Burden of organ donation after euthanasia in patients with psychiatric disorder

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SUMMARY
Organ donation after euthanasia (ODE) is rarely performed but the number has gradually increased over the years. It has been suggested that the preparatory investigations for organ donation parallel to the medico-legal procedures for euthanasia may be too much of a burden for the patients and their relatives. Furthermore, dying in an intensive care unit might contribute to this burden. Based on two patients who were granted euthanasia based on a psychiatric disorder, we show that the actual burden may be minimal for some patients and their relatives and may even be helpful in their process of euthanasia. Therefore, we propose that providing patients with information about donation of organs after euthanasia may be important to incorporate early in the medico-legal process of euthanasia instead of waiting for the patient to bring up organ donation, as currently advised in the Dutch guideline for ODE.

BACKGROUND
In 2012, the first patient donated his organs following euthanasia in the Netherlands. Organ donation after euthanasia (ODE) is rarely performed but the number has gradually increased over the years. ODE is complex and great care is necessary. The Dutch guideline for organ donation provides a good insight into the Dutch context and working method. For extra background information, refer to box 1. In the Netherlands, most patients who request euthanasia suffer from a malignancy, which precludes organ donation. In contrast, patients suffering from a neurodegenerative and/or psychiatric disease can donate their organs provided they are otherwise healthy and not above 75 years of age. Since 2012, a total of 74 patients have donated their organs after euthanasia. A quarter of these suffered from a psychiatric disorder, which is 3.5% (19 of 519) of all patients who received euthanasia due to suffering from a psychiatric disorder (no dementia) during this same time period. This low percentage may be due to the lack of familiarity with ODE, as well as the presumed burden to the patients and their relatives.

It has been suggested that the screening and preparation of patients for organ donation parallel to the medico-legal procedures for euthanasia may be a burden to the patients and their relatives. Furthermore, losing their loved ones in a technical medical setting (intensive care unit), compared with the intimate and peaceful atmosphere of their own home (which is common), and transferring the deceased patient to the operating room within 5 min following declaration of death may also be burdensome for the family. Finally, the procedure may be burdensome for the intensive care team, who are confronted with a person walking in alive and leaving their ward dead, while they are generally fighting for the life of very sick patients. Empirical data supporting these presumptions, however, are not available.

Positive aspects are also mentioned. For the family, it may be important that the chosen death of their loved one will help other patients. The motives for ODE might be self-determination and altruism, which are important motives for non-directed living donors, comparable with altruistic kidney donation to an unknown recipient. Whether these motives also apply to patients requesting ODE is not clear, especially to patients with a psychiatric disorder.

In the Netherlands, ODE is currently determined by two laws: the Termination of Life on Request and Assisted Suicide Act and the Organ Donation Act. According to the Dutch guideline for ODE, euthanasia and organ donation must be performed in an intensive care unit; however, both procedures need to be performed separately by different teams. Whereas the general practitioner or the psychiatrist will perform the euthanasia, screening, preparation and organ donation will be performed by the staff of the intensive care unit and the transplantation team. Therefore, it is necessary to have one procedure for euthanasia performed by the patient’s physician and a separate procedure for ODE performed by another physician and transplantation team. Moreover, patients should be explicitly informed that they can withdraw their consent for euthanasia or organ donation at any time.
Case report

Box 1 Background information about euthanasia and organ donation after euthanasia in the Dutch context

Euthanasia request of the patient: assessment of due care criteria (Dutch Euthanasia Act)
The patient requests for euthanasia by (multiple) conversation(s) with the general practitioner or the treating specialist. A written declaration of the patient is not obligated. Euthanasia is not a right of the patient and physicians are not obligated to perform euthanasia. If a physician is not willing to perform the euthanasia due to personal reasons, they express this to the patient as early as possible in the process. In this situation, the physician refers the patient to a colleague who is willing to perform euthanasia or to Expertise Center Euthanasia, a professional healthcare organisation that counsels and supports physicians who are helping patients with their request for euthanasia and provide care to patients who, for whatever reason, cannot be helped by their own physician (URL: Careful and caring - Expertisecentrum Euthanasie).

