Transpl Int (1999) 12: 182–187


ORIGINAL ARTICLE

**J. van Dalen**
**G.A. Blok**
**M.J. Morley**
**J. Morton**
**B. Haase-Kromwijk**
**R.A. Sells**
**R.W.G. Johnson**

# Participants' judgements of the European Donor Hospital Education Programme (EDHEP): an international comparison

Received: 5 June 1998
Received after revision: 1 December 1998
Accepted: 22 December 1998

J. van Dalen
University of Maastricht
Skillslab
P.O. Box 616
6200 MD Maastricht
The Netherlands

G.A. Blok (✉)
University of Maastricht
Department of Educational Research
and Educational Development
P.O. Box 616
6200 MD Maastricht
The Netherlands

M.J. Morley
Central Manchester Healthcare
NHS Trust
Department of Clinical
and Health Psychology
Rawnsley Building
Oxford Road
Manchester M13 9BX
United Kingdom

J. Morton
University of Liverpool
Department of Clinical Psychology
Whelan Building
Brownlow Hill, Quadrangle
Liverpool, L69 3GB
United Kingdom

B. Haase-Kromwijk
Eurotransplant International
Foundation
P.O. Box 2304
2301 CH Leiden
The Netherlands

R.A. Sells
Royal Liverpool and Broadgreen
University Hospital NHS Trust
Renal Transplant Unit
Prescot Street
Liverpool L7 8XP
United Kingdom

R.W.G. Johnson
Central Manchester Healthcare
NHS Trust
Renal Transplant Unit
Swinton Grove
Manchester M13 0EU
United Kingdom

**Abstract** The European Donor Hospital Education Programme (EDHEP) is a one-day workshop, aimed at providing guidelines for breaking the news of the death of a relative and for raising the issue of organ donation with bereaved relatives. Participants' judgements of the workshop in the Netherlands and in the United Kingdom were compared to determine whether EDHEP meets doctors' and nurses' training needs in breaking bad news and requesting organ donation. In both countries EDHEP appears to be greatly appreciated by intensive care medical and nursing staff; the judgements are more positive in the United Kingdom than in the Netherlands. It seems that, irrespective of their professional experience, intensive care staff consider EDHEP a valuable teaching programme that increases confidence in communicating with bereaved relatives about death and organ donation.

**Key words** Organ donation · EDHEP · Relatives · Training

## Introduction

Due to the success of organ transplantations since the development of modern immunosuppressants in the 1980s, waiting lists for donor organs have been increasing. The availability of donor organs does not keep up with the increasing demand. Currently, the refusal rate of organ donation by relatives is approximately 30%, with an additional 6% of the families of potential donors never being approached about donation [11]. Communication with relatives about donation is often quite difficult [13, 15, 20]. Attending to grieving families and making requests for organ donation requires personal insight and awareness of the needs of bereaved relatives as well as good communication skills, both of which may be influenced by experience [25]. Self-confidence in ap-

**Table 1** Overview of the European Donor Hospital Education Programme

| | |
|---|---|
| 1. Welcome and introduction | * Transplant coordinator |
| 2. Reasons for lack of donors<br>*Presentation* | * Logistics of donation procedure<br>* Overview of health professionals' reasons for hesitance to request donation |
| 3. Loss and separation *exercise* | * Acknowledgement of own reactions to loss |
| Coffee Break | |
| 4. Vignettes<br>*Brief videotaped dramatisation* | * Identification of the personal and the professional response to grieving relatives |
| 5. Health professionals can be effective<br>*Presentation* | * Insight into effective communication with grieving relatives |
| 6. Talking about loss<br>*Videotaped interviews with relatives who consented to organ donation* | * The relatives' perspective |
| Lunch Break | |
| 7. Sudden death<br>*Video drama* | * Communication guidelines when breaking news of death and requesting donation |
| 8. Breaking news of death<br>*Role-play with simulated relatives* | * Practise relevant communication skills<br>* Structured feedback to help identify strengths and weaknesses |
| Coffee Break | |
| 9. The donation request<br>*Role-play with simulated relatives* | * Practise relevant communication skills<br>* Structured feedback to help identify strengths and weaknesses |
| 10. Overview and summary<br>*Presentation* | * Overview of learning objectives<br>* Guidelines for protocols |

proaching relatives to request donation influences the consent rate. Malecki et al. [14] showed that nurses who were insecure and uncomfortable making the donation request mainly had refusals, in contrast to nurses who felt more secure and less uncomfortable. 'Lack of training' and 'fear of adding to relatives' distress' have been identified as important barriers to raising the topic of organ donation with families [26].

