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### Appointing 'trained donation practitioners' results in a higher family consent rate in the Netherlands: a multicenter study

Nichon E. Jansen, <sup>1</sup> Hendrik A. van Leiden, <sup>1</sup> Bernadette J. J. M. Haase-Kromwijk, <sup>1</sup> Nardo J. M. van der Meer, <sup>2</sup> Edwin Vorstius Kruijff, <sup>2</sup> Netty van der Lely, <sup>3</sup> Hans van Zon, <sup>3</sup> Arend-Jan Meinders, <sup>4</sup> Machteld Mosselman <sup>4</sup> and Andries J. Hoitsma <sup>5</sup>

- 1 Dutch Transplant Foundation, Leiden, The Netherlands
- 2 Department of Intensive Care, Amphia Hospital, Breda and Oosterhout, The Netherlands
- 3 Department of Intensive Care, St Elisabeth Hospital, Tilburg, The Netherlands
- 4 Department of Intensive Care, St Antonius Hospital, Nieuwegein, The Netherlands
- 5 Department of Nephrology, Radboud University Nijmegen Medical Centre, Nijmegen, The Netherlands

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decision-making process, donation request, family refusal, organ and tissue donation, training program.

#### Correspondence

Mrs Nichon E. Jansen MSc, Dutch Transplant Foundation, PO Box 2304, 2301 CH Leiden, The Netherlands. Tel.: +31-71-5795701; fax: +31-71-5766728; e-mail: n.jansen@ transplantatiestichting.nl

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#### Summary

The consent process for organ and tissue donation is complex, both for families and professionals. To help professionals in broaching this subject we performed a multicenter study. We compared family consent to donation in three hospitals between December 2007 and December 2009. In the intervention hospital, trained donation practitioners (TDP) guided 66 families throughout the time in the ICU until a decision regarding donation had been reached. In the first control hospital, without any family guidance or training, 107 families were approached. In the second control hospital 'hostesses', who were not trained in donation questions, supported 99 families during admittance. A total of 272 families were requested to donate. We primarily compared consent rates, but also asked families about their experiences through a questionnaire. Family consent rate was significantly higher in the intervention hospital: 57.6% (38/66), than in the control hospitals: 34.6% (37/107) and 39.4% (39/99). The 69% response rate to the questionnaire − ~5 months after death − showed no confounding variables that could have influenced the consent rate. Appointing TDPs in the intervention hospital to guide families during admittance and the donation decision-making process, results in higher family consent rates.

#### Introduction

The consent process for organ and tissue donation is difficult and complex. Not only for relatives who have to make decisions under emotionally stressful circumstances, but also for professionals who must ask the family about the intentions of the deceased in relation to donation. The Dutch Organ and Tissue Donation Act requires physicians to consult the donor register (DR), which comprises all medically suitable organ and tissue donors

before they approach the family. The DR is part of an opting-in system, requiring the donor or the family to explicitly consent to donation. The DR allows four registration options: 'consent (specified for which organs and tissues)', 'objection', 'decision by next of kin', and 'decision by a specific person'. In the Netherlands, 5.3 million (38%) of the 14.1 million Dutch citizens over the age of 12 have registered their preferences in the DR [1]. Approximately 60% of all eligible donors did not register in the DR; in those cases consultation of the DR shows

'no registration' [2]. When a patient who is eligible for donation is admitted to an intensive care unit (ICU), the DR is consulted first. If the DR shows no 'objection' or 'no registration', the relatives are approached to consent to donation. However, if a potential donor's preference is not registered, we do not know whether the patient ever discussed donation with relatives. Without knowing the deceased's wishes about donation, it is difficult for the bereaved to realize the interests of patients on the waiting list for transplantation, even though it has been shown that donation can help reduce grief in the longer term [3-5]. In many countries, relatives frequently refuse donation if the potential donor's preference is not known [6-11]. These figures are slightly better for some other countries [12,13]. In the Netherlands, family refusal is the main reason for losing potential donors. In 2010, 52% of all the families who were approached for organ donation refused. The refusal rate for tissue donation was 68% [2]. These percentages exclude DR 'objection' cases.

For professionals it is not easy to request donation, especially because it is no daily routine given the relatively low number of potential donors – there are approximately 215 organ donors (~12.3 p.m.p.) and 1500 tissue donors per year in the entire country [2]. In practice, in the Netherlands, an ICU physician (intensivist) asks for organ donation, while a medical resident asks for tissue donation, without any support of a transplant coordinator. The transplant coordinator only contacts the relatives after they have given consent for organ donation. Transplant coordinators have no role in tissue donation.

