

Doctors' attitudes to organ donation

BACKGROUND There is an increasing need for organs for transplantation purposes. Knowledge and attitudes among the medical team may affect the donation process. When respiration and cardiac activity are being sustained by artificial means, Norwegian law requires angiographic evidence of cessation of cerebral circulation as well as clinical examination before an organ donation can be carried out. We wished to survey Norwegian doctors' attitudes to organ donation and how donation processes are being addressed.

MATERIAL AND METHOD A questionnaire with pre-defined response alternatives was distributed to doctors in intensive-care units as well as to specialists and junior registrars in neurosurgery in Norwegian donor hospitals in 2008–2009.

RESULTS Altogether 435 doctors (55%) returned a completed questionnaire. A total of 315 of 420 (75%) responded that they would consider initiating organ-preserving treatment when there is no more hope for the patient, while 18% were uncertain and 7% responded that they would not consider this option. Altogether 68 of 424 (16%) maintained that if an organ donation was relevant and current legislation could be disregarded, clinical diagnostics would be sufficient to establish a diagnosis of death. Another 22% were uncertain, while 62% were of the opinion that clinical diagnostics would be insufficient. A total of 258 of 416 (62%) reported that in their opinion, the next of kin most often could understand the implications of total destruction of the brain when this was explained to them.

INTERPRETATION Future teaching should emphasise the opportunity for organ-preserving treatment in cases where a fatal outcome is expected.

The demand for organs for transplantation is increasing (1). Despite an increase in the number of transplantations in recent years, there are still patients on the waiting list who die each year without having received an offer of transplantation (1). The number of deceased organ donors has increased from 15.6 per million inhabitants in 1998 to 21.9 in 2013 (1). In 2007, the government established a national target of 30 donations per million inhabitants from deceased donors annually (2). In Spain, the crucial factors for its sustained high donation activity most likely include appropriate organisation, sufficient capacity in intensive-care units, competence and interest (3).

Transplantation activity is regulated by Norwegian law (4–7). Many countries require only clinical neurological diagnosis of death before organ donation is permitted, while other countries have additional, optional confirmatory tests (8). Norway is one of few countries with legislation that requires angiographic verification ceased cerebral circulation prior to organ donation in cases where respiratory and cardiac activity is maintained by artificial means (7).

Organ donation is a time-consuming and resource-intensive process that sets high demands for the knowledge and commitment of the medical team (9). In Norway, the treating doctor identifies potential organ donors. If an organ donation is possible, the issue of organ donation *must* be raised with the next of kin (5). Several factors are de-

emed important in order to attain consent for an organ donation: good communication with the next of kin (10), competence and attitudes to organ donation among the health personnel (11, 12) and an understanding on the part of the next of kin of the implications of cessation of cerebral functioning (12). During the last nine years, the frequency of refusals has varied from 17% to 33% (13).

We have previously shown that many doctors reported a failure to adhere to recommended practice in the encounter with the next of kin, and we proposed communication training in particular (10). On the basis of the same survey we now seek to present data on:

- Doctors' attitudes to and experience with organ donation and withdrawal of treatment.
- Doctors' assessments of the legal requirement for radiological verification of cessation of cerebral circulation.
- Doctors' assessments of resource needs and frameworks for organ donation.

Material and method

In November 2007 we contacted doctors responsible for donations in the country's 28 donor hospitals by email, requesting a list of all doctors who were permanently attached to or worked shifts in the intensive-care units, as well as all specialists and junior registrars in neurosurgery. We received names of 815 doctors, and in the autumn of 2008 we sent each of them a questionnaire

Stein Foss

stein.foss@ous-hf.no

Department of Transplantation Surgery
Oslo University Hospital, Rikshospitalet

Margaretha Sanner

Department of Public Health and Caring Sciences
Faculty of Medicine
Uppsala University

Juan Robbie Mathisen*

Department of Neurosurgery
Haukeland University Hospital

Hilde Eide**

Faculty of Health Sciences
Buskerud and Vestfold University College

Present place of work:

* Aleris Hospital, Bergen

** Hilde Eide was employed by the Oslo and Akershus University College of Applied Science at the time when the study was implemented.

