Obtaining consent for organ donation from a competent ICU patient who does not want to live anymore and who is dependent on life-sustaining treatment; ethically feasible?

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Abstract

We anticipate a further decline of patients who eventually will become brain dead. The intensive care unit (ICU) is considered a last resort for patients with severe and multiple organ dysfunction. Patients with primary central nervous system failure constitute the largest group of patients in which life-sustaining treatment is withdrawn. Almost all these patients are unconscious at the moment physicians decide to withhold and withdraw life-sustaining measures. Sometimes, however competent ICU patients state that they do not want to live anymore because of the severity of their illness or the poor prognosis and ask for withdrawal of life-sustaining measures like mechanical ventilation. Do we consider the unconscious patient as potential organ donor before withdrawal of mechanical ventilation? This is paradoxically rare in the case of the conscious ICU patient. Is it practically possible and ethically feasible to obtain consent for organ donation from this group of patients?

Introduction

Since the first observational descriptions of brain dead patients by French and German neurologists in the late 1950s, many thousands of artificially ventilated patients in intensive care units worldwide have been declared dead after the determination of irreversible failure of determined brain functions, and in almost all cases in favour of organ donation for transplantation.[1,2] Brain death has always been a rare outcome of intensive care treatment of patients with severe brain damage due to traumatic brain injury, or severe forms of stroke (subarachnoid haemorrhage [SAH] and intracerebral haemorrhage). Recently it was demonstrated that the percentage contribution of brain dead organ donations to the total of organ donations has been decreasing significantly in the Netherlands in the past 15 years.[3] Due to changes in demographics, increased traffic safety, improved treatments like early coiling of cerebral aneurysms and legislation prohibiting smoking (an important risk factor for SAH) in public places we anticipate a further decline of patients who eventually will become brain dead.[3] Considering the fact that the brain dead donor is the ideal organ donor, since only when brain dead is diagnosed there's the possibility to procure the heart and the organs will generally have a better quality, an anticipated decline in brain dead donors means a further setback for transplantation medicine. Therefore many initiatives are developed and deployed in order to decrease the gap between patients awaiting an organ and the number of actual organ donors. These initiatives include a better organization of donor care on a national, regional and hospital level inspired by the Spanish model or a change in the system of consent.[4] Several European countries like Spain, France, Belgium, Austria and Sweden adapted a form of

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DOI: 10.1177/1477750912474762

presumed consent or opt-out.[5] Some North European countries like the UK, Denmark Germany and the Netherlands have considered a system of opt-out but eventually choose to maintain their current system of opt-in.[6,7] Taking into account the diminishing supply and the growing need for organ transplantation, one has to pursue and analyse every potential area of improvement.

The intensive care unit (ICU) is considered a last resort for many patients with severe and multiple organ dysfunction. Therefore it is the hospital department with the highest mortality rate. Approximately 15% of all admitted patients die on a mixed ICU. End of life care is considered a vital part of the ICU. The majority of the patients who die on the ICU die as a result of withholding or withdrawing life sustaining treatment.[8] According to a paper by Sprung *et al.*[9] the primary reasons for the end of life decisions are unresponsiveness to therapy (no diagnosis reported in the paper), neurological reasons, chronic disease and multiorgan failure. In a recent paper, Verkade *et al.*[10] studied the incidence of withdrawal of life-sustaining treatment in various group of patients in a single centre, mixed ICU in the Netherlands. Patients with primary brain failure constituted the largest group of patients (86/174, 49.4%) in which life-sustaining treatment was withdrawn. Specifically this group of patients is most likely to be eligible to eventually donate organs after death, but only a few will eventually reach the state of brain death. For this reason donation of organs after circulatory death is increasingly considered. In the Netherlands the number of donations after circulatory death increased from 118 patients in the period 1995–1999 to 453 patients in the period 2005–2009 according the annual reports of the Dutch Transplant Foundation.[3,11] At the same time the amount of brain dead organ donors is significantly declining. Nowadays in many countries, organ donation after circulatory death forms an important source for kidney, liver and lung transplantation. All these patients are deeply unconscious or deeply sedated at the moment life-sustaining measures are withdrawn.[12]