Other studies into improving consent rates primarily focus on the request for donation, for example by (in-house) staff from organ-procurement organizations or staff experienced in requesting consent for donation participating in the request process [14-18]. However, it has been shown that this type of 'collaborative requesting', in other words, the patient's clinician and a transplant coordinator jointly requesting organ donation, does not sufficiently increase the consent rate [19]. A 'long-contact' strategy may be more effective. The amount of time spent with the relatives might be more important than the actual topics discussed in the lead-up to a request for donation [20,21]. One hospital therefore decided to setup a special team of ICU nurses and trained them according to the 'Communication about Donation' program, to provide long-contact guidance to relatives. Our intention was to study whether the combination of longterm contact and training would be decisive in increasing consent rates. We therefore included two other control hospitals (CH) in our study, one hospital with some form of family guidance but without training, and another hospital without any extra family guidance or training. Furthermore, we evaluated the families' feelings about the entire donation consent process, by asking them to complete a questionnaire.

#### Materials and methods

#### Study set-up

To understand the high family-refusal rate better and to help professionals broach the subject of donation with relatives, the Dutch Transplant Foundation conducted a pilot study between December 2007 and December 2009. We developed a training program called 'Communication about Donation' [11]. There have been similar training programs in the Netherlands in the past, European Donor Hospital Education Program (EDHEP) [22], but the present one meets the latest educational insights [22].

We selected three hospitals for our study, on the basis of average hospital size and expected numbers of organ and tissue donors. None of these hospitals had a transplant program. There was one hospital in the Netherlands with a special team of 14 part-time or former ICU nurses, we called this the 'intervention hospital' (IH). The nurses assisted the relatives of all patients throughout the period of admittance in the ICU, and thus had long-term contact with the families. The nurses were, however, not part of the treatment team and, before the pilot study started, they were not involved in the donation consent process. The intervention consisted of training the nurses in 'communication about donation'. Prior to training, all the nurses took part in a written assessment involving 34 questions on different topics, such as their competency in communication skills and techniques, knowledge about organ and tissue donation, and dealing with grieving bereaved. We incorporated the results of the assessment in the training to focus on specific areas of need. The training consisted of the following components; a practical training in communication skills and techniques, including role-playing with actors, and clinical instruction lessons in the practice of organ and tissue donation. After completing our training, the nurses were trained donation practitioners (TDP). A TDP is always available, 24 h a day. If a patient becomes an eligible donor, a TDP guides the relatives through the donation consent process. TDPs not only provide information about donation, but also emotional support. This method can be seen as a 'longcontact strategy': TDPs spend 4 h (or less when appropriate) with the family until a well-considered decision on donation has been made. During the pilot study, a psychologist organized supervision sessions based on evaluation forms completed by the TDP after each guidance process. Halfway through the pilot study, we organized a 1-day follow-up training.

In this study, we compared the IH with two CH. One CH had no special professionals providing care to a patient's relatives in case of an acute or planned admission to the ICU and donation was requested without any trained support. The second control hospital (CHwH) employed 'hostesses'. They were, however, not trained in any special program and had not been trained in the subject of donation. A hostess was available during the day to answer relatives' questions and arrange appointments with the physician in charge. Hostesses only provided nonmedical information, and after a potential donor had died, they had no specific role in the donation decision process.

Before we started the present study, the Medical Ethical Board of all three hospitals approved participation in this study.

#### Study evaluation

Hospital donation coordinators reviewed the medical records of all the patients who died in the three ICUs for eligible organ and/or tissue donors. We included in our evaluation all the deceased - except the ones with an 'objection' registration in the DR - whose relatives had been asked for organ and/or tissue donation. We first evaluated the effect of intervention on the relatives' consent to donation and compared these results to the control hospitals. In addition, we subsequently also evaluated the relatives' experiences in the three hospitals through a questionnaire. A donation coordinator of the hospital (who had had no role at all in approaching the relatives for consent to donation in any of the participating hospitals) approached the family by telephone ~6 weeks after the donation request. He asked the family for permission to pass on their address to a researcher. The researcher asked the relative who figured in the medical chart as first representative to complete a questionnaire. Four months after the patient had died; this relative received a letter accompanied by a reply card and questionnaire. Most relatives (69%) responded immediately, and returned the completed questionnaire. If the questionnaire showed that more members of a family had been present during the donation conversations, we also asked these other family members to respond to the questionnaire. These additional responses - 41 completed questionnaires - showed no significant differences compared with the questionnaires completed by the first representative, and were therefore excluded from our analysis.

