

Barriers toward organ donation in a Danish University Hospital

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Conflict of interest

No conflicts of interest

Funding

Departmental only

Submitted 30 October 2016; accepted 13 December 2016; submission 24 November 2015.

Citation

Sørensen P, Kousgaard SJ. Barriers toward organ donation in a Danish University Hospital. *Acta Anaesthesiologica Scandinavica* 2017

doi: 10.1111/aas.12853

Background: In Denmark, organ donation-rates are below the average in the western countries. We investigated the donor potential and identified barriers toward organ donation in a Danish university hospital.

Methods: All patients who died in Aalborg University Hospital in 2012 were retrospectively identified. Patients with a CT- or MRI-proven deadly brain-lesion were eligible for inclusion.

Results: Eighty-five patients with deadly brain-lesions were included, and of these 47 patients died in the intensive care unit (ICU). Older age and diagnosis of brain-hemorrhage and infarction were associated with admission to general ward (GW). In 62.4% of the patients the potential of becoming a donor was not identified. No donations occurred from patients dying from intracerebral hemorrhage or brain-infarction although they represented 44.7% of the potential donors.

Discussion: This study reveals a huge, unrecognized donation potential at our hospital. About 30% was lost because they were never admitted to the ICU. After primary admission to the ICU, 15.3% of the potential donors were lost because they were transferred to the GW. In patients who died in the ICU 17.6% of the patients were not evaluated as potential donors. The relatives refused donation in 17.6% of cases.

Conclusion: It would be possible to raise the donation rate considerably if patients with donation potential are intubated and admitted to the ICU. When active treatment is considered withdrawn, possibility of organ donation should be evaluated, and the next of kin be approached by experienced staff.

Editorial Comment

This article examines the issue many patients could technically meet organ donation criteria when they are in their final dying phase, but are not considered for donation. These practices are guided by each country's unique national regulations subject as well as by local medical culture. This single centre retrospective assessment identifies a relatively large number of local patients outside of the ICU who potentially could be donors.

The rate of organ donation from deceased has always been low in Denmark compared to other countries in the western world. The introduction of brain death as criterion equal to heart

fatality criterion in 1990 did not lead to a significant increase in the donation rates. Donation activity took mostly place in the neurointensive care units with neurosurgeons as primary actors

with an average rate of approximately 12.5 donors per million inhabitants (PMP) per year. In 2013 the rate was 10.4 PMP whereas Sweden and Norway had rates of 15.8 and 22.2 respectively.¹

In 2008 the Danish Center of Organ Donation was established, and in the following years several initiatives were taken with the aim of optimizing the existing donor potential. This resulted in a slight increase in number of donors, but still below average in Europe. This is in contrast with the fact that the attitude in the population is in favor of organ donation, as well as the attitude among healthcare staff.²

The patients' path from admission to they become organ donors is going through several steps, of which some are crucial, and concurrent barriers may occur. It is essential that ventilator supported patients with deadly brain lesions are recognized as potential donors. If this is not done, numerous patients with deadly brain lesions may never be evaluated as potential organ donors before life-sustaining treatment is withdrawn, and they die.

The actual number of potential donors in a hospital has never been investigated in Denmark. We conducted a study to evaluate the donor potential in Aalborg University Hospital (AaUH) during 1 year (2012). AaUH is a university hospital that gives service to 580 000 inhabitants, which is approximately 10% of the Danish population. The hospital has 29 intensive care beds, and covers neurosurgery, neurology, and cardiology.

Method

The Danish Health and Medicines Authority has approved this study.

Retrospectively we identified all patients who died in Aalborg University Hospital in 2012. The main diagnosis was registered together with comorbidity. Patients with cancer were excluded, as well as patients dying from multi-organ failure with circulatory collapse, since none of these patients would be suitable for donation.

Secondly, we identified patients with an acute lesion in the brain documented on CT- or MRI-scans performed just prior to death. We

evaluated the degree of severity of the brain lesions, and included all patients with a potential deadly brain lesion.