However sometimes competent ICU patients, who are dependent on intensive care measures like mechanical ventilation, state that they do not want to live anymore because of the severity of their illness and the poor prognosis and ask for withdrawal of life-sustaining measures in order to die.[13] In most cases in the Netherlands, the autonomy of these patients is respected and life-sustaining treatment is then indeed withdrawn. Recently we described two conscious patients who died on the ICU after they asked for withdrawal of life sustaining treatment.[13] In which way do they differ, besides the level of consciousness, from the other patients in which we withdraw treatment and in which we consider organ donation? Why do we not consider these conscious patients as potential organ donors before withdrawal of mechanical ventilation?

There is some experience with organ donation after planned deliberate termination of life (euthanasia) in Belgium,[14,15] but we are not aware of documented cases in which ICU physicians ask patients, before withdrawal of life-sustaining treatment, if they are willing to donate their organs after death. In the light of the scarcity of organ donors, perhaps we have to reconsider this point of view. The aim of this paper is to discuss the pros and cons of such a change in end of life care, focusing on the current ethics and the practical feasibility.

Scenarios

The following two cases that have been selected to engage the discussion of ethics.

Patient A, a 45-year-old electrician, is admitted to the general ICU after a fall from a ladder. The fall resulted in fractures of three cervical and one lumbar vertebra, and mild traumatic head injury. During his stay on the ICU he shows no improvements of his tetraplegic status. In the weeks thereafter it is impossible to wean the patient from the mechanical ventilator. He eventually regains full consciousness and can communicate with eye blinking and later by lip reading. He is informed about his clinical situation. The patient is well aware of his situation and the unavoidable restrictions for his future daily activities. Several weeks after admission, he repeatedly expresses a clear wish to have life sustaining treatment withdrawn and asks the ICU team to take him off the mechanical ventilator. After several deliberations between family members, various physicians, nurses and a clinical ethicist we agreed to offer him, according to his will, deep palliative sedation, followed by withdrawal of life sustaining treatment. After initiation of intravenous administration of midazolam the patient enters a deep sleep. Inotropic support and mechanical ventilation were withdrawn. After 15 minutes the patient died peacefully in the presence of his family.

Patient B a 45-year-old business administrator, is admitted to the ICU with severe neurological injury after a high-speed road traffic accident. A computed tomography scan shows several subdural haematomas, a skull fracture and compression of the brainstem. Because of the low Glasgow Coma Score (GCS) score the patient is intubated and connected to a mechanical ventilator. When the patient is neurologically assessed by a neurosurgeon he has a GCS of $E_1M_1V_1$, an absent pupil and corneal reflexes. However because of some intact brainstem reflexes the patient is not considered to be brain dead. After several weeks of ICU treatment, the patient shows no neurological improvement. In a multidisciplinary meeting it is decided to withdraw life-sustaining treatment based on the poor prognosis of the patient. When discussing this decision with the family, the treating physician also mentions the option of organ donation. Because the patient is not registered in the national donor register, the relatives of the patient are mandated by law to make the decision regarding organ donation. After much discussion they agree with organ donation according to the protocol of donation after circulatory death (DCD). In the presence of the family the mechanical ventilator and other life sustaining therapy are withdrawn. The patient dies after 30 minutes of cardiopulmonary arrest. After

the mandatory five-minute 'no-touch' period the patient is transferred to the operation theatre for organ retrieval.

Discussion

When comparing both scenarios there are many similarities but also some important differences. Both patients die as result of an action, namely the withdrawal of life-sustaining measures, which is done by the physician after multidisciplinary deliberation.[16] While in the first scenario the patient explicitly asks for the withdrawal of life sustaining measures in order to die, in the latter case the decision is made by a multidisciplinary group of physicians and other health-care workers. Both patients were suitable for organ transplantation after death but only the second patient donated his organs after the physicians asked consent of the family. The other, conscious, patient could have decided if he wanted to donate one or more organs, but was never approached with the question concerning organ donation.