#### Questionnaire

We developed the questionnaire in collaboration with the faculty of medical psychology of Erasmus MC University Hospital Rotterdam. A questionnaire comprised 27 questions – with four additional questions for the IH to eval-

uate the guidance by the TDP – divided into three sections. We covered several factors that may have influenced the decision-making process, as identified in many studies [15,19,20,22–26]. These factors include:

Sex and age of potential donor [15,20,24]. Satisfaction with health care [20,24,25]. The professional(s) approaching the family [19,20,22,26]. Information given about donation [20,23–25]. Knowing the deceased wishes [15,20,23–26]. Agreement between family members [15,20].

In the first section, we evaluated the respondents' socio-demographic profiles on the basis of the following items; sex, age, education, relation to the potential donor, and length of time between the (potential) donor's death and family's response to the questionnaire. The respondent's country of birth was asked and that of his parents.

In the second section, we evaluated satisfaction with health care and items that may affect the donation request process. We assessed whether the respondents were satisfied with the hospital care provided by the health-care professionals. Not only during admittance, but also at the moment of the death of their loved one, and at the moment the physician requested donation. The donation request process was evaluated on the basis of the number of professionals attending the request and whether donation had been requested for organs or tissues, or for organs and tissues. We also asked the respondents whether there had been sufficient opportunity to ask questions and if the obtained information contributed to a well-considered donation decision.

In the third section, we focused on factors that may affect the decision-making process. The questions dealt with subjects such as whether donation had ever been discussed, and if the respondent knew whether the donor's preferences were registered in the DR. The role of religion in the decision-making process was also investigated. If more members of a family had been present at the donation request, we inquired after the general agreement among these relatives about the donation decision. The final question addressed whether the respondent would make the same decision again.

#### Data analysis

To identify significant differences in the percentages of family consent for the three hospitals, we performed a two-tailed chi-square test. To prevent a positive effect from the cases with 'consent' in the DR, we excluded this category and analyzed family consent rate again. We assessed differences in the potential donors' sex and age

by a chi-squared test for categorical variables and a oneway anova for interval variables.

We analyzed the responses to the questionnaire to identify possible differences between the hospitals, other than the TDP, that could explain discrepancies in the consent rates. We examined univariate relationships between the questionnaire items for the three hospitals using a two-tailed chi-squared test for categorical variables and a one-way ANOVA for interval variables. For questions measuring the respondents' level of satisfaction or agreement a 4-point Likert scale ranging from 1 to 4 was used (very dissatisfied to very satisfied, and fully disagree to fully agree). Higher scores indicate a higher level of satisfaction or agreement. All data were analyzed using the Statistical Package for the Social Sciences (spss version 19.0, Nieuwegein, the Netherlands).

The family consent rates for organ and/or tissue donation, after excluding 'objection' in the DR, were analyzed

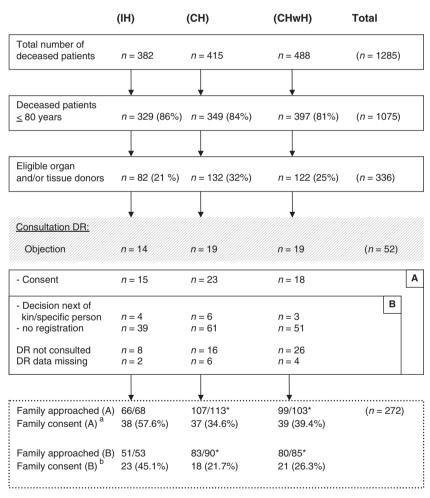
for the years preceding the study period (2004–2006) to calculate differences from baseline.

#### Results

In total, 1285 patients died in the three hospitals' ICUs, 1075 of them were younger than 80 years (Fig. 1). During the study period, 80 was the maximum age for donation. Of the 336 potential donors, 52 were excluded on the grounds of 'objection' being registered in the DR. The total number of families approached for donation was 272 of 284 eligible donors.

