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OVERVIEW

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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

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Abstract The competence of critical care staff when it comes to death and organ donation can make the difference between a family's agreeing to or refusing the latter. Doctors and nurses often feel uncomfortable approaching relatives about donation and attribute this to a lack of training. Bereaved relatives express dissatisfaction with inappropriate communication and support when brain death is announced and thereafter when a request for donation is made. The European Donor Hospital Education Programme (EDHEP) was designed to meet the training needs of critical care staff in breaking bad news, caring for the bereaved, and requesting donation. EDHEP is a two-part educational package consisting of a presentation about the donor shortage followed by a one-day workshop. The implementation of EDHEP throughout the world has been facilitated through effective national working groups and standardised "train the trainer" courses. Several countries anecdotally report increases in donation following implementation. Controlled evaluation of the effect(s) of EDHEP, which started at the end of 1995, focuses on the satisfaction of the participants with EDHEP, on the competence of the participants in breaking bad news and requesting donation, on the teamwork regarding death and donation, on the satisfaction of bereaved relatives, and on organ donation rates.

Key words Organ donation · EDHEP · Relatives · Training

Introduction

The development of transplant programmes throughout the world is limited due to a chronic shortage of donor organs [22]. Successful transplantation is generally regarded as offering a better quality of life to patients and their families. Organ transplantation is the only option for patients with end-stage liver or heart disease, and, in the case of end-stage renal disease, it is a more cost-effective treatment than dialysis [1]. The number of patients on waiting lists for transplantation has grown significantly over the past 5 years while the rate of donation appears to have reached a plateau or is even decreasing [21]. The procurement of organs depends on cooperation between different disciplines, and both the potential donor pool and rates of donation are influenced by a complex mix of organisational and professional variables. Loss of donor organs from the potential pool can occur by failing to identify a potential donor or by not approaching the family to request donation. Family refusal and poor management of the potential donor also reduces the availability of organs for transplantation [39]. In many countries, up to 35 % of relatives refuse consent for cadaveric donation, and a significant minority of relatives of potential donors may not be asked at all [11, 12, 39].

It is widely acknowledged that doctors and nurses find it difficult to deal with death and dying [23, 31, 34], and that they hesitate to ask for donation. At least two barriers in the communication with bereaved relatives have been identified: fear of adding to their distress, and the lack of training in communication skills [43]. Relatives may refuse donation for several reasons [41], but being asked to donate a family member's organs does not appear to affect their grief [25, 26, 40]. Inadequate communication or inappropriate support on the part of doctors or nurses will contribute to a family's reluctance to consider donation. It may also affect their satisfaction with the donation process. The timing of the request and the confidence of those who make the request will also influence how the of relatives of brain-dead patients will feel and react to any such request [3, 9, 25, 26, 40, 41]. However, little research has been devoted to the interpersonal competence of doctors and nurses in the areas of death and donation, or to the contribution of inappropriate or insensitive communication to family refusal [38]. There are few training opportunities that address all of the above issues, but there is increasing recognition that enhanced awareness of these interpersonal variables is necessary for improvement of communication with the bereaved. [23, 24, 31]. The need for training to improve competence in caring for the bereaved and to request donation is evident [35]; yet, there is little empirical validation of the effects of such training programmes [4, 38]. However, there is substantial evidence from general practice and oncology that particular communication skills can be improved with training based on identified needs [10, 16].

The need to train health care staff to request donation sensitively

Conveying bad news, explaining brain death, and approaching the next of kin for permission to donate places considerable demands upon doctors and nurses in critical care. The donation procedure implies an additional burden for the medical and nursing staff [29] in which caring for bereaved relatives and asking for donation are not the only difficulties. Doctors' and nurses' knowledge about and attitudes towards brain death, donation and transplantation may contribute to their difficulties with communication [15, 20, 46]. The concept of brain death, even when rationally understood, can cause confusion and mixed feelings, and can make it even harder to approach the family. A study from the United States revealed that only 35 % of a sample of 195 physicians and nurses from intensive care and neurosurgery units correctly identified the legal and medical criteria for determining brain death [46]. However, those staff who had participated in formal teaching about brain death and organ donation prior to being questioned were significantly more likely to know the criteria. Educating doctors and nurses about the criteria for organ and tissue donation, and underlining their role in making the request, has led to measurable increases in donation [5, 33].