Essential in the decision process surrounding the withdrawal of life-sustaining treatment in patients who are awake, as we discussed in detail in our previous paper, is respect for the autonomy of the patient. Dutch care-givers have to respect, by law (medical treatment agreement act [Wet Geneeskundige Behandelings Overeenkomst]), the wishes of the patient if they are understandable and within the accepted possibilities of medical care.[17,18] This also implies that a doctor is not allowed to start or continue a treatment that is not wanted by the patient. This is clearly stated in article 450 of the above-mentioned law: 'For all actions and treatments within the treatment contract the explicit approval of the patient is needed'. So there has to be no doubt concerning the cognitive functioning and competency of the patient.[13] According to Beauchamp and Childress an autonomous action should be made by someone (1) who acts intentionally, (2) with understanding of the consequences at hand and (3) without controlling influences that determine their action.[19] In the first case the decision to withdraw life-sustaining therapy is made by the treating physician after the explicit request of the patient. The patient made this request with the knowledge that the withdrawal of the mechanical ventilator and inotropic medication will result in a certain death. He acted intentionally with the limited means of communication he had at his disposal and family or friends did not influence his actions. Nevertheless he was not asked if he wanted to use the option of donating organs after his death.

The ethical basis of deciding to donate organs after death is that it is ideally an autonomous choice, made by the individual when he or she was healthy of mind. The central donor registry, which is an essential tool with regard to organ donation in the Netherlands, is based on this same respect for patient autonomy.[20] When an individual decides that he or she wants to donate organs or tissues after death, then this is effectuated, if possible, in almost all cases. In the case of no registration in the donor registry, the relatives of the patient are approached to consider permission for organ removal after death of the patient, as is described in the second scenario.

In the Netherlands, individuals can ask a physician for withdrawal of treatment, but also for intentional termination of life. This presupposes absolute voluntariness (seen from the patient) and a deliberate act (seen from the physician). It excludes every form of intentional, active, direct, non-voluntary termination of life. In the Dutch 'Termination of Life on Request and Assisted Suicide Act', the requirements of due care are described.[21]

This above-mentioned Act requires that the physician:

Holds the conviction that the request by the patient is voluntary and well considered;
Holds the conviction that the patient's suffering is lasting and unbearable;
Has informed the patient about the situation and about the prospects;
Holds the conviction that there is no other reasonable alternative in the light of the patients situation;
Has consulted at least one other independent physician who must have seen the patient and given a written opinion on the due care criteria;
Has terminated a patient's life or provided assisted suicide with due medical care and attention.

The same requirements, with exception of the last, are applicable for the scenario in which a competent patient on the ICU asks for termination of mechanical ventilation and other life-sustaining measures. In such a situation, taking the above-mentioned requirements in consideration, the request has to be taken seriously. If approved, the patient is brought to sleep with sedatives after which mechanical ventilation is withdrawn and the patient dies. Euthanasia (deliberate termination of life after injection of euthanatica) is very rare in the ICU setting in the Netherlands.[22] Withdrawal of life-sustaining measures is however common.[8,9,12]

Why then do we not just ask patients before withdrawal of mechanical ventilation whether they are willing to donate their organs? There are four arguments that can explain why the patient is not confronted with the donation request:

(1) The patient is not recognized as a potential donor;
(2) There is fear of creating a conflict of interest;
(3) There is fear of creating a self-fulfilling prophecy;
(4) There is fear of harming the doctor-patient relation.

The most obvious reason why the patient is not approached is probably because he's simply not recognized as a potential donor. In the, often emotional, process of handling the patient's request of withdrawing treatment, the focus of the medical team will primarily be on the legal and ethical issues involved with that process and therefore the possibility of organ donation will just not enter their mind in that stage. Since there is, until now, no documented experience with organ donation in these situations, the likelihood that this way of thinking will

change in short term is not great, thereby creating inevitably a vicious circle.