#### Higher consent rate in intervention hospital

We analyzed the outcome of all 272 requests for organ and tissue donation (Fig. 1). Sixty-six of these were in the IH, 107 in the CH, and 99 in the CHwH. The family consent



**Figure 1** Overview of the process from a patient dying in ICU, to family consent to donation (December 2007–2009). IH, intervention hospital; CH, control hospital; CHwH, control hospital with hostesses; DR, Donor Register. \*One family approached, no data on consultation of DR available.  $^{a}$ Relationship evaluated using chi-square test: Family consent (A) IH versus CH P = 0.003, IH versus CHwH P = 0.022.  $^{b}$ Relationship evaluated using chi-square test: Family consent (B) IH versus CH P = 0.004, IH versus CHwH P = 0.026.

Table 1. Potential donors' demographic profiles, families' responses to the questionnaire, and respondents' characteristics.

	Intervention hospital ( $n = 66$ )	Control hospital $(n = 107)$	Control hospital with hostesses $(n = 99)$	<i>P</i> -value for difference
Total number of potential donors $n = 272$				
Sex potential donor	Male 58%	Male 49%	Male 66%	P = 0.047*
Age potential donor (SD)	63.4 (13.6)	53.0 (16.6)	64.2 (11.2)	<i>P</i> < 0.001†
Total number of families approached for donation	66	107	99	Total $n = 272$
Number of families reached by phone	64 (97%)	95 (88.8%)	80 (80.8%)	239 (88%)
Number of families willing to pass on address	56 (87.5%)	86 (89.5%)	65 (81.3%)	207 (87%)
Response to questionnaire	41 (73.2%)	56 (65.1%)	45 (69.2%)	142 (69%)
Consent for donation	30 (73.2%)	29 (51.8%)	24 (53.3%)	83 (58%)
Refusal against donation	11 (26.8%)	27 (48.2%)	21 (46.7%)	59 (42%)
Total response to questionnaire $n = 142$	41	56	45	P-value for difference
Sex respondents	Male 34%	Male 52%	Male 29%	P = 0.46*
Age respondents	57.5 (14.4)	51.4 (12.4)	57.4 (11.0)	$P = 0.023\dagger$
Missing	2	0	0	
Relationship to deceased spouse	25 (61%)	25 (44.6%)	28 (62.2%)	P = 0.114*
Other relationships				
Child	9 (21.9%)	15 (26.8%)	10 (22.2%)	
Sibling	3 (7.3%)	5 (9%)	4 (8.8%)	
Parent	2 (4.9%)	9 (16%)	1 (2.2%)	
Other	2 (4.9%)	2 (3.6%)	2 (4.4%)	
Time in months between death of the potential donor and return questionnaire (SD)	4.41 (1.183)	4.68 (1.177)	6.04 (1.551)	<i>P</i> < 0.001†

<sup>\*</sup>Relationship evaluated using chi-square test.

rate was significantly higher in the IH (57.6%). Further sub-analysis showed that after dividing the responses into requests for tissue or organ donation, the only significant difference was the higher consent rate for organs in the IH (60%) compared to the CH (32.7%) (P < 0.022) (data not shown). After excluding potential donors with 'consent' registered in the DR, the family consent rate in the IH (45.1%) was significantly higher than in the CH (21.7%) and in the CHwH (26.3%) (Fig. 1). The average family consent rates (excluding potential donors with 'objection' registered in the DR) for the years 2004-2006 were 37.5% (39/104) for the IH, 34.2% (62/181) for the CH, and 29.2% (43/147) for the CHwH. The two-sided chi-square test showed no significant difference between the hospitals (P = 0.371). When these data are compared with the consent rate in the pilot period, only the IH showed a significantly higher rate (P = 0.010).

# Potential donors' demographic profiles, families' responses to questionnaires, and respondent' characteristics

Table 1 summarizes the potential donors' socio-demographic profiles, showing a significantly lower percentage of deceased males in the CH than in the CHwH, and a

significantly lower age of the potential donors in the CH than in the IH and the CHwH. We were able to reach by telephone 239 (88%) of the 272 families requested to donate (Table 1). Eighty seven percent (207/239) agreed to pass on their addresses to a researcher to receive a questionnaire; this corresponds to response rate of 73.2% in the IH, 65.1% in the CH, and 69.2% in the CHwH (Table 2). Of all respondents, 83 (58%) consented to donation and 59 (42%) refused. Fifty-five respondents gave additional information in the questionnaire about their reasons for refusing. The main remarks were; 'deceased assumed to refuse' (n = 19), 'not prepared for request' (n = 12), 'relatives against donation' (n = 11), and 'maintenance of body integrity' (n = 8). The respondents' demographic profiles showed that more females than males responded to the questionnaire, except in the CH (Table 1). The respondents' mean age was 52.3 years (range: 18-82 years), with a significantly lower age in the CH. Nearly all respondents were born in the Netherlands (≥96%) as were both parents (overall ≥92%) (data not shown). Education levels did not differ significantly between the hospitals. Relationships to the deceased were comparable, although in the CH there were more parents. For the CHwH, the mean length of time between the potential donor's death and the response to the question-

<sup>†</sup>Relationship evaluated using one-way ANOVA.