To help health professionals overcome these barriers, the Eurotransplant International Foundation initiated the development of the European Donor Hospital Education Programme (EDHEP) in 1991. EDHEP is a highly interactive, one-day workshop organised and hosted by transplant coordinators and moderated by communication skills training experts, preferably clinical psychologists. The workshop consists of different working formats, such as oral presentations, case studies, videotapes and exercises, including role plays with simulated relatives.

Evaluation of the programme by the first 430 participants in the Netherlands showed a high degree of satisfaction with EDHEP, as well as a high learning effect and a decrease in the 'barrier' to approach families for donation [7]. EDHEP was developed as an adaptable prototype, available to interested parties around the world. By 1998 EDHEP had been translated in 17 languages, and it is a recognised part of postgraduate training in 30 countries in and outside of Europe. The condition under which the programme was made available by the Eurotransplant International Foundation was that the original format be kept [28]. National topics have been added to the programme (e.g. legal issues in France, religious issues in Israel). Sixteen standardised 2.5-day "Train the Trainer" courses have accompanied the deployment of EDHEP in new countries and are conducted by the programme's authors and principal trainers in order to guarantee an acceptable similarity and quality control. Anecdotal reports of the positive reception of EDHEP have been equally apparent in such diverse countries as Saudi Arabia, Japan, Mexico and all of Europe. In the North West region of England, EDHEP was implemented in 1994.

A review of the degree to which EDHEP participants in the Netherlands and the United Kingdom are satisfied with the programme has been conducted. The main question to be answered is: to what extent has the deployment of EDHEP been successful?

EDHEP was designed to heighten the sensitivity of intensive care medical and nursing staff to relatives' needs in times of crisis and to provide guidelines for communication with bereaved relatives. The format of the day and the teaching aids used are specifically tailored to breaking the news of (brain)death and to raising the issue of donation (see Table 1).

The workshop is conducted in small groups with a maximum of sixteen participants, preferably eight doc-

tors and eight nurses, working in critical care. EDHEP takes place outside the hospital setting and its inevitable distractions [2, 3, 24, 28, 29].

The principal questions in this study are: is there a difference in satisfaction with, and in recognition of the issues addressed by EDHEP between participants from the Netherlands and those from the United Kingdom? Is there a difference between the reported learning effect and the requests for follow-up by EDHEP participants in the Netherlands and in the United Kingdom? Three specific issues are additionally addressed:

1. Sanson-Fisher et al. [22] recommend that for training to be effective it should be given within a context that is familiar and encountered in clinical practice. In the original EDHEP teaching material provided by the Eurotransplant International Foundation, one teaching video programme ('Vignettes') is in Dutch, with English subtitles. It was suggested that the 'Vignettes' programme be reproduced to suit national circumstances. After 1.5 years of experience in the United Kingdom with the original EDHEP 'Vignettes' programme, this was remade into an English version. Are participants more positive about teaching material that reflects their own national situation than about foreign teaching material?
2. Interactive training in communication skills appears to occur less frequently in medical and nursing schools in the United Kingdom than in the Netherlands [4, 5, 9, 19, 21, 27, 30, 31]. It has been reported that participants who have actually had practice in skills trainings report results on formal behaviour tests that are similar to those participants who only observed skills performance, albeit in clinical skills training [16]. Half of the participants in EDHEP have the opportunity to practise in role-plays with simulated relatives, whereas the other half observe these interactions with predefined observation forms. Is there a difference in learning effect for those who practise in a role-play compared to those who only observe? Are these differences national or international?
3. As has been noted in the implementation of EDHEP in Germany, the condition that EDHEP is conducted in mixed groups of doctors and nurses may create problems of acceptance amongst doctors [18]. What is the participants' judgement about the group composition? Is there a difference between these judgements in the two countries?

