Higher organ donation consent rates by relatives of potential uncontrolled donors versus potential controlled donors after death

Jentina Wind¹, Walther N.K.A. van Mook², Monique E.C. Willems¹ and L.W. Ernest van Heurn¹

¹Department of Surgery, Maastricht University Medical Centre, Maastricht, The Netherlands and ²Department of Intensive Care Medicine, Maastricht University Medical Centre, Maastricht, The Netherlands

Correspondence and offprint requests to: Tineke Wind; E-mail: t.wind@mumc.nl

Abstract

Background. Refusal to consent to organ donation is an important cause of the persisting gap between the number of potential organ donors and effectuated donors. In the Netherlands, organ donors include both uncontrolled donors: donors who die unexpectedly after cardiac death (DCD), after failed resuscitation and donors in whom death can be expected and donors after brain death, and controlled DCD donors: those who die after the withdrawal of treatment. Different donor type implies a different setting in which relatives are requested to consent to organ donation. It is unknown whether the setting influences the eventual decision for donation or not. Therefore, we compared the consent rate in potential donors who died unexpectedly (UD group) and in whom death was expected.

Methods. A total of 523 potential organ donors between 2003 and 2011 in the 715-bed Maastricht University Medical Centre, the Netherlands were included. Both the patients’ registration in the national donor register (DR) and the relatives’ refusal rate in the two groups were retrospectively assessed using data from the donation application database.

Results. There were 109 unexpected and 414 expected potential donors. The potential donors in the UD group were younger (mean age 52 versus 55 years, \( P = 0.032 \)) and more often male (68 versus 52\%, \( P = 0.003 \)). There were no significant differences in registration in the DR between the groups. The relatives’ consent rate in non-registered potential donors, or those who mandated the relatives for that decision, was higher in the UD group (53 versus 29\%, \( P < 0.001 \)).

Conclusions. Less than 50\% of the potential donors were registered in the national DR. Therefore, the relatives have an important role in the choice for organ donation. The relatives of potential donors who died unexpectedly consented more often to donation than those in whom death was expected.

Keywords: consent; organ donation; refusal

Introduction

Transplantation is the therapy of choice for many patients with end-stage organ renal failure [1]. However, the number of patients on the waiting list for transplantation exceeds the number of available organs by far. One of the factors limiting the number of organ donors is the refusal of relatives for donation. Since 1998, the national donor register (DR) in the Netherlands was based on the opting-in system [2, 3]. Since then, Dutch citizens older than 12 years have the opportunity to register and document their choice for organ and tissue donation. All citizens reaching the age of 18 years receive a donor form to encourage them to register. The DR provides four options: (1) permission for organ and tissue donation (with a possibility to exclude specific organs or tissues), (2) objection to organ and tissue donation, (3) leave the decision to the relatives and (4) leave the decision to a specific person. According to the 1998 Dutch Organ and Tissue Donation Act, it is mandatory for treating physicians to consult the DR for all deceased patients aged over 12 years who are potential candidates for organ/or tissue donation. The DR can be consulted when death is expected within 12 h and must be consulted before organ/or tissue donation is discussed with the relatives. Approximately 40\% of the Dutch population older than 12 years is registered in the DR [4]. Because of this low registration rate, the ultimate donation decision is frequently reposed with the relatives.

Donation after cardiac death (DCD) has been popularized over the past decades in the Netherlands. It has the potential to increase the donor pool 2.5–4 times, thereby substantially reducing the waiting lists for transplantation [5, 6]. In the Maastricht University Medical Centre (MUMC), 60\% of deceased donors are DCD donors, including both controlled and uncontrolled donors [7]. Uncontrolled donation, which is donation after failed resuscitation is a complicated and demanding procedure with a higher chance of failure. The setting is different from the setting in potential controlled DCD, Maastricht category 3 donors who die after discontinuation of treatment, when further treatment is considered futile. In this
group, the moment of withdrawal of treatment can be chosen within certain limits and organ donation can be extensively discussed with the relatives. Also, with relatives of potential brain death donors, patients with signs of brain death and in whom brain death is expected, there is time to explain and discuss donation. In contrast, in potential uncontrolled DCD, Maastricht category 2 donors the decision about organ donation has to be made in a much shorter time frame. Since these differences in setting may affect the relatives’ consent rate, we studied whether the consent rate for donation in uncontrolled donors was lower than the already low general consent rate for donation in uncontrolled donors (P = 0.813). The reason for not consulting the DR was reported in 72 of 78 cases, and included a non-Dutch nationality in 8 and age under 12 years in 5 cases. Other reasons included the known wish of the patient according to the relatives (n = 25), and legal reasons (n = 14), such as not a natural cause of death. Eleven relatives refused organ donation before the DR was consulted.