According to Danish legislation organ donation from deceased persons can only be done after whole-brain death is confirmed. The diagnosis is mostly done by clinical evaluation of brain stem reflexes after several preconditions has been met. One of the key preconditions is the documentation of a structural brain lesion that is irreversible, untreatable and with certainty deadly.

If a structural brain lesion cannot be seen cerebral angiography is used to support the clinical diagnosis.

All the patients included in this study had brain lesions compatible with this precondition.

Patients with non-lethal brain lesions were excluded.

We studied patient charts to register patient data, and to evaluate their paths in our hospital from admission to death.

Data were evaluated using SPSS-ver.22. $P < 0.05$ was considered statistically significant. For statistical analysis we used the Student *T*-test and Fishers Exact-test.

Results

We identified 1195 patients who died in 2012. We excluded all patients with a diagnosis of either cancer or multi-organ-failure.

Acute lesions in the brain were diagnosed on either CT- or MRI-scan in 145 patients just prior to death. In 60 cases the lesion was not considered to be severe enough to cause death. The most common nonfatal lesions were minor brain infarctions, hypoxic lesions, intracerebral bleedings, and subdural collections.

A total of 85 patients had a brain lesion considered deadly. These patients had a potential of progressing to a state where brain death and organ donation could be possible, and they were included in the study.

Fifty-five (64.7 %) patients were males. Mean age was 67 years. The most frequent brain lesion was intracerebral hemorrhage followed by subarachnoid or acute subdural hematomas. Another 15 patients died from anoxic brain damage following cardiac arrest. Nine patients

(10.6%) died from major brain infarction, two (2.4%) from brainstem hemorrhage, and one (1.2%) from traumatic brain injury. (Table 1)

Fifty-two patients (61.2%) were initially treated in the ICU whereas 33 patients were admitted to the GW. There was a statistically significant difference in the distribution between the ICU and the GW with respect to age and diagnosis. Patients admitted to the ICU were younger than patients in the GW, whereas patients with cerebral hemorrhage or infarction were less likely to be transferred to the ICU. (Table 1)

During hospitalization 21 patients were transferred to a different type of unit. Eight patients were transferred from the GW to the ICU. Sixty patients (70.6%) were treated in the ICU at some point of their hospitalization.

In total, 53 patients (62.4%) died from severe brain lesions without being recognized as potential organ donors and evaluated for donation. Twenty-five patients (29.4%) were never admitted to the ICU. Another 13 patients (15.3%) were transferred to GW as their clinical condition was considered to be hopeless. Another 15 patients (17.6%) died in ICU without recognition of their organ donor potentials.

In 32 patients (37.6%) the donor potential was recognized. In 29 cases the relatives were

approached and asked for permission to organ donation. In 17 cases (58.6%) the relatives refused organ donation. In five of those cases the refusal was noticed after formal brain death diagnosis.

In two cases donation was not possible because of poor organ function. In the end 10 of 85 became organ donors (11.7%). (Fig. 1)

The cause of death in the donors was anoxic brain damage in four, subarachnoid hemorrhages in three and another three cases suffered from acute subdural hematomas. Although patients dying from cerebral hemorrhage or infarction accounted for 44.7% of the potential donors, no donations were performed from this group.

All 85 patients had the potential to become brain dead due to the severity of their brain lesions. The 38 patients dying in the GW, though, died as a consequence of respiratory insufficiency and cardiac arrest, since they were not intubated allowing brain death to develop.

In 32 patients where donation potential was recognized signs of brain death were documented in 22 cases, and in 17 cases a formal brain death diagnosis was established.

The length of hospital stay from admission to death was on average 3.7 days (SD 4.8; CI 95%: 2.64–4.7). Fifty percent of the patients died within 48 h, and only 16 (18.8%) stayed in hospital for more than 7 days, because of prolonged period of active treatment in the ICU.

In every case, it was possible to determine the exact time when either initiation of treatment was withheld or curative therapy was withdrawn. The time span from this point until death occurred was on average 1.07 days (SD 0.07; CI 95% 0.93–1.2) and 72 patients (84.7%) died within 48 h from that point.