MAIN MESSAGE

Approximately one-half of all neurosurgeons and doctors in intensive-care departments of Norwegian donor hospitals responded to a questionnaire on organ donation.

The majority believed that respirator treatment of a deeply unconscious patient can be provided without causing any suffering for the patient.

Three out of four respondents would consider organ-preserving treatment when there is no hope for the patient, while one in four was uncertain or would not consider this option.

Where organ donation is possible, more than one-half believed that clinical diagnostics are insufficient to establish a diagnosis of death.

with a total of 33 questions. Thirty questionnaires were sent back because the doctor had left the department. The questionnaire had been prepared by Sanner and collaborators (9) and was translated and adapted to Norwegian conditions. Reminders were sent out in the autumn of 2008 and the winter of 2009. The method has been described in more detail in a previous publication (10).

The doctors' attitudes to and experience with organ donation, their assessments of the requirements for diagnosing death and viewpoints regarding resources and frameworks were investigated with the aid of twelve questions. The response alternatives and distribution of responses are shown in Tables 1–3. Results pertaining to background variables, learning needs and experience with donation have already been published in a separate article (10).

Processing of data was undertaken in SPSS and the sample is presented through descriptive statistics. The study has been approved by the Norwegian Social Science Data Services.

Results

Altogether 435 doctors (55.4%) responded. The number of responses to the various questions ranged from 348 to 433. The average age was 45.9 years (range 28–69 years). Women accounted for 27%. A total of 63% were specialists in anaesthesia/intensive-care medicine, 8% were specialists in neurosurgery or anaesthetics, and 5% had another specialty. The sample has been described in more detail in a previous publication (10).

The response distribution is shown in Tables 1–3. A total of 75% responded that they could imagine initiating medical treatment even when there was no hope to save the patient. Another 33% stated that in such cases, they most often/sometimes choose to discontinue respirator treatment rather than wait until clinical diagnostics of total destruction of brain function can be undertaken (Table 1). Altogether 16% were of the opinion that in cases where organ donation could be possible and current legislation could be disregarded, clinical diagnostics would be sufficient to establish a diagnosis of death (Table 2). A total of 74% were of the opinion that the deceased's doctor should be the one to raise the issue of organ donation (Table 3). All of 47% stated that relief from other tasks could be helpful in easing the work related to organ donation.

Discussion

We found that the respondents had different opinions regarding final treatment and organ donation. Three of four could imagine initiating organ-preserving treatment. Clinical

Table 1 Attitudes to and experience with final treatment and organ donation. Data from 435 doctors in intensive-care units, neurosurgeons and junior registrars in neurosurgery in Norwegian donor hospitals. The number who responded to each question is given in parenthesis.

Questions and response alternatives ¹	Response distribution (%)
Do you believe that respirator treatment of a deeply unconscious patient can be provided without causing any suffering to the patient? (n = 418)	
Yes, absolutely	82
Not always	17
Rarely	1
Never	0
Can you imagine initiating medical treatment to maintain organ function when there is no hope for the patient? (n = 420)	
Yes	75
Uncertain	18
No	7
If you see that a patient will not survive, do you choose to discontinue respirator treatment, rather than waiting until clinical diagnostics of total destruction of the brain function can be undertaken? (n = 419)	
Most often	7
Sometimes	26
Rarely	43
Never	24
Reason for discontinuing respirator treatment ² (n = 433)	
No patient should be given pointless treatment	43
Concern for the next of kin	40
Manage limited resources	32
Reduce the patient's suffering	30
Nobody should be treated only as a means for others	10

¹ The questions with response alternatives are grouped by topic

² Multiple responses possible

death diagnostics alone prior to organ donation were deemed unsatisfactory by the majority.