The potential donor was registered in the DR in 36% of the UD group (39/109) and in 41% of the ED group (169/414) (Table 1). The registration decision was not significantly different between the two groups; see Table 1.

The mean age of patients was lower in the UD group, 52 versus 55 years in the ED group (P = 0.032) and there were more male patients in this group, 68 versus 52% (P = 0.03) (Table 1). The final consent rate (thus including both consent in the DR and consent given by the relatives), was 61% (56/92) in the UD group and 45% (150/332) in the ED group (P = 0.007), which was fully explained by the higher consent percentage of the relatives of donors who were not registered in the DR. After excluding potential donors with ‘consent’ registered in the DR, the consent rate was 52% (39/75) in the UD group and 29% (74/253) in the ED group (P < 0.001). Reasons for objection could be categorized as known wish of the deceased, emotional reasons and religious/cultural/ language reasons (Table 2). In 35% of the UD group and 21% of the ED group, reasons for objection were not fully clarified. In the univariable and multivariable regression analyses, donation in a controlled setting (ED group) and older donor age were independent risk factors for objection to donation (Table 3).

Discussion

This study shows that the consent rate for organ donation in potential organ donors after a UD is higher than in potential organ donors in whom death is expected. These findings are in contrast to the expectation that the sudden notification of death and the accompanying immediate request for donation in the same initial meeting with the relatives would result in a higher refusal rate. Our results reveal the opposite; the consent rate was higher in the UD group, while there were no differences between the two groups in the registration outcome of the DR.

There are several possible explanations for the different consent rate for donation after UD and ED. First, the request for donation in the UD group is made after the patient has already died. This is a clear situation for the relatives, precluding doubts that donation may influence either the moment of death or end-of-life care. Furthermore, in the uncontrolled situation the number of relatives present is often smaller when donation is discussed. A larger group of relatives may be associated with more discussion, with a decreasing chance of permission for donation being granted. Finally, different from potential donors in the UD group who die in the emergency department, most potential donors in whom death is expected have been admitted to the ICU. The satisfaction of the perceived quality of care may also have an impact on the consent for donation; a negative perception of care is associated with a decrease in the consent rate [9, 10].

Materials and methods

The donation forms, which prospectively register all deceased patients, were retrieved from the Donation Application database for all patients who had died in the MUMC between 1 January 2003 and 1 January 2011. All potential organ donors, as identified by the treating physician, were analysed. Two different groups were compared, based on the moment of death and the time available to discuss donation with the relatives: potential donors with expected death (ED) and unexpected death (UD). The group in which death was expected (ED group) includes potential Maastricht category 3 DCD donors and potential brain dead donors, patients in whom brain death was determined after the consent for donation of the relatives. The patients in the ED group were admitted to the intensive care unit (ICU), coronary care unit, paediatric ICU, or neurological ward. Unexpected potential donors (UD group), included DCD category 2 potential donors, patients who died after failed resuscitation, almost without exception in the Emergency Room. After the declaration of death by the treating physician and a legally mandated ‘no touch’ period of 5 min, organ preservation with a double balloon triple lumen catheter was started. Simultaneously, the treating physician discussed organ donation with the relatives. In patients in the UD group, death and organ donation were thus both discussed simultaneously in a single conversation. If the relatives objected to donation, preservation measures were discontinued. Dutch legislation enables minor preservation measures after death and after consultation of the DR, but before the consent of the relatives is obtained.

In the ED group, the consent for organ donation was also requested by the treating physician. However, in this group, the decision to withdraw treatment or to assess brain death was discussed with the relatives, prior to a separate discussion about organ donation.

