Organ donation performance in the Netherlands 2005–08; medical record review in 64 hospitals

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Abstract

Background. The Netherlands has a low number of deceased organ donors per million population. As long as there is a shortage of suitable organs, the need to evaluate the donor potential is crucial. Only in this way can bottlenecks in the organ donation process be detected and measures subsequently taken to further improve donation procedures.

Methods. Within a time frame of 4 years, 2005–08, medical charts of all intensive care deaths in 64 hospitals were reviewed by transplant coordinators and donation officers. Data were entered in a web-based application of the Dutch Transplant Foundation, both to identify the number of potential organ donors (including donation after cardiac death), as well as to analyse the reasons for potential donor loss.

Results. In total, 23,508 patients died in intensive care units, of which 64% were younger than 76 years. The percentage of all potential organ donors out of the total number of deaths decreased from 8.2% in 2005 to 7.1% in 2008. Donor detection increased from 96% in 2005 to 99% in 2008. Of the potential donors, 17–21% recorded consent and 17–18% recorded objection in the national Donor Register. If the Donor Register was not decisive, the consent rate of families approached for organ donation was 35% in 2005, 29% in 2006, 41% in 2007 and 31% in 2008. The overall conversion rate (the number of actual donors divided by the number of potential donors) was 30%, 26%, 35% and 29% in these years. In the group of potential donor losses, objection by families accounted for about 60% during this study.

Conclusions. This study showed that the maximal number of potential organ donors is about three times higher than the number of effective organ donors. The main reason accounting for about 60% of the potential donor losses was the high family refusal rate. The year 2007 showed that a higher percentage of deceased organ donors can be procured from the pool of potential donors. All improvements should focus on decreasing the unacceptably high family refusal rates.

Keywords: conversion rate; Donor Register; family refusal; organ donation performance; potential organ donors

Introduction

As in many other countries, the waiting list for organ transplantation in the Netherlands is long, and patients die whilst waiting for transplantation, despite the increase in alternative ways of donation. The Netherlands not only has a history of the traditional heart-beating donation, but also of donation after cardiac death for kidneys, and more recently for liver and lung, and a large living kidney donor program.

In 1998, the Netherlands implemented a law on organ and tissue donation to increase the number of donors. A National Donor Register was implemented to give the Dutch population the opportunity to register their will on donation with four options; consent for donation (for all or some organs and/or tissues, refusal to donation, decision left to the family or decision left to a specific person. It is mandatory for physicians to consult the Donor Register in case of a potential donor. Since the introduction of the law 11 years ago, the number of deceased organ donors has fluctuated around 200 donation procedures. The year 2007 was an exception with an increase to 257 donors. The number of deceased organ donors is still not sufficient to meet the demand for transplantable organs. The Netherlands has a low number of deceased organ donors used for a transplant per million population (p.m.p.); 13.2 in 2005, 12.1 in 2006, 15.7 in 2007 and 12.3 in 2008 [1]. For example, our neighbour country, Belgium had an average of 25.5 organ donors p.m.p. within the same years.

As long as there is a shortage of suitable organs, the need to evaluate the donor potential is crucial. Only in this way can bottlenecks in the organ donation process be detected and measures subsequently taken to further improve donation procedure.
In our first study of potential organ donors in 52 intensive care units (ICUs) in the Netherlands between 2001 and 2004, it was not possible to compare the annual donation performance because not all ICUs registered deceased patients during this period [2]. In the present study, because of further implementation of medical record reviews in ICUs in the Netherlands, donation performance can be compared over several years.

Subjects and methods

Within a time frame of 4 years, 2005–08, medical charts of all patients who died in ICUs in 64 hospitals were reviewed to evaluate the donation performance. This represents almost two-thirds of all hospitals in the Netherlands. The hospitals included in the study were selected on the basis of a complete 4-year registration of the donor potential by donation officers or transplant coordinators. The hospitals ranged from university hospitals with transplantation facilities (in total four out of eight university hospitals), to hospitals with neurosurgery (seven out of nine) and hospitals without neurosurgery (43 out of 75). The contributing hospitals are representative for the total number of hospitals in the Netherlands. All ICUs had facilities for mechanical ventilation. All ICUs in a hospital were included, except for the Children’s and Coronary Intensive Care Units.