The physician judges whether the euthanasia request meets the first four of the six due care criteria of the Euthanasia Act in the Netherlands.14 (URL: Euthanasie en de wet: sterven met hulp van een arts | Levenseinde en euthanasie | Rijksoverheid.nl; URL: De 6 zorgvuldigheidsseisen van de euthanasiewet | Levenseinde en euthanasie | Rijksoverheid.nl). The due care criteria of the Dutch Euthanasia Act say that the physician must:
1. Be satisfied that the patient’s request is voluntary and well considered.
2. Be satisfied that the patient’s suffering is unbearable, with no prospect of improvement.
3. Have informed the patient about their situation and prognosis.
4. Have come to the conclusion, together with the patient, that there is no reasonable alternative to the patient’s situation.
5. 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 above have been fulfilled.
6. Have exercised due medical care and attention in terminating the patient’s life or assisting in the patient’s suicide.

After the physician is convinced that the request meets the due care criteria, in case of a psychiatric basis of the euthanasia request, a second independent psychiatrist must assess the decisional capacity of the patient, the diagnosis and reasonable alternatives to the patient’s situation to reduce the unbearable suffering. After this, the treating physician must be convinced that the request meets the due care criteria. Thereafter, an independent consultant physician judges if the due care criteria are met. If so, the patient decides with the treating physician how, where and when the euthanasia will be performed.

Euthanasia and organ donation: the procedure

According to the current Dutch guideline ‘organ donation after euthanasia’ (URL: richtlijn-ogaandonatie-na-euthanasie-versie-3-februari-2022.pdf; transplantatiestichting.nl), the patient considering euthanasia initiates the first conversations about the possibility of organ donation with the treating physician. The guideline states furthermore that it is important that two independent teams are involved, one to examine the euthanasia request (treating physician) and another team to judge if organ donation after euthanasia is possible (intensivist, organ donation coordinator, transplantation team).

Box 1 Continued

The treating physician must assure that the patient initiates the request himself, is able to take note of unbiased information about organ donation after euthanasia and has therefore made an informed decision based on the correct information about the consequences. The decision has to be made free from external pressure and the patient must be informed that they can withdraw permission at any time.

► The physician who will perform the euthanasia contacts the hospital organ donation coordinator. Thereafter, extensive examination takes place to judge medical suitability for organ donation. After the decision for organ donation has been made, the date for euthanasia is planned by the treating physician with the patient, relatives, intensivist, surgical team and transplantation team.

informed consent for an interview and to report the cases of their loved ones.

CASE PRESENTATION

Patient A (a woman in her 70s) was granted euthanasia based on an unbearable suffering from a treatment-resistant depressive disorder and a personality disorder not otherwise specified. When she requested for euthanasia, she explicitly expressed her wish to donate her organs after death.

Her motivation for organ donation originated in the death of a relative due to kidney failure while waiting for a donor kidney: “It shouldn’t be possible people die during dialysis without any prospect of a kidney donor.” After the death of her relative, she decided to donate her organs after her own death “so that the recipients get a bit of a life again.” She was informed about the burden of the procedures to her and her family and nonetheless insisted on ODE: “it is my life and my body, it’s important for me.” About the burden of dying in the intensive care unit, she simply said that “it is part of the procedures and organ donation is more important for me (to happen) than dying at home.” With regard to saying goodbye to her loved ones, which is part of euthanasia, she said:

During this process we (husband and I, eds.) grew towards the final moment of saying goodbye. We have discussed everything for the goodbye and my funeral together. Because of the organ donation, the farewell at the ICU might be brief, but that’s not something I dread.

While her husband was initially ambivalent about ODE, he respected her wish. Seven months after her death, he wrote a letter to the psychiatrist (ROV) where he stated: “I have experienced the whole process, including screening and preparation for the final moment in the intensive care, very carefully, both from a medical as well as personal perspective. All professionals have fully supported us emotionally.”

Patient B (a woman in her 30s) underwent ODE based on a treatment-resistant recurrent depression, an eating disorder and a personality disorder not otherwise specified. Her mother and one of her two brothers were interviewed (RM and ROV) on how they experienced ODE 3 years later. They considered the euthanasia was helpful during the grieving process as they were able to say goodbye to their loved one in a dignified manner instead of losing her by suicide (which they feared).

According to the patient’s relatives, she deeply wanted to grant other people a new chance for a healthy and happy life,
although it was no longer possible for her. She literally said she was happy to improve another’s life by donating her organs after euthanasia.