We compared the percentage of approached relatives and the consent rates in potential donors in the ED group and UD group, respectively. Continuous variables were presented as mean ± standard deviation (SD) if normally distributed, and as the median and the interquartile range otherwise. Categorical variables were presented as percentages. Baseline donor characteristics, outcome of the Donation Register and the recipient were compared between donor types (UD group versus ED group) with the independent-samples t-tests for normally distributed continuous variables, and with χ² tests for categorical variables.

Factors associated with objection were analysed with univariable and multivariable logistic regression analysis. A P-value ≤ 0.05 was considered statistically significant. SPSS version 16.0 for windows was used for the analysis (SPSS Inc., Chicago, IL, USA).

Results

There were 109 potential donors in the UD group and 414 potential donors in the ED group (Figure 1). In 14% of the UD group and in 15% of the ED group, the national DR was not consulted (P = 0.813). The reason for not consulting the DR was reported in 72 of 78 cases, and

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In the literature, patient and family characteristics as well as belief in the benefit of organ donation are known to be associated with the relatives’ willingness to donate [10]. Families of young, male, Caucasian patients are more likely to consent. Death due to trauma was also associated with consent. In our study, potential donors after UD were younger and more often male. Older age was associated with objection to donation. Understanding and accepting the concept of brain death by relatives of a potential brain death donor increases the consent rate [9, 11]. Relatives who had prior knowledge of patients’ wishes and a positive attitude towards organ donation are more likely to consent [12, 13]. Additional factors that positively correlate with consent for organ donation include the number of conversations, the topics discussed with relatives and the clarity with which the available information is presented [9, 12]. Relatives are more likely to consent when professionals mention that donation can help other people and less likely when discussing organ donation is perceived as ‘merely’ an obligation of the professional [9].

![Flowchart](chart.png)

**Fig. 1.** Overview of the potential donors to family consent 2003–11. *Family approached excluded objection and consent in the DR.

| Table 1. Potential donors’ characteristics, outcome of the DR and donation request |
|-----------------|------------------|------------------|------------------|
| Variable                     | UD group (n = 109) | ED group (n = 414) | P-value |
| Donor age (mean years, SD)   | 52 (15)           | 55 (15)          | 0.032   |
| Donor gender (male, %)       | 74 (68%)          | 215 (52%)        | 0.003   |
| Donation register consulted  | 94 (86%)          | 350 (85%)        | 0.813   |
| Outcome of consultation of the donation register |
| Not registered               | 55 (58%)          | 180 (51%)        | ns      |
| Consent                      | 17 (18%)          | 79 (23%)         | ns      |
| Decision relatives/specif person |
| Not consulted                | 13 (14%)          | 67 (19%)         | ns      |
| Outcome of donation request* | 39/75 (52%)       | 74/253 (29%)     | <0.001  |

UD group, unexpected death group; ED group, expected death group. In 4 cases in the UD group and 15 cases in the ED group, the donation was not discussed. *Request excluded registration with consent in the DR.

| Table 2. Reasons for relatives’ objection to organ donation |
|-----------------|------------------|------------------|
| Reason                          | UD group (n = 142) | ED group (n = 27) |
| No consent relatives*           | 19 (44%)          | 125 (68%)        |
| Emotional reason                | 2 (3%)            | 2 (1%)           |
| Religion/language/culture       | 2 (6%)            | 2 (1%)           |
| Known wish deceased             | 4 (12%)           | 10 (5%)          |
| Other                          | 6 (3%)            |                 |
| Missing                        | 12 (35%)          | 39 (21%)         |

*Objection of the relatives despite patient consent in registry: 3× in the ED group.

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Another important contributory factor is the decoupling of the notification of death or testing for brain death and the request for donation. If the relatives considered the timing of the request as poorly chosen, the consent rate is lower [15]. This is not supported by the results of our study. In the UD group, with a shorter period of time to take the donation decision and one conversation in which both death and donation were addressed, the consent rate was higher.

The approach and expertise of the person making the request is an important factor for obtaining consent. The optimal situation is when medical staff and the organ procurement organization coordinator approach the relatives together [16, 17]. This is not part of our routine practice in which the treating physician discusses the organ donation with the relatives. However, most of the physicians requesting organ donation in both the UD group and ED group received communication training which included the request for organ donation. Physicians who requested donation in the ED group were more experienced as a smaller number of intensivists were possible engaged in a larger number of conversations. A recent study showed that guiding families by ‘trained donation practitioners’ during ICU admittance increased the consent rate by 20% [18].