Discussion

Donation rates have throughout the years been low in Denmark compared to other countries in the western world. The donation rates were constant until 2008, when the new established Danish Center for Organ Donation initiated several activities leading to a slight increase in donation rates. However, the rates are still below average in Europe.¹

Table 1 Patients Characteristics.

	Total	ICU	GW
Gender	55 male/33 female		
Age*	67.0 Years	61.5	75.8
Diagnosis*			
Cerebral hemorrhage	26	12 (46.2%)	14
Subarachnoid hemorrhage	16	13 (81.2%)	3
Subdural hemorrhage	16	12 (75.0%)	4
Anoxic brain damage	15	15 (100%)	0
Cerebral infarction	9	4 (44.4%)	5
Brain stem hemorrhage	2	2 (100%)	0
Traumatic brain contusion	1	1 (100%)	0

Characteristics of 85 patients with deadly brain lesions. Distribution of diagnosis and location of initial admission with respect to diagnosis and age. ICU, Intensive Care Unit; GW, General Ward; * $P < 0.05$.

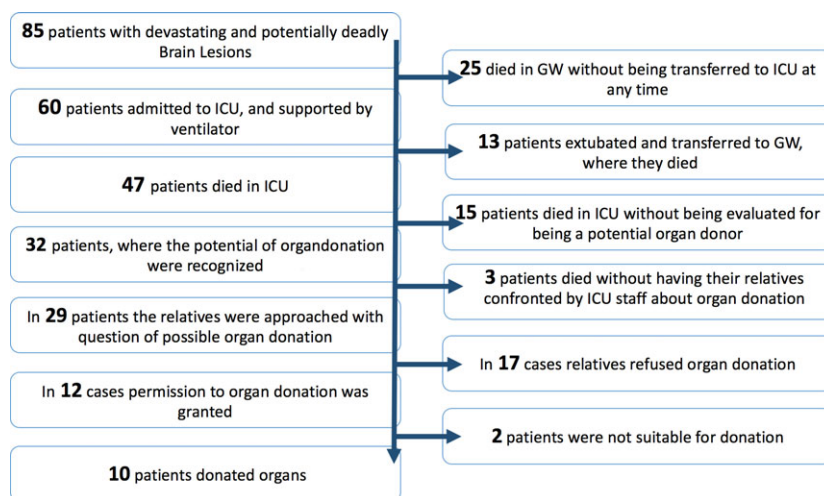


Fig. 1. Pathway of patients with deadly brain lesions. Flow chart presentation of the pathway of 85 patients from admission at hospital to donation is carried out in 10 patients. The chart shows where potential donors are lost for donation. [Colour figure can be viewed at wileyonlinelibrary.com]

This study shows that there are a substantial number of potential donors not being recognized in our hospital. It also shows that there are multiple reasons for this, and potential donors are 'lost' at four major steps as they proceed from admission until death occurs. (Fig. 1)

The first and most significant loss of potential donors occurs because they never reach the ICU, but stay in the GW until death. Old age, cerebral hemorrhage, and thromboembolic brain lesions are associated with significantly less probability of getting admitted to the ICU (Table 1). These factors could indicate a poorer prognosis and therefore determine that active treatment is withheld in the initial phase. Doctors may feel reluctant to intubate the patients at a time, when the prognosis is poor, or they do not want to occupy beds in the ICU with patients without a survival potential.

This is a major sole barrier toward the process of organ donation, not only in Denmark, but all over Europe, as seen in the ACCORD study from the EU Joint Action.³ This report, based on results from 67 hospitals in 15 European countries, shows that 68% of potential donors are lost at this step. Murphy et al. pointed out the necessity to have the right patient in the right place at the right time.⁴

The ICU bed capacity is often mentioned as a critical matter. In Denmark the ICU bed capacity is 6.7 beds/100 000 inhabitants, which is below

the average of 11.5/100 000 inhabitants in Europe.⁵ In Spain, the figure is 9.7/100 000, but despite being below European average Spain has the highest donation rate worldwide.^{1,6,7} This indicates that the ICU bed capacity is not the only limiting factor for donation.