Limitations

The limitations of this study have been described previously (10). The response rate is low, and it is reasonable to assume that those who have a particular interest and competence in organ donation may be overrepresented. We have no overview regarding the completeness of the lists supplied by the doctors responsible for donors.

It can also be questioned whether we have measured what we intended to measure. Some of the questions may have been interpreted differently by respondents. For exam-

ple, the question «Could you imagine initiating medical treatment to maintain the functioning of organs even if there is no hope for the patient?» permits varying interpretations. It was meant to include continued respirator treatment, but not elective ventilation (i.e. intubation and treatment for the sole purpose of organ donation).

We have read the responses in the context of common practice in Norway, where patients with severe head injuries will as a rule be intubated and their treatment continued, with life-saving as the primary objective. The fact that the study emphasises the attitudes and assessments of individual doctors, not departmental routines and organisation, is also a limiting factor.

Table 2 Assessments of requirements for death diagnostics in organ donation. Data from 435 doctors in intensive-care units, neurosurgeons and junior registrars in neurosurgery in Norwegian donor hospitals. The number who responded to each question is given in parentheses.

Questions and response alternatives ¹	Response distribution (%)
Do you trust clinical death diagnostics? (n = 422)	
Yes	74
No	26
If organ donation is possible and you disregard prevailing legislation, would clinical diagnostics be sufficient to establish a diagnosis of death? (n = 424)	
Yes	16
No	62
Don't know	22
Do you believe that the next of kin understand what total destruction of the brain implies once you have explained it? (n = 416)	
Yes, as a rule	62
It varies greatly	34
Uncertain	3
Rarely	1

¹ Questions with response alternatives are grouped by topic

Attitudes and experience

The time elapsing from withdrawal of neurointensive treatment to final cessation of cerebral circulation may vary from some hours to several days. When the patient's life cannot be saved, three out of four respondents were willing to initiate organ-preserving treatment (Table 1). The positive attitudes among doctors to organ-preserving treatment concur with the findings in a Canadian study (14). A circular from the Ministry of Health and Care Services (5) specifies that prevailing health and privacy legislation places major emphasis on the patients' right to co-determination and information. If it is known or if the next of kin believe that the dying person wished to become an organ donor after his/her death, this should be a deciding factor in whether organ-preserving treatment is initiated and continued until a total cessation of cerebral circulation has been established.

Wilkinson and Trough have described that the doctor's age, religion, race and personal attitudes may be decisive for whether organ-preserving treatment is initiated and that the patient's own values may easily be overruled in the process (15). Hynninen and collaborators point out the absence of internal guidelines for withdrawal of treatment in Scandinavian intensive-care units (16). There is reason to assume that this also

applies to the decision to prolong respirator treatment to facilitate an organ donation. Our experience indicates that practice regarding decisions to prolong or discontinue treatment may vary from one department to another, as well as within each intensive-care unit.

One in three respondents would most often/sometimes choose to discontinue respirator treatment in the face of expected death, instead of waiting until clinical diagnostics of total destruction of the brain function can be undertaken (Table 1). Most likely, this is based on organisational, financial and ethical considerations. Some claim that organ-preserving treatment violates the ethical principle of always treating the patient for the patient's own sake. Welin and collaborators (17) have shown that this is not necessarily the case, especially if the principle of autonomy, i.e. patient co-determination in matters pertaining to organ donation, is given greater weight in the ethical assessment.

Materstvedt and Hegvik (18) have argued that active treatment, including elective ventilation in view of organ donation, can be defended in light of ethically accepted ethical perspectives. This applies also when the patient's attitude to organ donation is unknown.