## Method

Programme evaluation has been shown to be a reliable technique to measure participants' satisfaction with a course [6, 8, 10]. The programme evaluation questionnaire is provided as part of the EDHEP training package by the Eurotransplant International Foundation. The English form of the questionnaire is a direct translation of the Dutch original. The translation was done by the authors of the programme, native Dutch and native English speakers, familiar with the concepts relating to training in the areas of bereavement and donation. The first section of the questionnaire consists of items detailing date, biographical information, position and experience of the participant and questions about the difficulty of the donation request. These questions are answered on a 10-point scale ranging from "no problem at all" to "extremely difficult". The second section of the questionnaire consists of statements about the organisation, information, teaching aids and learning effect of the workshop; it is to be answered on a 5-point scale ranging from "disagree completely" to "agree completely". In the final section, the participants indicate their desire for further information and training [12].

The forms were distributed, completed and subsequently collected at the end of each workshop to guarantee the highest possible response rate. The forms did not require identification of the respondent in order to reduce the likelihood of socially desirable responses.

Frequencies, descriptive statistics, one-way ANOVAs and chi-square tests were calculated with SPSS 6.1.2 for Windows, assuming a critical $P$ value of 0.001.

**Table 2** Descriptive statistics of respondents in the Netherlands (NL) and in the United Kingdom (UK)

| *Participants* | NL ($n = 1170$) | UK ($n = 382$) | *df* | Value |
|---|---|---|---|---|
| Doctors/nurses (%) | 33/61[a] | 16/81[a] | 1 | 48.3 |
| *Experience* | | | | |
| Mode: Previous contacts with bereaved relatives: Several times/month | 53%[a] | 56%[a] | 3 | 17.8 |
| Requests for organ donation: Never | 44%[a] | | | |
| 1–2 per year | | 43%[a] | 3 | 39.6 |
| Requests for tissue donation: Never | 49%[a] | 63%[a] | 4 | 37.4 |

[a] $P < 0.001$

## Results

Because of the procedure of distributing and collecting the forms, in total no more than 20 forms were lost. The response rate was therefore about 98%. The descriptive statistics of the EDHEP participants in both groups are shown in Table 2.

The proportions of doctors/nurses that attend EDHEP in both countries differ. The participants in the Netherlands are relatively more experienced in asking for tissue donation, whereas their English colleagues have relatively more experience in asking for organ donation.

Not every participant has (had) the opportunity to make the donation request. Formally, this is the responsibility of the doctor, although often a doctor and nurse pair conduct this interview. For this reason, the questions about the difficulty of the donation requests were

**Table 3** Difficulty of donation requests (10-point scale)

| | NL | | UK | | *df* | *F* |
|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | | |
| Organ donation | 5.42[a] | 2.21 | 6.02[a] | 2.44 | 1522 | 18.99 |
| Tissue donation | 4.86[a] | 2.19 | 6.29[a] | 2.47 | 1472 | 106.75 |

[a] $P < 0.001$

phrased in such a way that they were applicable to both professions. EDHEP participants from the Netherlands experience/expect less difficulty when asking for organ or tissue donation than their colleagues in the United Kingdom. In the Netherlands, asking for organ donation is seen as more difficult than asking for tissue donation. The judgements of the English participants are reversed (Table 3).

## Programme and learning effect

Satisfaction with the programme as well as the learning effect, as expressed by participants in both countries, are given in Table 4. Participants from both countries rate all aspects of the workshop (very) high. The organisation of the workshop, the instructiveness of simulated relatives and the learning effect are valued higher in the United Kingdom than in the Netherlands. The judgements about the recognition of the issues addressed and about the teaching aids in general are largely the same in both countries. The barrier to request donation is apparently lowered more, following EDHEP, in the United Kingdom than in the Netherlands.

Further analysis showed that there was no apparent relationship between duration of professional experience and the learning effect. The correlation between prior experience with the donation request and learning effect for Dutch doctors is –0.16 (Pearson, $n = 386$, $P < 0.005$), a significant, but not very strong, inverse relation. Doctors from the United Kingdom and nurses in both countries show no relationship between prior experience with the donation request and learning effect.