The medical information and the situation before death were the starting point to review medical potential organ donors. Data were entered in a web-based application of the Dutch Transplant Foundation. This application facilitates systematic reviewing of medical charts, not only to identify the number of potential organ donors (including donation after cardiac death), but also to analyse the reasons for potential donor loss. This methodology originated from an international programme, Donor Action, developed by Eurotransplant International, Organización Nacional de Trasplantes (Spain) and The Partnership for Organ Donation (VS) [3]. We restructured the methodology to be able to adapt to specific Dutch situations on organ procurement, for example four instead of two different outcomes of the Donor Register. Overall, in the Netherlands, nearly 5.2 million people registered their will on donation in the Donor Register; this represents almost two-thirds of all hospitals in the Netherlands. The annual number of potential heart-beating donors, where brain death was diagnosed, fluctuated between 93 and 147 (Table 2). The number of possible potential heart-beating donors, where brain death was not diagnosed because of non-medical reasons, was rather stable over the 4-year period (range: 179–189). Table 2 shows a higher number of ‘possible potential heart-beating donors’ than ‘potential heart-beating donors’. In the Netherlands, the final steps to diagnose brain death are often taken after donation is discussed with the family (in case there is no objection in the Donor Register) and they are in favour of donation. Then, the formal donation request will be made after brain death is diagnosed. Due to the rather low numbers of families in favour of organ donation, brain death is only diagnosed in a relatively small number of patients. The number of potential donors after cardiac death varied between 177 in 2005 to 159 in 2008. These are mainly donors with a controlled cardiac arrest (‘Maastricht classification category 3’) and to a lesser extent, uncontrolled cardiac arrest (‘category 2’). In total, the percentage of all potential (heart-beating and donors after cardiac death) organ donors out of the total number of deaths decreased from 8.2% in 2005 to 7.1% in 2008.

Donor detection and consultation of the Donor Register

Donor detection in ICUs increased from 96% in 2005 to 99% in 2008 (Table 2). Although consultation of the Do-

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**Table 1. Definition of potential organ donor**

<table>
<thead>
<tr>
<th>Definition</th>
<th>Specification</th>
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<tbody>
<tr>
<td>Potential heart-beating donor</td>
<td>Mechanical ventilation, brain death diagnosed, no medical contraindication, age 76 years or younger</td>
</tr>
<tr>
<td>Possible potential heart-beating donor</td>
<td>Mechanical ventilation, severe brain damage: Glasgow Coma Score of E1, M1, V tube, absence of one or two brainstem reflexes, no medical contraindication, age 76 years or younger. Brain death not diagnosed due to non-medical reasons (e.g. no consent)</td>
</tr>
<tr>
<td>– Mechanical ventilation, with or without severe brain damage, (did not meet the criteria for brain death), an infarct prognosis, no medical contraindication, age 66 years or younger</td>
<td></td>
</tr>
<tr>
<td>– Unsuccessful resuscitation, no medical contraindication, age 66 years or younger</td>
<td></td>
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</tbody>
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In the Netherlands, the legal consent system for organ donation is based on explicit consent for donation (opting-in). When a potential organ donor is identified, it is mandatory for the physician to consult the Donor Register. In case of an objection to donation, the brain death diagnosis will not be completed.

To review the number of potential organ donors, we used three definitions (Table 1). Together, these definitions reflect the maximal number of medical potential donors amongst all deceased patients in ICUs. Not only a patient with a brain death diagnosis was defined as potential organ donor, but also a patient with severe brain damage before brain death was formally declared. These patients had a Glasgow Coma Scale (GCS) of E1, M1, V tube, absence of one or two brain-stem reflexes, no absolute medical contraindication to organ donation and were under the age of 76 years. In the last situation, the final steps for brain death declaration (electroencephalogram and apnoea test) were not taken because of non-medical reasons, e.g. in the case of an objection by the coroner. For these cases, we used the definition ‘possible potential heart-beating donor’. The third definition is about potential donors who died after cardiac arrest.