Two out of five respondents stated that concern for the next of kin was the reason for

discontinuing respirator treatment. This may reflect a patriarchal attitude in the doctors. The next of kin may thereby be deprived of the opportunity to fulfil the patient's last wish (Table 1). One in three respondents stated that the reason was to reduce the patient's suffering. This contrasts with the opinion held by a majority of the respondents, who believed that respirator treatment can be provided to a deeply unconscious patient without inflicting any suffering (Table 1). One possible explanation could be that at the terminal stage, the assessment of suffering is transferred from the patient to the next of kin.

Diagnostics

Three out of four respondents trusted clinical death diagnostics, while only 16% considered clinical diagnostics to be sufficient to establish a diagnosis of death before an organ donation (Table 2). In a review article, Simpkin and collaborators have pointed out that diagnostic imaging as a supplement to clinical diagnostics helped raise the consent frequency from 44% to 71% (12). In Norway, the treating doctor routinely confirms the diagnosis of total destruction of the brain with the aid of diagnostic imaging. The certainty of a correct diagnosis may have an impact on the discussion and help increase the frequency of consent.

On the other hand, two out of five respon-

Table 3 Assessments of resources and frameworks in matters related to organ donation. Data from 435 doctors in intensive-care units, neurosurgeons and junior registrars in neurosurgery in Norwegian donor hospitals. The number who responded to each question is given in parentheses.

Questions and response alternatives ¹	Response distribution (%)
What do you personally believe would be of most help to ease your work with organ donation? ² (n = 348)	
Relief from other tasks when a donation comes up	47
Registration with donor cards	37
Clear guidelines in the department	25
Help from external personnel	14
Is there any form of «reward» connected to the donation activity? ² (n = 433)	
To me, it may feel good that the death led to something positive	76
It seems to provide some comfort for the family	81
Organ donations confirm the capacity/competence of the unit	37
Other forms	4
No – it's mostly a burden	2
Do you believe that the deceased person's doctor should be the one to raise the issue of organ donation? (n = 410)	
Yes	74
No, it would be better if an (external) doctor/nurse at the hospital, with special training for this purpose, could be responsible for the entire donation process.	26
Have you ever experienced that lack of intensive-care resources (beds/ personnel) has entailed that a patient with (likely) total destruction of brain function has not been assessed as a potential donor? (n = 418)	
Yes, often	2
Yes, rarely	40
No	57
Do you believe that more intensive-care beds in your hospital would help increase the number of donors? (n = 419)	
Yes, absolutely	12
Only to a limited extent	35
No	40
Cannot say	13

¹ The questions with response alternatives are grouped by topic

² Multiple responses possible

dents believed that it may vary or is uncertain whether the next of kin understand what «cessation of cerebral circulation» means, even when they have had it explained. Insufficient insight among the next of kin may drive their attitude in a negative direction (12).

Resources and frameworks

Organ donations account for a minor proportion of the daily activities of intensive-

care units, but the period of organ-preserving treatment is costly and resource-intensive. The extra cost of organ donation should be compensated in the DRG system (2). Organ donation is an additional workload for the doctor responsible. However, the fact that three out of four respondents stated that the question of organ donation should be posed by the deceased person's own doctor indicates that the doctors want to take this responsibility themselves.

One-third reported that limited resources were the reason for discontinuing respirator treatment of a potential donor. Giving priority to patients who need treatment, rather than performing an organ donation, may sometimes be necessary. In conflicts over priorities there is an argument for use of the DRG grant to hire additional personnel. To our knowledge, this is common practice in several donor hospitals.

Shortage of intensive-care capacity was not regarded as a major limiting factor for organ donation. This is positive, but the health authorities and the health enterprises ought to be aware of this risk if the number of intensive-care beds is reduced during merger processes or as part of cost-saving measures.

This study has received funding for operational costs from the Directorate of Health and the Norwegian Resource Group for Organ Donation. Other funding for the study was supplied by the authors' institutions.

Stein Foss (born 1957)

is transplantation coordinator and member of the Norwegian Resource Group for Organ Donation.