## Further information and training

The requests for further information and training reveal a marked difference between the participants from the two countries. In the Netherlands, 35% of the participants require more information compared to 44% in the United Kingdom (chi-square test, value 7.86, $df = 1$, $P < 0.005$). In the Netherlands, 29% of the participants show a desire for more training compared to 50% in the United Kingdom (chi-square test, value 46.56, $df = 1$, $P < 0.001$). The proportions of participants requesting further information and training in the United Kingdom are higher and the priorities are reversed.

## Origin of video vignettes

The 'Vignettes' video programme is a series of very short fragments of grief reactions of relatives, played by Dutch actors. For non-Dutch-speaking audiences the programme is subtitled. The vignettes are used to evoke personal as well as professional responses by the participants. After 1.5 years of experience with EDHEP in the United Kingdom, an English version of the 'Vignettes' programme was made. This version was highly comparable to the original; its intention was kept in the depiction of the scenes, using similar scenarios but English actors. Participants' judgements about the instructiveness of the different versions are given in Table 5.

The Dutch subtitled version was judged as less instructive by the participants from the United Kingdom than by Dutch participants. The participants from the United Kingdom judged the English version as high as the Dutch participants judged the Dutch version.

## Participation in role play

The influence of participation in the role play session on the learning effect was different for the two countries. In the United Kingdom, a difference in reported learning effect was apparent between participants who played the role of a doctor or a nurse (mean 4.13, SD 0.55) and those who did not (mean 3.89, SD 0.75). The difference

**Table 4** Satisfaction with EDHEP and learning effect (5-point scale)

| | NL | | UK | | *df* | *F* |
|---|---|---|---|---|---|---|
| | Mean | SD | Mean | SD | | |
| Organisation | 4.50[a] | 0.41 | 4.63[a] | 0.41 | 1550 | 28.35 |
| Information recognisable | 4.36 | 0.53 | 4.44 | 0.55 | | |
| Teaching aids | 4.29 | 0.43 | 4.37 | 0.45 | | |
| Simulated relatives | 4.43[a] | 0.56 | 4.74[a] | 0.43 | 1544 | 98.76 |
| Learning effect | 3.86[a] | 0.52 | 4.04[a] | 0.65 | 1547 | 28.70 |
| Barrier to donation request reduced | 3.61[a] | 0.87 | 3.87[a] | 0.87 | 1529 | 25.36 |

[a] $P < 0.001$

**Table 5** Instructiveness of different versions of 'vignettes' teaching video programmes (5-point scale)

| | NL | | | UK | | |
|---|---|---|---|---|---|---|
| | Mean | SD | *n* | Mean | SD | *n* |
| Dutch 'vignettes' programme | 4.16[a] | 0.72 | 1170 | 3.84[a,b] | 0.88 | 241 |
| UK 'vignettes' programme | not shown | | | 4.13[b] | 0.76 | 141 |

[a] $P < 0.001$; $df = 1408$, $F = 37.81$
[b] $P < 0.001$; $df = 381$, $F = 11.21$

is significant at the $P < 0.001$ level (one-way ANOVA; $df = 346$, $F = 11.01$). In the Netherlands, participants who played a role and those who only observed report a mean learning effect of 3.88 and 3.86, respectively (SD in both groups 0.52).

### Group composition

The English participants rated the group composition higher than the Dutch did (NL: mean 4.58, SD 0.63; UK: mean 4.75, SD 0.57; $df = 1529$, $F = 19.80$, $P < 0.001$). This difference is accounted for only by the groups of nurses: UK nurses appreciate training in mixed groups of doctors and nurses more than Dutch nurses do (NL: mean 4.63, SD 0.58; UK: mean 4.77, SD 0.54; $df = 1010$, $F = 13.56$, $P < 0.001$). Doctors' judgements are equally high in both countries (NL: mean 4.51, SD 0.69; UK: mean 4.59, SD 0.75; $df = 440$, $F = 0.71$, $P$ = NS).

## Discussion

The results from the evaluation in the United Kingdom are highly similar to the results of the first group ($n = 430$) of EDHEP participants in the Netherlands [7]. In Germany and Denmark, similar results have been published [1, 17, 18, 23].

