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The most important reason for lack of organ donation is family refusal

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ABSTRACT

INTRODUCTION: There is a worldwide shortage of organs for transplantation. This survey aims to compare two periods in the 2000s at a large neuro-intensive care unit with respect to de facto organ donors, potential organ donors and reasons for non-donation.

MATERIAL AND METHODS: This survey is a retrospective examination of all patients who died in the Neuro-intensive Care Unit at Rigshospitalet from 1/1 2000 to 30/6 2003 ("the first period") and from 1/1 2007 to 30/6 2010 ("the second period").

RESULTS: The number of patients who died in the Neuro-intensive Care Unit was 350 in the first period and 270 in the second period. Approximately half of all deceased patients in a neuro-intensive care unit are potential organ donors. Of the potential donors, 42 (27%) in the first and 48 (37%) in the second period became de facto donors. The main reason for non-donation among potential organ donors was lack of consent from next of kin (44% and 40%). The median time from brain death to recovery of organs in the second period was 5 h 45 m.

DISCUSSION: The conversion rate tends to rise. Few people took an active standing against organ donation (10% and 2%); yet many family members refused to consent to organ donation. Consent was provided by the deceased in only 12% and 21% of the cases. The Danish organ procurement team is highly effective with a median time from brain death to recovery of organs of 5 h 45 m. **FUNDING:** not relevant.

TRIAL REGISTRATION: not relevant.

Organ donation is considered an optimal treatment for several end-stage medical conditions. There is a mismatch between the need for and the availability of organs.

In Denmark in 2009, 63 patients died while waiting for an organ, and 553 patients were on the waiting list [1]. Patients in need of organs far outnumber the organs available.

There are several reasons that may explain the shortage of organs, including lack of consent from either the deceased patient before illness or from next of kin. Other reasons could be non-recognition of a potential donor and that some patients are unsuited for donation due to haemodynamic instability. The 2000-2010 period saw extensive discussion of organ donation in Denmark. In departments with many brain deaths, key-personnel were appointed to take care of potential donors, all doctors were taught how to request consent (European Donor Hospital Education Programme courses) and the general staff were taught what brain death is and how organ donation takes place. Furthermore, the Danish Centre for Organ Donation (DCO) was established at the end of 2007, serving multiple purposes, including:

- Optimization of the conversion of potential organ donors to de facto organ donors.
- Coordination of the efforts to further organ donation nationwide.
- Improvement of the care for the next of kin to organ donors.
- Strengthening of effort to educate staff at relevant units.

The public, too, has been involved in the increased focus and were addressed in several campaigns to raise awareness of organ donation.

Organ donation from a brain dead donor requires the following:

- The patient must be declared brain dead.
- Consent must be obtained.

In Denmark, brain death can be declared when the relevant statutory criteria (Executive Order no. 1249 of 06/12/2006) are met. This can happen in two ways: Either by cerebral angiography or by clinical brain stem testing. Correspondingly, consent can also be given in two ways:

- By the deceased himself/herself before illness either by registration in the donor registry or by informing the next of kin.
- By the next of kin.

Brain death is primarily seen in neuro-intensive care units. Brain death is most frequently caused by a brain lesion or a brain disease such as head trauma, cerebral haemorrhage (**Figure 1**) or brain tumour.

ORIGINAL ARTICLE

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FIGURE

Cerebral haemorrhage.



This survey aims to compare two periods, one from the start of the 2000-2010 decade and one from the end of that period at a large neuro-intensive care unit. The two periods were compared with respect to:

- 1. Number of de facto organ donors.
- 2. Number of potential organ donors.
- Number of cases where consent was given by next of kin compared to the number of cases where consent was given by the patient himself/herself.
- 4. How brain death was established.
- 5. Time from brain death to recovery of organs.
- 6. Reasons for non-donation.

MATERIAL AND METHODS Material

The survey include all patients who died at the Neuro-intensive Care Unit at Rigshospitalet (RH) from 1/1 2000 to 30/6 2003 ("first period") and from 1/1 2007 to 30/6 2010 ("second period"). Patients registered as dead in the patient-administrative system in the Neuro-intensive Care Unit were included. The same investigator collected information in both periods. The information needed was collected from the patient records and the organ procurement team's files. In the study period, the unit at RH was one of two large neuro-intensive care units accepting patients from the eastern region of Denmark. Patients from The Faroe Islands and Greenland were all admitted at RH.

The restructuring of neurosurgery in the eastern region of Denmark in 2010 occurred after the end of the second study period.

Methods

The survey was a retrospective examination of all deaths in the Neuro-intensive Care Unit at RH. Information collected from the chart included:

- Time of death, age, gender, cause of brain lesion/ disease.
- Was the deceased a de facto donor?
- Was the deceased a potential donor?
- Was the deceased unsuited for organ donation?
- Was the patient not brain dead?

De facto organ donors

Information about who had provided consent, how brain death was established and the time of brain death and recovery of organs was collected.