The author has completed the ICMJE form and declares no conflicts of interest.

Margareta Sanner (born 1947)

is a registered psychologist, PhD, Associate Professor of Community Medicine and researcher.

The author has completed the ICMJE form and declares no conflicts of interest.

Juan Robbie Mathisen (born 1950)

is a specialist in neurosurgery.

The author has completed the ICMJE form and declares no conflicts of interest.

Hilde Eide (born 1953)

is professor of clinical communication and health counselling and director of studies.

The author has completed the ICMJE form and declares no conflicts of interest.

References

1. Scandiatransplant. Transplant and waiting list figures 1998 og 2013. www.scandiatransplant.org/data/scandiatransplant-figures [20.10.2013].
2. Antall organdonasjoner skal økes – flere skal få tilbud om en livreddende transplantasjon. Pressemelding fra Helse- og omsorgsdepartementet 24.9.2007 www.regjeringen.no/nb/dep/hod/pressemelder/pressemeldinger/2007/antall-organdonasjoner-skal-okes--flere-.html?id=481608 [20.10.2013].
3. Rodríguez-Arias D, Wright L, Paredes D. Success factors and ethical challenges of the Spanish Model of organ donation. *Lancet* 2010; 376: 1109–12.

>>>

4. LOV-1973-02-09-6. Lov om transplantasjon, sykehusobduksjon og avgivelse av lik m.m.
5. Rundskriv I-6/2008. Om regelverket som gjeld organdonasjon og samtykke.
6. LOV-1999-07-02-63. Lov om pasient- og brukerrettigheter.
7. Rundskriv I-39/1997. Forskrift om dødsdefinisjon i relasjon til lov om transplantasjon, sykehusobduksjon og avgivelse av lik m.m.
8. Wijndicks EF. Brain death worldwide: accepted fact but no global consensus in diagnostic criteria. *Neurology* 2002; 58: 20–5.
9. Sanner MA, Nydahl A, Desatnik P et al. Obstacles to organ donation in Swedish intensive care units. *Intensive Care Med* 2006; 32: 700–7.
10. Eide H, Foss S, Sanner M et al. Organdonasjon og norske legers behov for opplæring. *Tidsskr Nor Legeforen* 2012; 132: 1235–8.
11. Roels L, Spaight C, Smits J et al. Critical Care staffs' attitudes, confidence levels and educational needs correlate with countries' donation rates: data from the Donor Action database. *Transpl Int* 2010; 23: 842–50.
12. Simpkin AL, Robertson LC, Barber VS et al. Modifiable factors influencing relatives' decision to offer organ donation: systematic review. *BMJ* 2009; 338: b991.
13. Bakkan PA. Årsrapport organdonasjon 2013. Oslo universitetssykehus, Rikshospitalet. www.norod.no/mod/folder/view.php?id=54 (14.2.2014).
14. Shemie SD, Cupido CM. The management of brain death and organ donation in Canadian children. *Pediatr Crit Care Med* 2000; 1: A46.
15. Wilkinson DJ, Truog RD. The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. *Intensive Care Med* 2013; 39: 1128–32.
16. Hynninen M, Klepstad P, Petersson J et al. Process of foregoing life-sustaining treatment: a survey among Scandinavian intensivists. *Acta Anaesthesiol Scand* 2008; 52: 1081–5.
17. Welin S, Sanner MA, Nydahl A. Etisk acceptabelt med icke-terapeutisk ventilasjon av möjlige organdonator. *Läkartidningen* 2005; 102: 1411–6.
18. Materstvedt LJ, Hegvik JA. Organdonasjon, elektiv ventilasjon og etikk. *Tidsskr Nor Laegeforen* 2004; 124: 2501–3.

Received 14 February 2013, first revision submitted 20 June 2013, accepted 20 March 2014. Editor: Siri Lunde Strømme.