Table 2. Respondents' satisfaction with care given and factors that may affect the donation request process.

Total response to questionnaire $n = 142$	Intervention hospital $(n = 41)$	Control hospital $(n = 56)$	Control hospital with hostesses $(n = 45)$	<i>P</i> -value for difference
Satisfaction*				
About admission period in hospital	82.9% (34/41)	92.6% (50/54)	93.2% (41/44)	P = 0.468§
Missing	0	2	1	
With the care at the moment of death	92.6% (38/41)	92.8% (52/56)	93.2% (41/44)	P = 0.188§
Missing	0	0	1	
With the way the physician requested donation	97.3% (36/37)	96.2% (51/53)	92.5% (37/40)	P = 0.263§
Missing	0	3	5	
Number of ICU professionals present				
during request, apart from physician				
TDP	100% (41/41)	0	0	
ICU nurse	29.3% (12/41)	75% (42/56)	71.1% (32/45)	
Chaplin/other	2.4% (1/41)	7.1% (4/56)	4.4% (2/45)	
Donation requested for:				
Tissues only	15 (38.5%)	11 (20.8%)	12 (30.8%)	P = 0.173§
Organs and/or tissues	24 (61.5%)	42 (79.2%)	27 (69.2%)	
I do not knowt	2	3	6	
Agreement‡				
Information during the donation	97% (33/34)	86.5% (42/52)	83.8% (31/37)	P = 0.168§
conversation enabled us to make a well-considered decision				
Not applicable† (decision beforehand)	2	3	4	
Missing	5	1	4	

TDP = trained donation practitioners.

§Relationship evaluated using chi-square test.

naire was significantly longer. This hospital participated a few months later.

#### Satisfaction with health care and factors that may affect the donation request process

We analyzed the respondents' level of satisfaction with hospital care for three items (Table 2). The proportion of outcomes 3 and 4 on the 4-point Likert scale showed a high satisfaction in all participating hospitals. No significant differences were observed.

The number of ICU nurses attending the request for donation was the highest in the CH. In the IH, more families who had been requested for tissues than for organs responded to the questionnaire than in the CH. In all three hospitals, the respondents had the opportunity to ask questions. This was answered positively by 94.6% in the IH, 88.7% in the CH, and 93% in the CHwH (data not shown). We analyzed the respondents' level of agreement on the question 'whether a well-considered decision could be made on the basis of the information obtained during the donation conversation'. The proportion of outcomes 3 and

4 on the 4-point Likert scale was highest in the IH (97%) (Table 2). If a respondent had made the donation decision beforehand, the questionnaire showed 'not applicable'.

## Factors that may have affected the decision-making process

Approximately 69% of all respondents had previously discussed donation with their loved one (Table 3). Approximately 42% of all respondents confirmed they knew whether the donation preference of the potential donor had been registered in the DR. Religion played a minor role in the decision-making process, it affected only one respondent in the IH, five in the CH, and three in the CHwH (data not shown). When more family members had attended the donation request, agreement between these relatives was 100% in the IH and CHwH, and 88.5% in the CH (data not shown). The final question – whether respondents would make the same decision again – was answered positively by 90% in the IH, 92.7% in the CH, and 83.7% in the CHwH (data not shown).

<sup>\*</sup>Measured using a 4-point Likert scale ranging from very dissatisfied (1) to very satisfied (4). The proportion of outcomes 3 and 4 in the total response per hospital is shown.

<sup>†</sup>The options 'I do not know'/'Not applicable' were excluded from the statistical analysis.

<sup>‡</sup>Measured using a 4-point Likert scale ranging from fully disagree (1) to fully agree (4). The proportion of outcomes 3 and 4 in the total response per hospital is shown.