Potential organ donors

The potential organ donor is a patient who is, in all probability, brain dead, but a brain stem test may not have been performed. In this survey, these patients are those who are described to be brain dead, but where:

- No next of kin was present.
- The patient himself/herself refused donation.
- The next of kin refused donation.
- The transplant procurement team refuses donation.
- No donation was performed due to forensic examination.
- The patient was not recognized as a potential organ donor.
- Potential donors include de facto donors.

Non-potential donors

The deceased patients in the Neuro-intensive Care Unit who are non-potential donors are either:

- Unsuited for donation, or
- not brain dead.

Causes why patients were unsuited for donation were:

- Haemodynamic instability
- Multi-system organ failure
- Sepsis
- Metastasizing cancer.

Deceased patients who were not brain dead were:

- Not on a ventilator.
- Off the ventilator before brain death occurred.
- Dead shortly after arriving at the hospital.

Those who were off the ventilator were cases in which relatives would not wait for brain death to occur or in which chances of survival to a decent life were very slim. Due to Danish law, brain death can first be established after six hours of coma.

Statistics

All statistic calculations were performed in Microsoft Excel 2003 or SAS Enterprises 4.2. The level of significance was set to p < 0.05. The χ^2 -test was used for Tables 1, 2 and 4 and Fisher's exact test for Table 3.

Trial registration: not relevant.

RESULTS

In the first period, 376 patients died, 15 records could not be found, while 11 died of a non-cerebral cause. In the second period, 299 patients died, six records could not be found and 23 died of a non-cerebral cause. This leaves 350 patients in the first period and 270 in the second for investigation.

The male/female ratio was 57%/43% and 54%/46% in the first and second period, respectively. The median age of the deceased was 57 years in the first period and 54 years in the second period.

The causes of brain lesions in the two periods were comparable. The causes were: Head trauma (37% and 39%), subarachnoid haemorrhage (26% and 29%), intracranial haemorrhage (27% and 23%), cerebral tumour (5% and 4%) and "other" (5% and 3%).

The donors

The ratio of potential to non-potential donors is shown in **Table 1**. Among the potential donors, the ratio of donors to non-donors is shown in **Table 2**.

There was a non-significant increase in relative amount of potential donors from the first to the second period. Furthermore, we observed a non-significant trend towards an increase in the conversion of potential donors to de facto donors from the first to the second period.

Consent

Among de facto donors, five (12%) were registered in the donor registry prior to illness in the first period, while this was the case for ten (21%) in the second period. In the remaining cases, consent was given by the next of kin.

Brain death testing

Cerebral angiography was used in only one case (2%) in the first period and in nine cases (19%) in the second. Clinical examinations were used in the remaining cases.

The donation process

The donation process was evaluated only by time from time of death to recovery of organs. This parameter was only investigated in the second period and was 3 h 40 m (10-percentile), 5 h 45 m (median) and 9 h 33 m (90-percentile).

TABLE

Potential organ donors among all deaths. The values are n (%). $\chi^2\text{-test:}$ p = 0.234.

	First period	Second period
Potential donors	153 (44)	131 (49)
Non-potential donors	197 (56)	139 (51)
Total	350 (100)	270 (100)

TABLE 2

De facto organ donors among potential organ donors. The values are n (%). χ^2 -test: p = 0.097.

	First period	Second period
Donors	42 (27)	48 (37)
Potential donors, but non-donation	111 (73)	83 (63)
Total	153 (100)	131 (100)

TABLE

Reasons for non-donation among potential organ donors. The values are n (%). Fisher's t-test: $p=0.123. \label{eq:potential}$

	First period	Second period
No next of kin	4 (3)	2 (2)
Donation not considered	12 (8)	11 (8)
No consent – own will	15 (10)	3 (2)
No consent – next of kin	67 (44)	53 (40)
Contraindication – transplantations coordinator	12 (8)	13 (10)
Forensic examination	1 (1)	1(1)
Donors	42 (27)	48 (37)
Total	153 (100)	131 (100)

The potential donors

The reasons for non-donation among potential organ donors are shown in **Table 3**. The main reason for nondonation among the potential donors was refusal to donate by the next of kin. The largest change observed between the two periods was the decrease in refusal to donate from the patient himself/herself prior to illness.

The non-potential donors

The reasons for being a non-potential donor are shown in **Table 4**. In the group of non-potential donors, some changes were observed between the two periods; thus, in the first period, the main reason was "not on a ventilator", while in the second period the primary reasons were "not suitable" and "ventilator turned off".

DISCUSSION

In Denmark and worldwide, there is a shortage of organs available for transplantation. The process from the iden-

TABLE 4

Reasons for being a non-potential organ donor. The values are n (%). $\chi^2\text{-test:}$ p = 0.114.