Her brother said that she first spoke to him about her wish to donate her organs after euthanasia, fearing that this would burden her mother. He comforted her that dying in the intensive care unit would not be burdensome for him. Her mother considered an autonomous choice of her daughter to be most important: “my daughter requesting euthanasia was a really hard thing to accept, but I really supported her evident wish to donate her organs afterwards and it was not an extra burden for me.” Also, “my daughter clearly stated which organs she wanted to donate after her death.”

According to the relatives, the organ donation did not interfere with the process of saying goodbye. There was an intense and intimate period of weeks before the euthanasia took place: “the night before the euthanasia we had dinner with the family, it was a very cozy evening together. The last weeks before the euthanasia she (the patient, eds.) was quite relaxed and very consciously saying goodbye to everyone.” The relatives were quite positive about their experience afterwards:

A week before the euthanasia several medical examinations took place. The health care workers were very helpful and showed the room (designated for the euthanasia in the ICU). For the final moment of farewell, we were allowed to bring big vases with flowers to hide the monitors, she did not have to wear hospital clothes… there was no distraction from intimacy, because we were completely in the moment.

According to the protocol, within 5 min following declaration of death, her daughter’s body was transferred to the operating room. Looking back, the mother told us: “because this moment was decided for us, I was freed from the burden of leaving my daughter alone after she passed away.”

Decision making
As organ donation and euthanasia are two different trajectories, two different medical teams were involved and had to independently judge the decisional capacity of the patients. In general, the responsible physician assesses whether a patient has decisional capacity by judging according to the decisional capacity criteria described by Appelbaum and Grisso\(^1\) regarding communication, understanding, appreciation and reasoning. Both patients were judged fully competent to make decisions regarding both organ donation and their request for euthanasia. As determined by law, this was confirmed prior to carrying out the euthanasia. Although it was no longer possible for her, she, while facing euthanasia, was able to make such an altruistic choice to help unknown people. They were satisfied that the wish of their loved one was fulfilled.

OUTCOME AND FOLLOW-UP
Patient A donated her lungs, the cornea of one eye and one kidney. These organs were successfully transplanted in different recipients.

Patient B donated her liver, kidneys, lungs and pancreas, which were all successfully transplanted in different recipients. The relatives of patient B were proud and full of respect that she, while facing euthanasia, was able to make such an altruistic choice to help unknown people. They were satisfied that the wish of their loved one was fulfilled.

DISCUSSION
Both patients were clear in their desire to donate their organs, although their relatives were initially ambivalent. Physicians may become hesitant to continue an ODE discussion in the context of family ambivalence, while from a legal point of view relatives have no influence when the decisional capacity of their loved ones is not compromised. Altruism and autonomy were important drivers for both patients to donate their organs after euthanasia.\(^2\) These motives are in line with those of living organ donors.\(^3\) Regarding the necessary additional procedures, both patients experienced no additional burden from the preparatory investigations for organ donation and judged the perspective of dying in an intensive care unit outside the intimacy of their home as acceptable.

In contrast to the presumed burden of ODE, their relatives did not report any burden at all. In fact, the relatives were proud that their loved ones could contribute to the better life of other people. Moreover, the farewell at the intensive care unit instead of at home was not reported to be stressful in any way and the relatives felt supported by the physicians who performed the euthanasia as well as the staff of the intensive care unit. This is probably because, in the Netherlands, dedicated nurses and intensivists take care of these patients. Moreover, dying in an intensive care unit did not interfere with the farewell process itself, as in both cases sufficient time was available for the patients to say goodbye to their relatives in the weeks before euthanasia was performed.

Although generalised conclusions are not possible based on these two cases, our findings contradict theoretical reflections on ODE in the literature.\(^1\) To our knowledge, empirical data on the burden among relatives involved in ODE are lacking. Therefore, future studies are needed to explore whether our findings are likely to pertain either to these specific cases only or to receiving euthanasia on psychiatric grounds, or whether these findings are more generalisable.