In our study, we found 38 patients dying outside the ICU, which is a little more than three patients each month, that on average stays 1.07 days, before death occurs. With a capacity of 29 ICU beds in our hospital, it is a limited amount of extra ICU beds that are needed to make donor potential evaluation possible for these patients.

Organ donation in Denmark has traditionally been associated with neurosurgical patients and neurointensive care units with mainly neurosurgeons as primary actors in the donation process.

Furthermore, it is necessary to improve awareness of potential donors suffering from non-neurosurgical diseases. Subdural and subarachnoid hemorrhages are the most frequent diagnoses among patients who donate organs, but also patients with brain lesions secondary to hypoxia contributed to the total number in this study. It has become apparent that there is a potential for organ donation among patients suffering from hypoxic brain lesion secondary to cardiac arrest. Reynolds et al. showed that, when using a formalized multimodal neurological assessment 72 h after cardiac arrest, it was

possible to achieve a 10-fold increase in the donation rate from this patient group.⁸

We identified no donations from patients with cerebral hemorrhage or thromboembolic brain lesions although they accounted for 44.7% of the potential donors. The reason for this is mainly because this group of patients was less likely to get admitted to the ICU. Sairanen reported the same paradox, and revised the local guidelines, so that more patients were admitted to the ICU, which resulted in a fivefold increase in the donation rate.⁹

The next step was 13 patients that initially were admitted to the ICU, but later were transferred to the GW. Due to poor prognosis, active treatment was withdrawn, and they were disconnected from the ventilator and referred to a GW awaiting death. In these cases, the only explanation is that the patients were not detected as being potential donors.

The same situation applies for 15 patients who died in the ICU. In these patients, the conditions were in place for developing brain death and hence evaluation for donation, since they were connected to a ventilator, but the opportunity was missed.

It is necessary to improve the donor detection activity. It is obvious that many potential donors are overlooked both inside and outside the ICU, because doctors do not recognize that severely brain damaged patients may evolve brain death if intubated. Doctors may also fail to recognize, that brain death has evolved in patients already in the ICU, when unfamiliar with the brain death diagnosis.

The fourth step of significant loss of potential donors is refusal from relatives. It is quite surprising to see that the refusal rate is nearly 60%, when next of kin were approached with the question of possible organ donation. This is one of the highest rates ever reported.^{10–12}

Finally, refusals from relatives need further attention. In general family refusal rates are high in Denmark ranging between 20% and 40%. The high proportion of refusals in 2012 at AaUH indicates that the circumstances surrounding the family approach is not optimal. The families are approached by the doctors on duty.¹¹ There are no formal demands to their education in communication, though the European Donor Hospital Education program

(EDHEP) has been available for more than 25 years in our country.¹³ There are studies documenting that experienced communicators have less refusals than unexperienced.¹⁴ Still many other factors influences the relatives decision than the communication alone.¹⁵

Special training of doctors seems necessary, unless we should adapt the Spanish concept of having special trained coordinators to deal with the rather unique situation of asking for permission to organ donation in all situations. In Spain the refusal rate is as low as 16.4%.^{12, 16} A special trained coordinator may also assist in donor detection inside the ICUs, and constantly monitor patients with devastating brain lesions. With the support from the newly governmental National Action Plan for Organ Donation, and new recommendations from the Danish National Health and Medicine Authority to prioritize admission of potential donors to the ICU there is hope that the national donation rate can be improved significantly in the coming years.

This retrospective study has some limitations. Very ill patients may get treatment withheld in the initial phase before definite diagnosis is established. Another possible bias is that patients inside the ICU may develop unrecognized devastating brain lesions. All together this indicates that the actual numbers of potential donors could be even higher.

In conclusion, there is a need for a multi-modal effort to overcome in-hospital barriers toward organ donation.

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