	First period	Second period
Unsuited for donation	60 (30)	48 (35)
No, on a ventilator	68(35)	31 (22)
Ventilator turned off	59 (30)	51 (37)
Fast death	10 (5)	9 (6)
Total	197 (100)	139 (100)

tification of a potential organ donor to the conversion of him/her into a de facto organ donor is lengthy. One way to increase the number of organs is a survey investigating elements in this process with a view to identifying and clearing any bottlenecks.

Approximately half of deceased patients in the Neuro-intensive Care Unit are potential organ donors (Table 1). The conversion rate tends to increase (nonsignificantly) (Table 2) and has increased by 37%.

The main reasons for the increase in the conversion rate are the decrease in refusal to donate from the deceased patient himself/herself and the decrease in refusal to donate from next of kin. Refusal to donate from next of kin is the main reason for non-donation among potential organ donors. Similar refusal rates can be found in the literature [2, 3].

Among the de facto donors, the number of cases where consent is given by the organ donor prior to illness doubled from the first to the second period.

The reasons for these changes are unknown. As mentioned in the introduction, there has been much focus on organ donation in Denmark, targeting both the general public and health-care professionals. This may explain the changes, but many things have happened in parallel and one can only speculate as to their association with trends in organ donation.

The political goal in Denmark is to reduce the rejection rate from next of kin to 20%. In the 2011 annual report from the DCO [4], a rejection rate from next-ofkin of 23.3 % was recorded for the Neuro-intensive Care Unit at RH. This number is based on registration immediately after the death of the patient, while this study is based on detailed reviews of patient charts. Furthermore, based on one of the author's daily experience from the Neuro-intensive Care Unit, the 23.3% rejection rate reported in the DCO report seems too low.

Time from brain death to recovery of organs is one among many ways to measure the effectiveness of the organ procurement team. A longer interval from brain death to recovery of organs can lead to poorer organ function [5-7]. In this survey, the median time in the second period was 5 h 45 m, while the 10-percentile and the 90-percentile were 3 h 40 m and 9 h 33 m, respectively. The interval could not be measured in the first period due to lack of reliable data regarding when the recovery of organs took place. The period from brain death to recovery of organs can be difficult for the next of kin, and withdrawal of consent for organ donation in this period has been seen. This, together with poorer organ function, is the reason why we try to recover the organs as fast as possible in Denmark.

It is hardly possible to increase the amount of potential organ donors from a neuro-intensive care unit. Therefore, to increase the amount of organ donors, the conversion of potential donors to de facto organ donors must be increased. Lowering the number of refusals to donate due of contraindications found by the transplant procurement team or due to forensic examination is not possible. There are, however, other ways to increase the conversion rate.

The DCO plays a crucial role in educating the staff at relevant units. A well-educated staff enhances the chances of recognizing all potential organ donors. In this survey, 8% in both periods were not recognized as potential organ donors. This is similar to the 9.7% found by the DCO [4].

The refusal rate from next-of-kin is affected by how the request for consent to donate is presented [8, 9]. Again, the education of staff members is important in lowering the rate of refusal from the next of kin. In this survey, there is a trend towards a lower refusal rate from the next of kin. This could be due to the foundation of the DCO (in late 2007) and the increased focus on the subject.

In the second period, few of the potential organ donors refused to donate before illness. This is in contrast with the very large proportion of refusals from the next of kin. This indicates that more of the potential organ donors would have become de facto organ donors if they had made their position on the matter clear before the brain lesion/disease. The large decrease in refusals by the deceased patients prior to illness observed from the first to the second period suggests that the focus on organ donation may have shifted public opinion towards a more pro-organ donation position.

The number of potential organ donors from regular intensive care units and non-intensive care units remains unknown. In the former, the reason for non-donation may be lack of awareness that patients are possible donors, in the latter the reason may be ethical concerns about ventilating patients for the sole purpose of organ donation. These questions beg further investigation.

No next of kin present can be a reason for nondonation under Danish law. With the assumption of presumed consent, these might have become potential organ donors. In countries where presumed consent is Organs donated in Denmark.



in place, citizens are organ donors until they say otherwise. Presumed consent may further increase the conversion rate as it sends a message about the public opinion on the matter. Presumed consent is a factor that may help increase the donation rate [10].

Donation rates can vary substantially between countries with similar legislation. In 2010 in Denmark, there were 13.0 per million population (p.m.p.) deceased donors, whereas Norway had 20.8 p.m.p. [4]. The reason for this difference needs to be established through further investigation.

CONCLUSION

Approximately half of deceased patients at a neuro-intensive care unit were potential organ donors (44% and 49%, respectively). The conversion rate increased from the first period to the second (from 27% to 37%) due to lower refusal rates from both the deceased patient himself/herself prior to illness (10% to 2%) and from the next of kin (from 44% to 40%). Consent from de facto donors come from the deceased patient himself/herself in few cases (12% and 21%, respectively). When brain death is established and consent is obtained, the time to recovery of organs is short (median 5 h 45 m).

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