The DR was not consulted in almost 15% of the potential donors in both groups, although this is legally mandated in the Netherlands. Reasons mentioned for not consulting the DR included the known wish of the patient according to the relatives (n = 23) and refusal of the relatives despite the unknown outcome of the DR (n = 11). In the ED group, the relatives of three patients objected to donation despite consent in the DR. The decision of the deceased in the DR is a will that has to be respected. In the physicians’ education regarding organ donation it should be underscored that the DR has to be consulted, before discussing organ donation with the relatives.

The overall family consent rate in our study was low: 49% of all families approached and 35% if potential donors with registered consent were excluded. Countries with an opting-out system have higher consent rates than countries with an opting-in system, but lack of a uniform way to compare the consent rates makes it difficult to compare countries [19]. However, in Belgium and Spain donation rates have improved since an opting-out system has been implemented.

There are some limitations to this study. First of all, it is unknown if the results of this single-centre study can be generalized, although the differences between the setting of controlled and uncontrolled donation also exist in other hospitals. Furthermore, potential donors after brain death (DBD) and controlled DCD donors were combined in one group. Most studies that address the decision on organ donation ‘only’ include relatives of brain dead patients. In this study, the request for donation in both DBD and controlled DCD donors is made before brain death is confirmed with additional tests. The decision to discontinue treatment did not depend on the confirmation of brain death. Brain death was confirmed only if there was consent for organ donation. Therefore, separation of the ED group into DBD and controlled DCD donation would include an unacceptable bias in favour of DBD donors.

**Conclusion**

The consent for organ donation is higher after unexpected death in an uncontrolled setting, than in potential donors after expected death in a more controlled setting, despite the short period of time in which relatives of a potential uncontrolled donor have to take a decision about organ donation.

Conflict of interest statement. None declared.

**References**

Rapid resolution of severe sustained low blood pressure in haemodialysis patients after successful renal transplantation

Lindsay Muscroft1, Daniel Zehnder1,2, Simon Fletcher2, Nithya Krishnan2, Duncan Watson3, Buddhaavarapu Murthy3 and Rob Higgins2

1Warwick Medical School, University of Warwick, Coventry, UK, 2Renal and Transplant Unit, University Hospitals Coventry and Warwickshire, Coventry, UK and 3Critical Care, University Hospitals Coventry and Warwickshire, Coventry, UK

Correspondence and offprint requests to: Lindsay Muscroft, E-mail: lindsaymuscroft@gmail.com or lindsay.muscroft@uhl-tr.nhs.uk

Abstract

Background. Low blood pressure occurring in the absence of volume depletion, anti-hypertensive medication, heart failure or cortisol deficiency occurs in ~5–10% of haemodialysis patients, and can result in serious complications. The pathophysiology of this syndrome is poorly understood.

Methods. We describe eight cases with dialysis-associated hypotension who underwent renal transplantation. Four patients were severely hypotensive with a systolic blood pressure (SBP) <100 mmHg before and during dialysis, and four had a SBP usually <100 mmHg during dialysis, but usually >100 mmHg between sessions. All had donor-specific human leukocyte antigen antibodies. Six patients underwent pre-transplant plasmapheresis, which was curtailed in two because of further falls in blood pressure. Two patients experienced clotting of their arteriovenous fistula. In one patient cryofiltration was used, which was tolerated without severe falls in the BP. The remaining patient, who had hypotension-associated retinal vein thrombosis before transplant, was supported with an epinephrine infusion and did not receive plasmapheresis.

Results. Post-transplant, the first patient did not receive pressor therapy and died from bowel ischaemia. The other seven patients were supported with inotropes on critical care. The administration of steroids did not reverse hypotension. The mean pre-treatment SBP was 96 mmHg (range 71–110, SEM 5.0). After inotropes were withdrawn and graft function was established, the mean SBP was 127 mmHg (range 113–149, SEM 4.9) (P < 0.01).

Conclusions. Renal transplantation was performed successfully and safely in patients when pressor therapy was used to treat severe dialysis-associated hypotension and, moreover, the blood pressure normalized rapidly after graft function was established.

Keywords: antibody-incompatible transplantation; blood pressure; chronic hypotension; end-stage renal failure; haemodialysis