**Table 3.** Factors that may have affected the decision-making process.

Total $n = 142$	Intervention hospital $(n = 41)$	Control hospital $(n = 56)$	Control hospital with hostesses $(n = 45)$	<i>P</i> -value for difference
Donation discussed	in the past			
Yes	29 (70.7)	38 (67.9)	31 (68.9)	P = 0.120*
Missing	0	0	1	
Do you know if pot	tential donor register	ed donation prefere	nces in the DR	
Yes	15 (38.5)	22 (47.8)	16 (40)	P = 0.897*
I do not knowt	2	10	4	
Missing	0	0	1	

Values in parentheses are in percentages.

**Table 4.** Responders' opinion about guidance and information given by the trained donation practitioner (TDP) in the IH; for those who consented to donation and those who refused donation.

Total $n = 41$	Consent $(n = 30)$	Refusal ( $n = 11$ )
Satisfaction with guida	nce TDP	
Very satisfied	15 (57.7)	5 (50)
Satisfied	9 (34.6)	4 (40)
Dissatisfied	2 (7.7)	1 (10)
Very dissatisfied	0	0
Missing	4	1
Information given by T	DP	
Very clear	11 (44)	3 (30)
Clear	13 (52)	6 (60)
Unclear	1 (4)	1 (10)
Very unclear	0	0
Missing	5	1
Satisfaction with inform	nation given with the requ	est for donation
Very satisfied	8 (33.3)	2 (20)
Satisfied	16 (66.7)	8 (80)
Dissatisfied	0	0
Very dissatisfied	0	0
Missing	6	1
Additional information	played a role in decision-r	naking process
Yes	6 (24)	0
No	19 (76)	10 (100)
Missing	5	1

Values in parentheses are in percentages.

The questionnaire for the IH contained four additional variables concerning the presence of a TDP. Satisfaction with guidance was high (>90%), irrespective of whether the respondent consented to or refused donation (Table 4). The information provided was clear (≥90%) and the content was satisfying to all respondents. The additional information played a role in the decision-making process for 24% (6/25) of the families who consented to donation.

#### Discussion

The Dutch Transplant Foundation performed a multicenter study by training an existing special group of former

or part-time ICU nurses in 'Communication about Donation'. All these professionals had intensive contact with the next of kin from the moment the patient's admission to the ICU, without being part of the treatment team. We examined the hypothesis that training and appointing TDPs on an intensive care unit would result in a higher family consent rate. We found that the overall consent rate in the IH was indeed significantly higher than in the two control hospitals.

We analyzed various factors in all three hospitals to be sure that no confounding variables could have influenced the consent rate. Although we found a significantly lower age of potential donors in the CH, higher ages turned out to be associated with a higher family-refusal rate. It is therefore unlikely that a lower donor age had a negative influence [27,28]. The significantly lower percentage of males in the CH could have affected the consent rate, but the overall consent rate for male donors was not significantly higher than for female donors (42.6% vs. 41%) (data not shown). Therefore, we assume that the potential donor's sex had no significant effect.

The respondents' profiles differ significantly with respect to 'length of time between the potential donor's death and the family's response to the questionnaire'. This finding cannot have influenced the consent rate, as the request for donation always occurred around the time of death of the potential donor. However, it is conceivable that it could have had an effect on the respondent's recollection of items in the questionnaire.

Our hypothesis that families in the IH would be more satisfied was not confirmed. Questionnaires for the all participating hospitals recorded high satisfaction scores. Although higher consent rates were indeed achieved by the IH appointing TDPs, relatives were not more satisfied.

Whether the relatives knew the deceased' wishes regarding donation could also have influenced the consent rate [25,26,29–32]. No significant differences were seen between the hospitals, except with regard to the general agreement between family members about

<sup>\*</sup>Relationship evaluated using chi-square test.

<sup>†</sup>The option 'I do not know' was excluded from the statistical analysis.

the donation decision (data not shown). According to Rodrigue *et al.*, family disagreement is associated with a higher number of refusals. However, because of the small numbers in the CH this could not have had a major effect on the consent rate [20].

Our study faced several limitations. Of all the families concerned, 12% could not be reached by telephone and we were therefore unable to request them to participate in the study. The time between the request for donation and completing the questionnaire was approximately 5 months. Because of this time gap, it is conceivable that the relatives' recollections were not always accurate. In addition, the results of the questionnaires may have a selection bias, as the respondents include more families who consented to donation. Furthermore, this study was not randomized, like the ACRE study in the United Kingdom [19]. There were too many practical problems to randomize this study, and we therefore included two control hospitals in the study.