**Results**

**Donor potential**

The 64 hospitals recorded 23 508 patients who had died in ICUs during the 4 years. Forty-six percent were <76 years of age, of which 88% were mechanically ventilated (Figure 1). The total number of potential organ donors was 1818; these patients did not have absolute medical contraindications (unknown cause of death, unknown identity, non treatable sepsis, malignancy except some brain tumours, active viral infections, active tuberculosis and anencephaly) to donation. The annual number of potential heart-beating donors, where brain death was diagnosed, fluctuated between 93 and 147 (Table 2). The number of possible potential heart-beating donors, where brain death was not diagnosed because of non-medical reasons, was rather stable over the 4-year period (range: 179–189). Table 2 shows a higher number of ‘possible potential heart-beating donors’ than ‘potential heart-beating donors’. In the Netherlands, the final steps to diagnose brain death are often taken after donation is discussed with the family (in case there is no objection in the Donor Register) and they are in favour of donation. Then, the formal donation request will be made after brain death is diagnosed. Due to the rather low numbers of families in favour of organ donation, brain death is only diagnosed in a relatively small number of patients. The number of potential donors after cardiac death varied between 177 in 2005 to 159 in 2008. These are mainly donors with a controlled cardiac arrest (‘Maastricht classification category 3’) and to a lesser extent, uncontrolled cardiac arrest (‘category 2’). In total, the percentage of all potential (heart-beating and donors after cardiac death) organ donors out of the total number of deaths decreased from 8.2% in 2005 to 7.1% in 2008.

**Donor detection and consultation of the Donor Register**

Donor detection in ICUs increased from 96% in 2005 to 99% in 2008 (Table 2). Although consultation of the Do-
The Donor Register is the starting point for the consent process, the Donor Register was not always consulted when the potential organ donor was identified; consultation rose from 85% in 2005 to 92% in 2007, but decreased in 2008 to 88%. There are legal reasons for not consulting the Donor Register for potential organ donors, as when the age of the patient is <12 years old and if the patient was not a Dutch citizen. When the Donor Register was consulted, the number of registered consent rose from 17% in 2005 to 21% in 2007 and 2008. There are legal reasons for not consulting the Donor Register for potential organ donors, as when the age of the patient is <12 years old and if the patient was not a Dutch citizen. When the Donor Register was consulted, the number of registered consent rose from 17% in 2005 to 21% in 2007 and 2008. The number of registered objection was stable at 18% in 2005, 2006 and 2008, and 17% in 2007. Registration in the Donor Register ‘leaving the decision to the family’ accounted for 5% in 2005, 10% in 2006, 6% in 2007 and 5% in 2008. However, the largest group of potential donors without a registration accounted for about 57% during the study period.

**Family approach**

Among potential donors for whom no objection was found in the Donor Register, the family was approached with the request for donation. In the Netherlands, when a potential donor has registered consent in the Donor Register or on a Donor card, the physician will only ‘inform’ the family of this consent for donation and asks the family ‘approval’ instead of consent to start the organ donor procedure (Figure 1). Only if the family has severe objections to organ donation is it possible to follow their wishes. In practice, when consent was registered in the Donor Register, the family still objected to donation between 4% and 11% (Table 2). If no consent or objection was found in the Donor Register, the family was not approached in 6–10%. The consent rate of families approached for organ donation was 35% in 2005, 29% in 2006, 41% in 2007 and 31% in 2008.
Donors reported and actual donors

When consent for donation was given, not all donors were reported to the organ procurement organisation (OPO). From the donors that were reported, organ procurement did not always take place. Reasons for donor losses at this stage of the donation procedure included donor management problems, technical or surgical reasons, or that the cardiac arrest did not occur within 2 hours after ventilator switch off.

The numbers of actual donors from which organs were procured were 137 in 2005, 117 in 2006, 172 in 2007 and 123 in 2008. The conversion rate (the number of actual donors divided by the number of potential donors) was 30% in 2005, 26% in 2006, 35% in 2007 and 29% in 2008.

Figure 2 summarizes the cumulative effect of potential donor losses due to each step in the donation process. Out of all medical potential donors, only 33–44% was both detected and had a final consent for donation given by the family. Within the group of potential donors that were lost, the objection by families accounted for 57–62% during these years.

The Dutch Transplant Foundation, as an organ procurement organisation, registers the number of organ donors reported to the OPO from ‘all’ hospitals in the Netherlands [5]. In our study, we detected two-thirds of all national reported donors.

