicide (EAS) was first legalized in the Netherlands in 2002. To permit EAS the medical 'due care criteria' of the Termination of Life on Request and Assisted Suicide Act (TLRASA) should be met, i.e., the request should be (1) voluntary and well considered and (2) expressed after informed consent about diagnosis and prognosis. (3) Suffering should be unbearable, with no prospect of improvement and (4) no reasonable alternatives should be available. According to the Euthanasia Code 2018 of the Royal Dutch Medical Association (RDMA), an independent expert must be consulted in case of severe dementia to assess the decision-making capacity regarding the EAS request. [1]. The Dutch regional euthanasia review committees (RTE) judge afterwards for all EAS cases whether the due care criteria were met and publish a selection of their reports.
The Dutch law is progressive, as EAS for cases with unbearable suffering from chronic diseases which do not necessarily result in death in the near future is permitted, e.g., for psychiatric disorders and dementia [2, 3].
Over the past years, the number of dementia EAS cases has increased. Most cases were reported as concurrent request, meaning that the patient was still competent to make a decision regarding EAS at the time of implementation. However, a small number of requests based on written advance euthanasia directives has been granted, i.e., the condition has already progressed further and at the time of EAS, the patient's decision-making capacity was insufficient. [3]. An American research group has compared concurrent and advance dementia EAS cases in the Netherlands [4]. However, this study was primarily quantitative and advanced EAS cases were compared to a highly selective subgroup of concurrent cases [5].
Aim - To explore key elements influencing the RTE's judgement on whether the due care criteria have been met of EAS cases in severe dementia based on written advance euthanasia requests.

Method(s)

Qualitative study of reports of the RTE published online. The RTE published 94 of the 947 dementia EAS cases they reviewed from 2012 to 2019 and 6 cases from 2020 [6-13]. From those 100 cases, we first selected all 40 cases in which a written euthanasia directive was mentioned. Additionally, we included 3 EAS cases with cognitive impairment due to Alzheimer, Huntington, and multiple CVAs mentioned in the study of Mangino et al. [4] Secondly, two independent researchers (AvdB, GM) selected the advance requests, for which the criterion was incompetence to make a decision regarding EAS. The same researchers subsequently extracted factual data independently of one another (see appendix) and judged the due care criteria, especially criterion 1, i.e., competence to make a decision regarding EAS. Data extraction results were discussed with the entire research group. All disagreements between both researchers could be resolved by discussion with a third researcher (RM).

Results

A total of 21 EAS cases were selected. 12 (57%) patients feared admission to a care facility and 6 (29%) future suffering. Body language played a role in the physician's judgment in 13 (62%) cases. The request of 8 (38%) patients was ambivalent or ambiguous. 6 (29%) patients were aware of EAS at the time of implementation, 9 (43%) unaware, whereas awareness remained unclear in another 6 (29%) cases. While at least 2 physicians have to be involved by law and 3 physicians according to the Euthanasia Code 2018, which also mandates a second opinion, in 13 (62%) cases ≥4 physicians were involved. Moreover, physicians disagreed in 9 (43%) cases on whether the due care criteria had been met.

The RTE judged that 4 (19%) cases were not conducted in accordance with the due care criteria. In 1 of these 4 cases (2014-02) only the criterion of unbearable suffering was not fulfilled. In the other 3 cases, the request was not deemed voluntary and well considered. More specifically, the used directives were unclear (2016-85 and 2017-103) or not updated (2012-08 and 2017-103). Notably, in one case (2014-02), although the directive was drafted 20 years before death, the RTE considered the request voluntary and well considered as the patient had discussed the topic with her GP on numerous occasions. In another case (2016-85) the physician secretly sedated the patient and continued the implementation when she reacted negatively. The RTE deemed this incompatible with the principles of medical due care, arguing that (the suggestion of) coercion must be avoided at all costs.

In 5 cases, while the physician did not consult an independent expert to establish the patient's decision-making capacity, as mentioned in the Euthanasia Code 2018 [1], the RTE found the procedure in accordance with the due care criteria. The RTE explicitly mentioned that the physicians had acted diligently in their contact with the patients and maintaining the medical records, but also stated in 3 of these cases that consulting an independent expert would have been strongly preferred. Methodological considerations - The RTE publishes all EAS cases which would contribute to a better interpretation of the law and/or guide physicians. Selection bias regarding advance requests will be limited, as the extensive debate has led to publication of many advance request cases. We cannot exclude that involvement of a large number of physicians in some cases was due to the lengthiness of the process, in which the due care criteria were not met initially, but were fulfilled over time. This may also explain some of the disagreement between involved physicians.

Conclusions

Examination of the RTE's judgment underlines the need for a clear euthanasia directive in advance request cases, as in 2 cases the criteria voluntary and well considered were not met because of this. Additionally, it becomes apparent that it is essential that the patient confirms their request after writing the directive.
The RTE did not consider consulting an independent expert to establish the patient's decision-making capacity essential for the due care criteria to be met. However, this solely applied when physicians acted diligently.
Recommendations – We would recommend updating a written directive at least every year and think it would be helpful for physicians to regularly discuss the EAS request with their patient and to encourage them to be specific and elaborate in their advance directive. This will facilitate interpretation of the request and the directive in later stages.
Furthermore, physicians should be familiar with the specific requirements of the Euthanasia Code.

References

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Appendix

Patient characteristics

	No.	**%**
Men	10	47,62
Women	11	52,38
Age:		
50-60	2	9,52
60-70	6	28,57
70-80	6	28,57
80-90	6	28,57
>90	1	4,76
Diagnosis:		
Alzheimer	16	76,19
CVA	1	4,76
Huntington's Disease	1	4,76
Vascular dementia	2	9,52
Semantic dementia	1	4,76
Unspecified dementia	1	4,76
Years diagnosed before EAS:		
<2	3	14,29
[2;4>	6	28,57
[4:6>	4	19,05
[6;8>	2	9,52
[8;10>	4	19,05
≥10	2	9,52
Personal experience with dementia	12	57,14
Place of residence at time of EAS:		
Home	9	42,86
Nursing home/care facility	12	57,14

Fear of nursing home/care facility	12	57,14
Fear of future suffering	6	28,57
Fear of waiting too long for EAS	0	0,00
EAS refused by primary physician	9	42,86
EE (End-of-Life Clinic) involved	10	47,62
Body language important	13	61,90
Audio/video evidence used	7	33,33
Request ambiguous/ambivalent	8	38,10