The present study is unique in our Dutch system. So far, no other study proved a positive effect on family consent rate. Compared to other countries, the Netherlands has no experience with the standard availability of transplant coordinators for collaborative requesting. In Spain, intensivists are also transplant coordinators [14], in the USA and UK organ-procurement staff is involved in the organ-donation request [15,33,34]. The strength of our approach is a special training in combination with support for the families from the moment of admittance to the intensive care unit. The conversation about donation is thus a natural completion of the guidance process. Siminoff et al. [18] suggested a positive effect of training on family consent rate. The importance of emotional and informational support of families is consistent with the outcomes of other studies [25,35].

In conversations with the TDP, some families brought up the subject of donation themselves. This tendency of families initiating discussions about donation is not unique for the Netherlands [36]. In some cases, the TDP had already carefully explored the family's wishes. The families were therefore not taken by surprise when the donation request was made. The TDP also played an important role during the approach for donation. Because of the interplay between physician, TDP and ICU nurse, it did not matter who first broached the subject of donation. The TDP was present all the time to give information, answer questions, and provide emotional support during the entire decision-making process.

Our results suggest that the 'Communication about Donation' training *and* the long and intensive contact between the TDP and next of kin were decisive factors in the statistically significant higher consent rate for donation. Our findings are corroborated by the results of the

ACRE study in the United Kingdom, where the increase in consent rates was not reflected by collaborative requesting. This seems in contradiction to our results. The difference with our study is the long-contact strategy, which is also suggested as a solution by the authors of the ACRE study [19]. We recommend appointing TDPs in many more hospitals in the Netherlands, as this could increase the number of organ and tissue donors considerably.

#### **Authorship**

NEJ: designed and performed the research, analyzed the data, and wrote the manuscript. HAvL: participated in the research design, in the writing of the paper, and data analysis. BJJMHK: participated in the research design, and revised the manuscript. NvdM: participated in the research design, and revised the manuscript. EVK: participated in the performance of the research, collection of the data, and revised the manuscript. NvdL: participated in the research design, and revised the manuscript. HvZ: participated in the performance of the research, collection of the data, and revised the manuscript. AJM: participated in the research design, and revised the manuscript. MM: participated in the performance of the research, collection of the data, and revised the manuscript. AH: participated in research design, in the data analysis, in the writing of the paper.

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#### References

- 1. Kerkrade, Donor Register. Annual report 2008 of the Donor Register. 2009, The Netherlands, Dutch.
- 2. Leiden, Dutch Transplant Foundation. *Annual report 2010 of the Dutch Transplant Foundation*. 2011, The Netherlands, Dutch.
- Cleiren MP, Van Zoelen AA. Post-mortem organ donation and grief: a study of consent, refusal and well-being in bereavement. *Death Stud* 2002; 26: 837.

- Merchant SJ, Yoshida EM, Lee TK, Richardson P, Karlsbjerg KM, Cheung E. Exploring the psychological effects of deceased organ donation on the families of the organ donors. Clin Transplant 2008; 22: 341.
- Stouder DB, Schmid A, Ross SS, Ross LG, Stocks L. Family, friends, and faith: how organ donor families heal. *Prog Transplant* 2009; 19: 358.
- Barber K, Falvey S, Hamilton C, Collett D, Rudge C. Potential for organ donation in the United Kingdom: audit of intensive care records. *BMI* 2006; 332: 1124.
- Doyle AM, Lechler RI, Turka LA. Organ transplantation: halfway through the first century. J Am Soc Nephrol 2004; 15: 2965.
- 8. Sheehy E, Conrad SL, Brigham LE, *et al.* Estimating the number of potential organ donors in the United States. *N Engl J Med* 2003; **349**: 667.
- 9. Wesslau C, Grosse K, Krüger R, *et al.* How large is the organ donor potential in Germany? Results of an analysis of data collected on deceased with primary and secondary brain damage in intensive care unit from 2002 to 2005. *Transpl Int* 2007; **20**: 147.
- Opdam HI, Silvester W. Identifying the potential organ donor: an audit of hospital deaths. *Int Care Med* 2004; 30: 1390.
- Jansen NE, van Leiden HA, Bernadette BJJM, Hoitsma AJ. Organ donation performance in the Netherlands 2005– 2008; medical record review in 64 hospitals. *Nephrol Dial Transplant* 2010; 25: 1992.
- 12. Frutos MA, Blanca MJ, Ruiz P, Mansilla JJ, Seller G. Multifactorial snowball effect in the reduction of refusals for organ procurement. *Transplant Proc* 2005; **37**: 3646.
- Roels L, Spaight C, Smits J, Cohen B. Donation patterns in four European countries: data from the donor action database. *Transplantation* 2008; 86: 1738.
- 14. Matesanz R. Factors influencing the adaptation of the Spanish model of organ donation. *Transpl Int* 2003; **16**: 736.
- 15. Siminoff L, Mercer MB, Graham G, Burant C. The reasons families donate organs for transplantation: implications for policy and practice. *J Trauma* 2007; **62**: 969.
- 16. Shafer TJ, Davis KD, Holtzman SM, Van Buren CT, Crafts NJ, Durand R. Location of in-house organ procurement organization staff in level I trauma centers increases conversion of potential donors to actual donors. *Transplantation* 2003; 75: 1330.
- 17. Nathan HM, Conrad SL, Held PJ, et al. Organ donation in the United States. Am J Transplant 2003; 3(Suppl. 4): 29.
- 18. Siminoff LA, Marshall HM, Dumenci L, Bowen G, Swaminathan A, Gordon N. Communicating effectively about donation: an educational intervention to increase consent to donation. *Prog Transplant* 2009; **19**: 35.
- ACRE Trial Collaborators. Effect of "collaborative requesting" on consent rate for organ donation: randomised controlled trial (ACRE trial). BMJ 2009; 339: b3911.