The workshop is based on the needs expressed by intensive care medical and nursing staff, which is reflected in the appreciation of the issues addressed. Participants report high satisfaction with the programme and its learning effect, irrespective of their prior professional experience and country of origin.

The difference in educational culture may be reflected in a higher satisfaction with this highly interactive teaching programme in the United Kingdom, where this is a relatively new teaching format. This conclusion is supported by the finding that the participants who actively took part in the role play session in the United Kingdom reported a higher learning effect than those who merely observed the role play, whereas in the Netherlands these two groups showed no difference in reported learning effect. It has been demonstrated that the programme is adaptable and that satisfaction with the programme is increased when parts are nationalised.

Participants in both countries are satisfied with the group composition. This is a nuance of the issue raised by Muthny in Germany [18], who discusses the possibility of mono-disciplined groups. It has not been shown that this would increase the proportion of doctors attending the workshop. Furthermore, it would not model what is advocated in the workshop: breaking the news of the death of a relative and asking for donation is a team effort, in which collaboration is much needed.

These findings support the view that EDHEP is adaptable to diverse national circumstances. The issues addressed appeal to health care professionals in different countries, as has been suggested in other publications. The 1-day workshop promotes increased confidence in communicating with bereaved relatives about death and organ donation. This will increase the probability of a higher quality of communication, more satisfied relatives and the possibility of more donor organs.

**Acknowledgements** The development of EDHEP was made possible by funding from Sandoz Pharma/Novartis Pharmaceutical, Basel, and was facilitated by the Eurotransplant International Foundation, Leiden, and the Rowland Dyson Company, London. EDHEP training in the Netherlands and in the United Kingdom was made possible financially by the Dutch Kidney Foundation, the Dutch Heart Foundation, the Dutch Department of Health, the British Department of Health, the North West Regional Health Authority, Central Manchester Healthcare NHS Trust, Royal Liverpool & Broadgreen University Hospital NHS Trust, Novartis Pharmaceutical United Kingdom, and Roche Products, Ltd. Production of the teaching videotape 'Vignettes' in the United Kingdom was made possible by a grant from Roche Products, Ltd.

## References

1. Birkeland SA, Christensen AK, Kosteljanetz M, Svarre HM (1997) Rise in organ donations. Lancet 349: 1558
2. Blok GA, Dalen J van, Jager K, Wight C, Ryan M, Wijnen R (1993) Omgaan met rouw en donatie: een vaardigheidsprogramma. [Dealing with grief and donation: a skills programme] In: Metz JCM, Scherpbier AJJA, Houtkoop E (eds) Gezond Onderwijs-2. Universitair Publicatie Bureau, Nijmegen, pp 41–48
3. Blok GA, Dalen J van, Jager K, Ryan M, Wijnen R, Wight C, Morton JM, Morley M, Cohen B (1999) 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 12: 161–167