In the year 2007, the number of actual donors increased significantly. This could be explained by an increased number of potential donors and an increased consent rate of families in 2007 that was shown in this study. A possible factor of influence could be the Dutch ‘Donor Show’, broadcasted on 10 June 2007. This television programme involved a terminally ill 37-year-old woman, who would select a kidney recipient out of three candidates to donate one of her kidneys. Due to this controversial programme, there was media attention for donation not only at a national level but also internationally. A possible side effect of

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Table 2. Potential organ donors among all deceased patients in ICUs of 64 hospitals and donor performance characteristics per year

<table>
<thead>
<tr>
<th></th>
<th>2005</th>
<th>2006</th>
<th>2007</th>
<th>2008</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total deaths ICU</td>
<td>5638</td>
<td>5690</td>
<td>6222</td>
<td>5958</td>
</tr>
<tr>
<td>Potential heart-beating donors</td>
<td>1.9% (107)</td>
<td>1.6% (93)</td>
<td>2.4% (147)</td>
<td>1.5% (89)</td>
</tr>
<tr>
<td>Possible potential heart-beating donors</td>
<td>3.2% (180)</td>
<td>3.3% (189)</td>
<td>2.9% (179)</td>
<td>3.0% (179)</td>
</tr>
<tr>
<td>Potential cardiac death donors</td>
<td>3.1% (177)</td>
<td>2.8% (162)</td>
<td>2.6% (159)</td>
<td>2.7% (159)</td>
</tr>
<tr>
<td>Total potential organ donors</td>
<td>8.2% (464)</td>
<td>7.8% (444)</td>
<td>7.8% (485)</td>
<td>7.1% (425)</td>
</tr>
<tr>
<td>Identified donors/potential donors</td>
<td>96% (444/464)</td>
<td>96% (428/444)</td>
<td>99% (480/485)</td>
<td>99% (420/425)</td>
</tr>
<tr>
<td>Consulting DR/identified donors</td>
<td>85% (377/444)</td>
<td>89% (379/428)</td>
<td>92% (441/480)</td>
<td>88% (369/420)</td>
</tr>
<tr>
<td>a. Approval by family/families informed</td>
<td>95% (60/63)</td>
<td>92% (61/66)</td>
<td>96% (86/90)</td>
<td>89% (67/75)</td>
</tr>
<tr>
<td>b. Families approached/identified donors</td>
<td>90% (282/312)</td>
<td>94% (275/293)</td>
<td>93% (295/316)</td>
<td>93% (258/277)</td>
</tr>
<tr>
<td>c. Consent by family/families approached</td>
<td>35% (99/282)</td>
<td>29% (80/275)</td>
<td>41% (121/295)</td>
<td>31% (79/258)</td>
</tr>
<tr>
<td>Number of organ donors reported to the Dutch Transplant Foundation</td>
<td>155</td>
<td>137</td>
<td>205</td>
<td>144</td>
</tr>
<tr>
<td>Number of organ donors (organs procured)</td>
<td>137</td>
<td>117</td>
<td>172</td>
<td>123</td>
</tr>
</tbody>
</table>

DR= Donor Register.

*Identified potential donors with consent or objection in the DR were excluded.

 Families are informed when consent was found in the DR.

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Fig. 2. Outcome of the Donor Register (DR) in combination with the family approach.
this television programme could be the increased awareness for organ donation and transplantation. To gain insight into the possible effect of the Dutch ‘Donor Show’, we analysed the family decision per month during the study period (Figure 3). The monthly figures on the families' decisions to consent or object to donation show that the increased consent rate in 2007 was not concentrated around the Dutch Donor Show, but was higher during the whole of 2007 starting from February.

**Discussion**

**Conversion rate**

A review of medical charts of deceased patients in ICUs is important to gain insight into the process of donation, from donor identification to retrieval of organs. This study showed that the maximal number of potential organ donors is about three times higher than the number of actual organ donors. The overall conversion rate (the number of actual donors divided by the number of potential donors) in Dutch ICUs was 30% with a range between 26% and 35% during the years 2005–08. When compared to ICU studies in other countries, this rate is dramatically low. Conversion rates were 37–49% in Spain, 42% in the United States, 45% in the United Kingdom, 47% in Germany, 43% in France and 48% in Belgium [6–8,10]. The increase of the conversion rate in 2007 can be explained by a higher consent rate by approached families.