In both cases, the choice of ODE was raised by the patients themselves. The physicians complied with the Dutch guideline,\(^3\) as according to the main recommendation in this guideline\(^6\) a physician should not raise the topic of organ donation with a patient who requests euthanasia. However, the timing and the manner in which the ODE is discussed with the patients are a matter of debate.\(^3\) Regarding the relatives of patient B stated that physicians have the obligation to give information about the possibility of organ donation when patients request euthanasia for them to make a fully informed and autonomous decision. According to the Donation Act, all physicians have the obligation to check the donor registration when facing a dying patient.\(^23\) To support patients in their (potential) choice about organ donation, they should receive all medical and legal information about ODE in an unbiased way.\(^23\) We propose that this should be given at the earliest convenience after a request for euthanasia, as making an informed choice according...
to the patient’s own preferences and values is often an interactive process. These recommendations are in line with the model of shared decision making, which has been shown to contribute to the most appropriate outcome for the patients and their relatives in case of complex healthcare issues.

The present case report shows many areas that should be explored in future research. Some patients who would otherwise donate organs after euthanasia might not donate unless they are informed about the option for ODE early in the medical-legal process. In this context, it is important to realise that donations can contribute to dignified dying, give meaning to their lives and can support relatives in their grief. Furthermore, ODE may also help reduce the rising number of patients on the waiting list for organ donation. Currently, about one-fifth of patients on these waiting lists are successfully transplanted each year. Mixed method studies are the most appropriate to explore the number of patients requesting ODE and to explore in more depth how we can optimise the necessary assessments and procedures fully respecting the personal preference of each individual patient and their relatives without any external pressure.

Learning points

- It should not be presumed that combining euthanasia and organ donation is a burden to the patients and their relatives.
- Organ donation validates the autonomy and altruism of patients who request for organ donation after euthanasia.
- A dedicated team in the intensive care unit is highly valued by patients who donate their organs after euthanasia and their relatives.
- We strongly recommend providing all medical and legal information about organ donation after euthanasia at the earliest convenience after a patient’s request for euthanasia.

Case report

The patient and family members in this case report stated that the previously assumed burdensome aspects of ODE were not present.

During the interview, patient A stated: “I have several examinations at the hospital this week, which I don’t see as a burden but as a necessity for organ donation which is a strong wish of mine.”

When publishing this case report both patients already passed away, making an additional patient’s perspective impossible. The family members were able to explain their perspective in more detail.

Husband of patient A: “I can fully relate to the rendering of the interview with my wife. In retrospect there is only one thing important to mention. Unfortunately, due to the COVID-19 pandemic only two relatives were allowed at the ICU; I would have preferred that more relatives were there for support.”

The family of patient B was also very clear about the timing to bring up the possibility of ODE after euthanasia.

Mother of patient B: “I think, that as a doctor, you have the obligation to let your patient make a well-informed choice about this subject. Therefore, you don’t have to wait for the patient himself to bring up the subject of organ donation after euthanasia.”

Brother of patient B: “I think doctors should list it as an option because I didn’t know it was even an option. This way people can make their own choice, just like they can choose euthanasia themselves.”

Introduction of all coauthors to both patients

In addition to the case report, patient A also agreed to be interviewed on video for training purposes. The coauthors have taken part in these interviews. Before and after these interviews, the authors have spoken to the husband.

The mother of patient B as well as her son have been interviewed during a clinical case conference at our department. Before having participated in this clinical demonstration, the coauthors have spoken to her in more depth.

Contributors

GM wrote the first draft of the manuscript, contributed to analyses and interpretation of the interviews, was responsible for the first literature search and contributed to the final draft. ROV interviewed the patient and the relatives, contributed to interpretation of the interviews, commented on the drafts of the manuscript and contributed to the final draft. JB contributed to interpretation of the interviews, contributed to the literature search, commented on the following drafts and contributed to the final draft. RM interviewed the patient and the relatives, was responsible for the planning, contributed to interpretation of the interviews, commented on the drafts of the manuscript and contributed to the final draft. He is responsible for the overall content as guarantor. The guarantor accepts full responsibility for the finished work and/or the conduct of the study, had access to the data, and controlled the decision to publish.

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Competing interests

None declared.

Patient consent for publication

Next of kin consent obtained.

Ethics approval

As the interviews did not involve subjective the patient or their relatives to any procedure or require them to follow any particular rules of behaviour, this report fell outside the scope of the Medical Research Involving Human Subjects Act (WMO) and thus formal ethics approval was not required.

Provenance and peer review

Not commissioned; externally peer reviewed.

Case reports provide a valuable learning resource for the scientific community and can indicate areas of interest for future research. They should not be used in isolation to guide treatment choices or public health policy.

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