4. Busari JO, Scherpbier AJJA, Boshuizen HPA (1997) Comparative study of medical education as perceived by students at three Dutch universities. Adv Health Sci Educ 1: 141–151
5. Cantwell BM, Ramirez AJ (1997) Doctor-patient communication: a study of junior house officers. Med Educ 31: 17–21
6. Cook DA, Brown LM, Skakun EM (1997) Factors which influence the outcome of student evaluation of teaching. In: Scherpbier AJJA, Vleuten CPM van der, Rethans JJ, Steeg AFW van der (eds) Advances in medical education. Kluwer, Dordrecht, pp 545–547
7. Dalen J van, Blok GA, Kranenburg J, Haase B (1996) European Donor Hospital Education Program. Transplant Proc 28: 398–399
8. Dolmans DHMJ, Wolfhagen HAP, Schmidt HG, Vleuten CPM van der (1994) A rating scale for tutor evaluation in a problem-based curriculum: validity and reliability. Med Educ 28: 550–558
9. Frederikson L, Bull P (1992) An appraisal of the current status of communication skills training in British medical schools. Soc Sci Med 34: 515–522
10. Gijselaers WH (1988) Kwaliteit van het onderwijs gemeten: studies naar de betrouwbaarheid, validiteit en bruikbaarheid van studentoordelen. [Measuring quality of education: studies of reliability, validity and feasibility of student judgements] (Dissertation) University of Limburg, Maastricht
11. Gore S, Taylor RMR, Wallwork J (1991) Availability of transplantable organs from brain stem dead donors in intensive care units. BMJ 302: 149–153
12. Jager K, Ryan M, Dalen J van, Blok G, Wijnen R (1991) European Donor Hospital Education Programme, Moderator's Manual. Eurotransplant International Foundation, Leiden
13. Kirste G, Muthny FA, Wilms H (1988) Psychological aspects of the approach to donor relatives. Clin Transplant 2: 67–79
14. Malecki MS, Hoffman MC (1987) Getting to yes: how nurses' attitudes affect their success in obtaining consent for organ and tissue donations. Dialysis Transplant:276–278
15. McGough EA, Chopek MW (1990) The physician's role as asker in obtaining organ donations. Transplant Proc 22: 267–272
16. Mir MA, Marshall RJ, Evans RW, Hall R, Duthie HL (1984) Comparison between videotape and personal teaching as methods of communicating clinical skills to medical students. BMJ 289: 31–34
17. Muthny FA (1995) Das Gespräch mit den Angehörigen plötzlich Verstorbener als zentraler Schlüssel zur Organspende -Notwendigkeiten und Möglichkeiten psychosozialer Fortbildung am Beispiel des EDHEP-programms. [Communication with the next of kin of the suddenly deceased as the key to organ donation -needs and potential of psychosocial postgraduate training: EDHEP as an example] Transplantationsmedizin 7: 66–70
18. Muthny FA (1996) Fortbildungsprogramm zur Gesprächsführung mit den Angehörigen plötzlich Verstorbener als Beispiel von Kommunikationstraining und affektiv-emotionalen Lernzielen in der ärztlichen Ausbildung. [Postgraduate training in talking with the next of kin of the suddenly deceased as an example of communication skills training and affective-emotional teaching objectives in medical education] Med Ausbildung 13: 57–64
19. National Health Service Authority (1993) What seems to be the matter: communication between hospitals and patients. HMSO, London
20. Prottas J, Batten HL (1988) Health professionals and hospital administrators in organ procurement: attitudes, reservations, and their resolutions. Am J Public Health 78: 642–645
21. Royal College of Physicians (1997) Improving communication between doctors and patients. Working Party on Communication in Medicine, London
22. Sanson-Fisher R, Cockburn J (1997) Effective teaching of communication skills for medical practice: selecting an appropiate clinical context. Med Educ 31: 52–57
23. Schweidtmann W, Muthny FA (1997) Einstellung von Ärzten zur Organtransplantation -Ergebnisse einer empirischen Studie. [Doctors' attitudes towards organ transplantation – results of an empirical study] Transplantationsmedizin 9: 2–7
24. Stevens P, Jager KJ, Ryan M, Blok G, Dalen J van (1992) The European Donor Hospital Education Programme (EDHEP). In: Charro FT de, Hessing DJ, Akveld JEM (eds) Systems of donor recruitment. Erasmus University Press, Rotterdam, pp 105–109
25. Verble MS, Worth JK (1986) Family counseling. In: Brightbill FS (ed) Corneal surgery: theory, technique and tissue. CV Mosby, St. Louis
26. Wakeford RE, Stepney R (1989) Obstacles to organ donation. Br J Surg 76: 435–439
27. Whitehouse CR (1991) The teaching of communication skills in United Kingdom medical schools. Med Educ 25: 311–318
28. Wight C, Jager K, Cohen B, Dalen J van, Blok G, Wijnen R (1995) The European Donor Hospital Education Programme. In: Englert Y (ed) Organ and tissue transplantation in the European Union. Martinus Nijhoff, Dordrecht, pp 175–179
29. Wight C, Jager K, Blok G, Dalen J van, Cohen B (1996) Overview of the European Donor Hospital Education Programme. Transplant Proc 28: 422–423
30. World Health Organisation (1993) Doctor-patient interaction and communication. WHO, Geneva
31. Wouda J, Wiel HBM van der (1992) Communicatieve vaardigheden: een diagnose en een advies. [Communication skills: diagnosis and advice] Bull Med Onderwijs 11: 116–118