**Family refusal rate**

The main reason for potential donor losses is the high family refusal rate when the family is asked about donation. When the potential donor did not consent or object to donation during life, in the Donor Register or by donor card, the overall refusal rate was 66%. The refusal rate of all families approached, thus including patients with consent in the Donor Register was 53.5%. This is higher than the family refusal rates of 24.3% in Spain, 46% in the United States, 41% in the United Kingdom and 10.5% in France and Belgium [6–8,10]. However, sound comparisons of rates between countries can be disputable because of differences in the definition of a potential organ donor and family refusal [11].

Our study did not give insight into the reasons ‘why’ families refused donation, and further research is therefore necessary to focus on this issue. The high refusal rates for post mortem donation are in great contrast with the fact that the Netherlands has the highest number of living donation in Europe. Questions arise as to why there is this difference. This may be because the medical need for transplantation is more visible to the donor in the situation of living donation, and therefore, the willingness to donate is higher. Or, in case of post mortem donation, because family members do not know the wishes of their loved one when registration of the Donor Register is lacking. A refusal to donation in this situation is possibly a safer answer for families. The law on organ donation in the Netherlands is from this perspective counter-productive, and an opting-out system might lead to a higher family consent rate. The number of living donations in the Netherlands could also increase as a consequence of the worse prospect to receive an organ from a deceased donor, or an increase could be due to the better survival rate of transplanted kidneys after living donation, or both [12].

We could not identify the reasons for the higher rate of consent of families in 2007. These rates were higher during the whole year 2007 and not specifically just before or after the Donor Show in June. However, the public awareness on organ donation was stimulated by the media hype around the Donor Show which started months before the programme. In the weeks following the television programme, an additional 12 000 registrations in the Donor Register were reported, almost all of them with consent for donation [4].

**Improvements in donation performance**

The year 2007 showed that a higher percentage of deceased organ donors can be procured from the pool of po-
tential donors. This study clarifies that the focus for improvement should be on the family approach of potential donors. Siminoff et al. studied factors influencing families' consent for donation and concluded that the way families are approached by health-care practitioners is crucial [13]. De Jong et al. analysed from an interview study of donor and non-donor families that the request for donation should be made in a way that meets the families' informational and emotional needs [14]. The Dutch Transplant Foundation started a project to improve the decision making process. With the financial help of the Dutch Ministry of Health, a new training programme was developed for all professionals who approach families to request for organ and/or tissue donation. This training follows after years of experience with the European Donor Hospital Education Programme (EDHEP) [15]. Reasons for a new training were not inspired by a lack of quality of this training, but due to the persisting high family refusal rate in the Netherlands and the need to train as many professionals as possible. The EDHEP training was mainly organized by university hospitals, inviting a maximum of 14 professionals per full-day training, within the transplant region.

The project of the Dutch Transplant Foundation started with interviewing professionals to investigate their needs of training, resulting in the following main recommendations. It was ascertained that what was desired was an ‘in hospital’ training of maximum 4 hours, according to the latest insight in teaching methods, resulting in a blended-learning training with an e-learning module, to follow at home or at work, and a practical training. The training will not only focus on communication techniques and skill, but also on how to inform a grieving family and what information on donation can be given. The gold standard within the practical training, as in EDHEP, is to practise life-like situations together with an actor. The hypothesis is that when families are approached by trained professionals, they will be better informed and are thus capable of making a well-considered choice for donation.

Training of professionals is only one part of the focus. The other focus should be made in education of the public. Family refusal rates are high in cases where the potential donor did not register his or her will on donation in the Donor Register, which is the case in ~60% of the Dutch population of 18 years and older. When donation is not discussed within the family beforehand, it will be more difficult to decide in favour of donation at the moment a loved one dies. Apart from a yearly campaign for teenagers who become 18 year old, there will be special media campaigns for target groups [16]. After the Dutch Donor Show, the Dutch Ministry of Health initiated ‘a Masterplan Organ donation’ with all counterparts in the field of organ donation. One of the elements of this plan is to improve the information and education of the public, for example about the concept of brain death and donation. Another element is to improve the support of the donation process and to stimulate new initiatives for organ procurement in hospitals.

All initiatives are taken to tackle the main problem in the donation process in the Netherlands: the unacceptably high family refusal rates.

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References


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