Some scholars will reason that a conflict of interest will arise in such a situation, but we do consider this a moral fiction. The autonomous patient asks voluntarily for termination of life (as in the Belgium cases of organ donation described by Ysebaert *et al.*[14]) or termination of life sustaining measures. It is important to realize that it is not the physician who initiated this, but the patient himself. The physician follows the voluntary and well-considered request. What if the patient asks, besides the request for termination of life or withdrawal of mechanical ventilation, for organ donation after death? Do we have reasons to reject this? We cannot conclude this. We therefore argue that there are no moral objections for asking the patient for organ donation if the request for life termination or withdrawal of ventilation is granted. A conflict of interest can only then arise when the physician himself initiates the process of considering withdrawing of life support for the patient. Although we certainly appreciate an open patient/physician relationship in which all aspects of treatment can be discussed, the initiative for withdrawing treatment in a conscious patient (in analogy with euthanasia) should always come from the patient alone. A 'helping hand' in this decision process is indeed, in cases like this, the key to an unwanted conflict of interest.

Another point of concern that some will mention is the introduction of a potential self-fulfilling prophecy. At this moment when this patient category is not yet recognized as a potential donor this risk is negligible. However, when this changes, the general public may be inclined to think that physicians would be tempted to be deliberately pessimistic about the patient's prognosis to enhance the patient change of request for withdrawal of treatment. Although this is a non-rational factor, it is unfortunately in concurrence with the documented fear of the general public that doctors will be tempted to prematurely declare death in order to procure organs.[23] Distrust of society and henceforth a negative discussion in the lay press, although non-rational, should be regarded as a real threat for the proposed scenario.

In fact, all the arguments proposed in this paper are within Dutch law. Moreover the corner stone for this proposal is that the patient himself must first ask for treatment withdrawal and a second (independent) physician must approve. Therefore it is almost impossible to create a self-fulfilling prophecy in this scenario. The proposed scenario is in fact fully in line with, the generally well supported intention of the Organ Donation Act in the Netherlands; giving everyone the chance to donate his or her organs after dying.[24]

A last argument that may be put against this proposal is the fact that the patient himself may experience pressure in the choice he has to make. Some will argue that the patient will be aware of the fact that 'yes' to the donation question is the desired answer and since the patient is dependent on his physician to withdraw treatment and the provision of care in that process, the patient may feel forced to give an answer that pleases the care-giver, even though it may be in contradiction with his personal values. However, a patient that dares to ask his treating physician to stop a treatment that has been supported by his physician shows already a high level of self-differentiation. The fact that both doctor and patient have been able to discuss such a delicate matter together gives proof of a well-formed doctor–patient relationship. Therefore we think it's highly unlikely that a well self-differentiated patient with a good doctor–patient relation will be tempted to choose something that is against his own principles or values in such a situation.

Organ donation after circulatory death is legally and ethically accepted in many Western countries, taking the dead donor rule in consideration. The dead donor rule is the ethical and legal rule that requires that donors are not to be killed to obtain their organs.[25] The dead donor rule is vital for the donation and transplantation system and helps to maintain the public trust in organ donation after death. After five minutes of circulatory arrest with no ventilation the patient is considered dead and organ removal can take place. The situation is equal in cases where an unconscious patient with devastating neurological damage dies after withdrawal of mechanical ventilation, as in cases where a sedated patient, who was conscious before sedation, dies after withdrawal of mechanical ventilation. Both patients are then equal and suitable for organ donation. For this reason we see no obstacles for organ donation in the described context.

Conclusions

In a medical community in which withdrawal of life-sustaining measures in unconscious and in conscious ICU patients is accepted, where organ donation after death is common practice, and in which there is a shortage of organs for transplantation, there can be no moral objection to ask certain conscious ICU patients to donate their organs after death. Although withdrawal of mechanical ventilation on request of the patient on the ICU is rare and therefore the number of organs that come available is limited, it is still well worth considering. We argue that there are no valid moral and legal objections against it; it is ethically feasible and practically possible to ask the patients for organ donation after death.

Conflict of interest: None.
Funding: None.

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