Although opinion polls suggest that a majority of the general public favours donation, their response to the request for organ donation from a beloved family member is not nearly as positive. The factors that determine the attitudes of the general public and of health care professionals in the areas of organ donation and transplantation are complex and poorly understood [35]. The attitudes of doctors and nurses towards donation appear to influence the donation rates in a number of ways. The willingness of doctors and nurses to participate in organ procurement programs is strongly related to their attitudes about the value of transplantation and about the lack of donors, the perceived value and acceptability of making a donation request of bereaved relatives, and the degree to which they are prepared to make a donation request [15, 19, 29, 37]. Experience and training enhance their confidence in approaching families and improve the manner in which a request is made by the doctor or nurse; those who feel insecure and uncomfortable making the request have more refusals than those who do not [17]. There is increasing evidence that families who have donated organs appreciate being offered the choice, although sensitive handling of the relatives by medical staff before, and particularly af-

ter, donation is not always apparent [4, 25, 26]. While there is always a degree of urgency to proceed with the donation procedure, there is empirical evidence that relatives are much more likely to consent to organ donation if the request is made some time after they have been informed that brain death has occurred [8, 9, 27]. Families who consent to donation also express more satisfaction with the donation procedure when they are given sufficient time between the announcement of brain death and the request so that they can accept the fact that their loved one has died [3]. Relatives of potential donors may not comprehend the diagnosis of brain death [8, 26], and those who refuse donation appear to have far less understanding of brain death than those who consent [8].

Background to the development and format of the European Donor Hospital Education Programme (EDHEP)

Educational initiatives designed to increase donation must address several aspects of professional competence in making the donation request. For such training to be effective, it needs to draw upon a combination of validated educational methods, tailored to the working circumstances of the participant, which allow maximal transfer to the working routine [36]. Nurses' self-confidence appears to improve following attendance at an educational programme that addresses issues similar to those of the EDHEP workshop [28]. Traditional didactic teaching methods should be supplemented with experiential methods that raise awareness and understanding of grief, and thereby underscore the need for clear and sensitive communication with the bereaved [45]. These teaching methods should interlink and reinforce principles of good practice in breaking bad news and in requesting organ donation and allow participants the opportunity to apply these principles within simulated encounters with relatives of brain-dead patients. The use of simulated patients or relatives provides a realistic and effective method to help participants identify their own strengths and weaknesses in communication [2, 32, 42].

Good practice regarding breaking news of brain death and requesting donation

Clear and appropriate communication from doctors and nurses is particularly needed to ensure that brain death is understood as death before a request can be made. Breaking bad news and requesting donation should always be made in planned interviews. Ideally, a doctor and a nurse should discuss these issues with the next of kin, accompanied by supportive relatives or friends, in a comfortable and adequately furnished room [1, 44]. It is important to break news of brain death fairly early in the conversation [16] and to show understanding and empathy, especially by reflecting the bereaved relatives' feelings and by attending to their concerns. Discussing the near future should ideally be initiated by the family. It is essential that all information be presented to the family in a clear and truthful manner, avoiding technical jargon. When explaining brain death, it should be made very clear that this means the person is dead. Relatives should be told, sometimes more than once, what is going to happen next. The donation request should be made during a separate consultation, subsequent to that in which the death is announced [9, 27]. During the donation procedure, there must be close cooperation among all the staff members with regard to communication with the family. The latter must have a clear idea of the donation procedure without feeling under pressure to consent. They must know which organs are suitable for donation. The time schedule must also be addressed. Discussing the operation procedure can remove any fears the family may have about the body being mutilated. Prior to seeing the body, relatives must be warned that organ donors look much paler than brain-dead patients who do not donate organs. It is important to offer relatives the opportunity to see the body after the donor operation and to encourage them to view the body at as many stages as possible to give them a realistic perception of the loss.

Format of the European Donor Hospital Education Programme (EDHEP)

The European Donor Hospital Education Programme (EDHEP) was developed in 1991 to address the above issues by helping medical and nursing professionals to feel more comfortable in dealing with bereavement and donation. EDHEP consists of a hospital-based lecture and an interactive workshop, both of which are in a well structured, fixed format. The moderators are provided with detailed manuals in which the two parts are described. The separate parts contain slides, presentations, exercises and instructions. EDHEP was produced and developed by a team of professionals including clinical psychologists from the University of Maastricht, a Dutch transplant coordinator and a consultant from Eurotransplant, in close collaboration with a communication specialist from The Rowland Company [13, 14]. Three pilot studies were conducted in the Netherlands in 1991 with an expert 'target group' of senior consultant intensivists and senior intensive care nurses. Their comments led to the final version of the programme that has been used since. EDHEP was developed as an adaptable prototype allowing for adjustments to meet national demands.

Table 1 The Grief Response and Donation Request workshop (EDHEP)

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

Part one: meeting the donor shortage

EDHEP Part one, a background briefing called 'Meeting the Donor Shortage', is a hospital-based lecture given by the transplant coordinator. It is a slide presentation that covers the history and state of the art in organ and tissue transplantation. The aim of this lecture is to raise awareness and understanding of organ and tissue donation and transplantation among all levels of medical, nursing and paramedical staff. The briefing is described in a manual and it is suitable for adaptation, depending on local and national circumstances. This briefing is followed, at a later date, by EDHEP Part two, 'The Grief Response and Donation Request' workshop (Table 1). The remainder of this article focuses on this workshop.