- Rodrigue JR, Cornell DL, Howard RJ. Organ donation decision: comparison of donor and nondonor families. *Am J Transplant* 2006; 6: 190.
- 21. Aldridge A, Guy BS. Deal breakers in the organ donation request process. *Health Mark Q* 2008; **23**: 17.
- 22. Blok GA, van Dalen J, Jager KJ, *et al.* The European Donor Hospital Education Programme (EDHEP): addressing the training needs of doctors and nurses who break bad news, care for the bereaved, and request donation. *Transpl Int* 1999; **12**: 161.
- 23. Burroughs TE, Hong BA, Kappel DF, Freedman BK. The stability of family decisions to consent or refuse organ donation: would you do it again? *Psychosom Med* 1998; **60**: 156.
- 24. De Jong W, Franz HG, Wolfe SM, *et al.* Requesting organ donation: an interview study of donor and nondonor families. *Am J Crit Care* 1998; 7: 13.
- 25. Sque M, Long T, Payne S. Organ donation: key factors influencing families' decision-making. *Transplant Proc* 2005; **37**: 543.
- Siminoff LA, Arnold RM, Hewlett J. The process of organ donation and its effect on consent. *Clin Transplant* 2001; 15: 39.
- 27. van Leiden HA, Jansen NE, Haase-Kromwijk BJ, Hoitsma AJ. Higher refusal rates for organ donation among older potential donors in the Netherlands: impact of the donor register and relatives. *Transplantation* 2010; 90: 677.
- 28. Brown CV, Foulkrod KH, Dworaczyk S, *et al.* Barriers to obtaining family consent for potential organ donors. *J Trauma* 2010; **68**: 447.
- 29. Siminoff LA, Lawrence RH. Knowing patients' preferences about organ donation: does it make a difference? *J Trauma* 2002; **53**: 754.
- Rodrigue JR, Cornell DL, Howard RJ. Does family disagreement affect donation decisions by next of kin? *Prog Transplant* 2008; 18: 179.
- 31. Siminoff LA, Gordon N, Hewlett J, Arnold RM. Factors influencing families' consent for donation of solid organs for transplantation. *JAMA* 2001; **286**: 71.
- 32. Rodrigue JR, Cornell DL, Howard RJ. The instability of organ donation decisions by next-of-kin and factors that predict it. *Am J Transplant* 2008; **8**: 2661.
- 33. Verble M, Worth J. Overcoming families' fears and concerns in the donation discussion. *Prog Transplant* 2000; **10**: 155.
- Simpkin AL, Robertson LC, Barber VS, Young JD. Modifiable factors influencing relatives' decision to offer organ donation: systematic review. *BMJ* 2009; 21: 338.
- 35. Jacoby L, Jaccard J. Perceived support among families deciding about organ donation for their loved ones: donor vs nondonor next of kin. *Am J Crit Care* 2010; **19**: 52.
- 36. Rodrigue JR, Cornell DL, Krouse J, Howard RJ. Family initiated discussions about organ donation at the time of death. *Clin Transplant* 2010; **24**: 493.