Facilitating the wishes of patients who choose both MAiD and organ donation

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The linked article by Downar and colleagues presents guidance for policy for managing deceased organ donation in conscious, competent donors who request medical assistance in dying (MAiD) in the Canadian context.[1] Preparing guidance for policy in this area is not easy. Arriving at sound recommendations requires scrutiny of the procedure in terms of its desirability and due care, key principles in medical ethics (e.g., protection of autonomy and nonmaleficence), and safeguarding the rights of physician conscientious objectors not to be involved. This article is a reflection on the Canadian guidance and the creation of the Dutch clinical guideline currently in use in the Netherlands.

The first clinical guideline for conducting organ donation after MAiD was presented in 2017 to the Minister of Health in the Netherlands, where the practice of organ donation after MAiD started in 2011.[2–5] The need for responsible guidance in the Netherlands arose in response to spontaneous performance of the procedure and the existence of only basic practice manuals, which raised critical questions about related ethical, legal, medical and logistical issues.

Experience in the Netherlands has shown that the wish for organ donation after MAiD originates from patients themselves. The idea of donating their organs after death gives them a sense of purpose and fits with the autonomous determination of the final phase of their life. For many patients, it offers a paradoxical possibility to do good with the diseased body that has also led them to request MAiD.[5] Furthermore, for recipient patients with failing organs, greater availability of donor organs is desirable.

However, it is important to protect patients from harm. To be eligible for MAiD, patients must have a grievous and irremediable medical condition. This makes them vulnerable and susceptible to influence. As death results in organ availability, there is potential for conflicts of interest. Patients could feel pressured to choose MAiD because of a suggestion that they could donate their organs, thus compromising patient autonomy.

Although patients should be informed of the option of organ donation after MAiD, they should be able to choose the procedure and change their minds — without feeling any pressure — right up until death. In the recently published Dutch guideline, the importance of avoiding pressure led to a recommendation to take a "patient-initiated request" approach.[3] For example, the mention by a trusted physician of the possibility of organ donation after a patient's request for MAiD could be perceived as a suggestion by the physician and would not be consistent with the recommended approach. This emphasis does, however, mean that general information about organ donation after MAiD should be available through public channels.

It is clear from Dutch and Canadian legislation that the decision to undergo MAiD must be separate from, and precede, the decision to donate organs. However, one might interpret this to mean that the patient may be approached by parties with an interest in donation after their decision to undergo MAiD. But this ignores the dynamic nature of the patient's decision-making process. Often the decision is not straightforward; sometimes people change their minds about MAiD right up until the end. To what extent are patients still free to change their minds after encountering parties with an interest in donation? For the Dutch guideline, this resulted in reinforcement of Eurotransplant's fundamental policy rule for organ donation after MAiD to "keep procedures as separate as possible" by having all contact regarding donation, at the initiative of the patient, take place via a trusted person, such as the family doctor.[6]

KEY POINTS

- Experience has shown that the desire for organ donation after medical assistance in dying (MAiD) originates from patients themselves because it offers a welcome possibility to do good with the diseased body that has also led them to request MAiD.
- The explicit focus of a guideline dealing with organ donation after MAiD must be on preserving the patient's autonomy and avoiding doing harm, to preserve the confidence and trust of the public and society as a whole.
- To avoid any real or perceived conflict of interest, health care professionals providing end-of-life care and MAiD for a patient should not be involved in discussions regarding donation.
- The interests of the conscious, competent patient requesting MAiD always take priority over whatever organs they may be able to pass on.

Where a patient's desire to undergo MAiD is driven by the desire to donate organs, this would conflict with the basic legal requirements of due care for MAiD itself and would be unlawful in the Netherlands. Responsibility for recognizing that the patient's desire to be an organ donor is driving their decision, and acting accordingly to deny the request, lies with the MAiD provider.

Ensuring nonmaleficence includes protecting the "dead donor rule"; that is, the patient must be deceased before organ procurement commences. However, the 5 minutes of circulatory arrest required for determination of death reduces the quality of the donor organ, and this creates a potential conflict of interest. Strict, burdensome, arterial monitoring can confirm absence of pulse for 5 minutes if anterograde assessment methods of circulation absence are undesirable for the sake of optimizing the quality of the donor organ.[5]

Protection from nonmaleficence also includes protecting the vulnerable patient from unnecessary burden. The choice to donate organs after MAiD means the patient must submit to preparatory investigations, admission to hospital while conscious, and placement of an arterial line; they must die in unfamiliar surroundings with next of kin initially having only a limited time to grieve over the body. The Dutch guideline offers the option of limited donation, which means minimal preparatory investigations; however, this usually means that fewer organs can be recovered and transplanted.[3] A newly developed approach that minimizes patient burden without compromising organ quality or quantity is organ donation after MAiD in the home.[7–9] This enables the patient's wishes to be implemented with minimal disruption to the dignity of dying outside the hospital, in more familiar circumstances.[10] The experience of dying at home is separated from subsequent investigations, biological death and organ donation in hospital, using an anesthesia bridge by ambulance transfer relatively independent of transport duration. The first domestic case of organ donation after MAiD in the Netherlands was accompanied by a national broadcast.[10]

Concerns have also been raised regarding the direct influence of MAiD itself on organ quality, as well as disease transmission via donor organs. These concerns apply to organ donation generally. In 50 cases of organ donation after MAiD in the Netherlands to date, no issue has arisen regarding damage to organs as a consequence of the process of MAiD, but research is still needed. Potential risks will need to be balanced against the seriousness of the organ recipient's illness.

Safeguards must exist to ensure that health care workers with conscientious objections to MAiD have the freedom not to be involved in organ donation after MAiD. Medical assistance in dying is not considered a medical treatment in the Netherlands; its provision is not compulsory. It is important to consider and identify all the stages in the process, from MAiD request until implantation of the donor organ, when an objection could apply. A related ethical issue is whether to disclose to the potential organ recipient that the organ was donated after MAiD. Decisions regarding these issues must reflect regional values.

When preparing policies for a sensitive subject such as organ donation, the explicit focus must be on the patient undergoing MAiD. To preserve the confidence of the public, policies must clearly centre on protecting the patient who has chosen MAiD. With procedural decisions, the interests of the living patient who has chosen MAiD always take priority over whatever organs they might pass on after death. The linked guidance for policy represents an important step toward creating a Canadian guideline to support health care workers for the benefit of the patient who chooses organ donation after MAiD.

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