Part two: The grief response and donation request workshop

'The Grief Response and Donation Request' workshop is a one-day, highly interactive, programme, preferably held outside the hospital, where group members cannot be disturbed by hospital matters. EDHEP is hosted by the transplant coordinator and conducted with small mixed groups – preferably eight doctors and eight nurses – working in critical care. Each group should consist of doctors and nurses from different hospitals and different units of hospitals in order to neutralise any particular local difficulties and to encourage an exchange of experiences. The workshop is moderated by two experienced communication skills trainers, ideally clinical psychologists, experienced in working with medical and nursing staff. The day allows the participants to move from their personal response to bereavement and donation to appropriate professional responses. Short presentations about loss, grief and crisis intervention alternate with exercises in which participants can discuss and apply the theory previously expounded. In Table 1 the programme and its aims are described.

During the morning session, participants have the opportunity to reflect on their knowledge of, and personal and professional attitudes towards loss, bereavement and donation. One communication skill that is emphasised throughout the morning is 'reflection of feeling'. This communication skill enables the health professional to acknowledge the relatives' emotional reaction, to facilitate their expression of emotion, and to help direct communication during a crisis. Guidelines for good practice when breaking bad news and making the donation request, based upon consensus from research, are then presented [9, 16, 24, 27, 30]. Videotapes of relatives' experiences identify and reinforce some of these guidelines. Awareness of the guidelines for approaching families about brain death and donation are emphasised during two role plays – breaking news of brain death and requesting donation – that account for a large part of the afternoon session. The participants are divided into two groups and those who do not play a role use observation assignments to direct their attention. The role plays are discussed af-

terwards and feedback is given by the simulated relative, the observers and the trainer. Finally, the satisfaction of the participants with the workshop is evaluated using a programme evaluation questionnaire that offers the opportunity for both quantitative and qualitative feedback [6, 7].

Implementation and evaluation of EDHEP

Nineteen standardised 22-day "Train the Trainer" courses have so far accompanied the implementation of EDHEP in new countries, conducted by the programme's authors and principal trainers. The international "Train the Trainer" course is designed to guarantee the quality of the EDHEP workshop and also to supply national working groups with guidelines regarding particular activities and tasks needed to implement EDHEP. Under these conditions the complete EDHEP teaching package is available from Eurotransplant International Foundation in The Netherlands. Thus far, EDHEP has been implemented in over 30 countries all over the world, and the programme has been translated into 17 languages. The first 430 participants in the Netherlands expressed a very high degree of satisfaction with EDHEP, as well as a high learning effect and a decrease in the 'barrier' to ask for donation. There were no differences in the judgements of participants with regard to their region, profession, gender or experience in critical care. Different moderators and transplant coordinator combinations did not lead to differences in satisfaction. The learning effect was primarily attributed to the feedback of the moderators, practising with simulated relatives, watching videotaped interviews with bereaved relatives and using observation assignments during the exercises [6]. Similar results were found in an international comparison of participants' judgements about EDHEP [7].

Conclusion

In the face of the continuing shortfall of donor organs across the world, there have been successful efforts to remedy the situation by changing the law [20] and by professionalising and strengthening the transplant coordinator networks [18]. The need for education for health care professionals regarding organ procurement has been well documented. Even a brief training can positively influence donation rates, if only temporarily [5, 33]. However, an effective medical training programme in the area of donation should not only focus on knowledge about transplantation and donation (EDHEP Part one), but also at the difficulties that doctors and nurses experience in communicating with the bereaved and in requesting donation (EDHEP Part two). EDHEP Part two, 'The Grief Response and Donation Request' workshop, has been designed as an awareness-raising programme to sensitise doctors and nurses to the issues involved in breaking bad news and requesting donation. By 1998, it had become a recognised part of postgraduate training in over 30 countries in Europe, the Far and Middle East and Latin America. In all of these countries, participants judgements about the programme are very positive. There are anecdotal reports of increases in donation rates [44].

The potential donor pool and rate of donation are influenced by many organisational and professional factors. Adequate and sensitive communication with bereaved families is not automatically followed by a consent for donation as relatives tend to respect the wish of the deceased. Hence, any effect of EDHEP on organ donation rates can only be indirect. Research into the effectiveness of EDHEP is therefore focused on intermediate variables, such as the quality of communication, teamwork and satisfaction of bereaved relatives.

The potential of the EDHEP programme to increase the competence of the intensive care staff, satisfaction of the bereaved and subsequent organ donation rates [44] underlines the need to evaluate organisational and interpersonal competencies in the procurement of donor organs. The issues addressed in the EDHEP workshop are considered to cover the domain of communication relating to death and donation in a broad sense. It is therefore important to assess how, and to what degree, the issues addressed affect the competence (knowledge, attitudes, self-efficacy and communication skills) of critical care staff and the teamwork in intensive care, the satisfaction of bereaved relatives and donation rates. In the period 1995–1998, an international collaborative research project between the Netherlands and the United Kingdom was conducted to investigate the effects of EDHEP on the competence of staff, on the collaboration in intensive care units, on the satisfaction of bereaved relatives and on organ donation rates. The results are expected to be published shortly.

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