

The experience of relatives asked for organ donation

The original project, obstacles, findings, and unexpected results

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Summary

In this article we describe the aims of a Swiss cohort study in bereaved relatives who were asked for organ donation. Their experience in the ICU was assessed six months after the donation request by questionnaire (quantitative approach) and, in a subgroup, by interviews (qualitative approach). The difficulties of running such a multicentre study are reported in detail. A short overview of

general findings is given. The unexpected results, namely the impact of our findings on communication skills training in ICU staffs, and the change engendered in the clinical practice of transplantation coordinators in the follow-up of donor families, are described in detail.

Key words: organ donation; brain death; relatives

Most studies about the experience of bereaved relatives asked for organ donation have been done in the USA, whereas research devoted to this subject in Europe is rare [1–3]. As no data on this subject existed in Switzerland the experience of Swiss relatives asked for organ donation was investigated six months after their decision for or against donation.

In this article, the aims of the study and the difficulties encountered are reported. After an overview of our findings, unexpected changes – educational issues and the clinical care of bereaved relatives – are described in more detail.

The original research project

The aim of our study “The experience of relatives who consented or not to organ donation: A prospective study six months after their decision” (Swiss National Foundation study #4046-58619), was to clarify the following issues:

- Perception of the quality of care given by the ICU staff
- Perception of the information process concerning brain death
- Knowledge of the wishes of the deceased regarding organ donation
- Perception of the request for organ donation
- Stability of the decision to donate or not to donate over time
- Influence of the donation request upon the mourning process

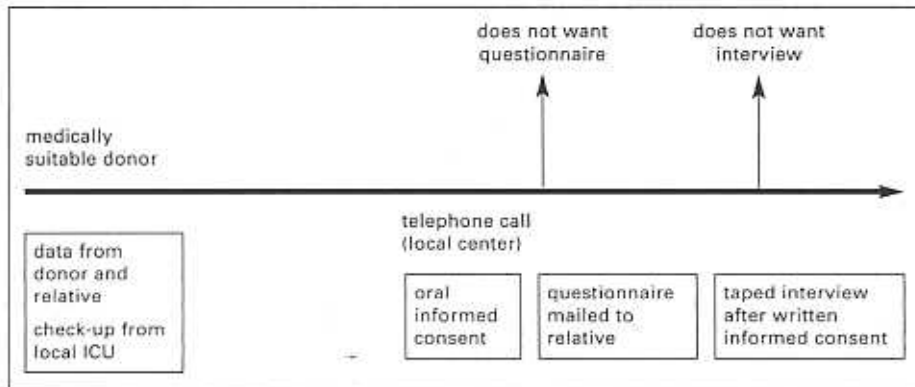
- Current attitudes and beliefs about brain death and organ donation

- Suggestions to improve the performance of the ICU staff based upon personal experience

To investigate these aims a combination of a quantitative (questionnaire) and a qualitative approach (interview) was chosen. The study design is shown in figure 1.

A structured questionnaire addressing the above mentioned issues was sent to the bereaved relatives six months after the organ request [4]. To investigate the experience of the bereaved relatives in more detail interviews were performed with some of them. The tape recorded interviews were transcribed verbatim and analysed according to Grounded Theory [5].

Figure 1
Study design.



Unexpected obstacles

When and how to contact the relatives

In the original grant application it was planned to ask bereaved relatives immediately after the organ request if they agreed to be contacted again by phone after six months. Consenting relatives would receive a telephone call from a member of the local ICU who would explain the study purpose and invite the relative to participate.

The Basel ethical committee rejected the original grant application for two reasons:

First, it was found unethical to ask bereaved relatives immediately after the organ request; they should rather be contacted six months after the incidence. And second, the committee wanted a clearer definition of who would ask the relatives for participation in the study.

Therefore, we changed the study design as shown in figure 1.

The resubmitted application describes the circumstances when and by whom relatives were contacted: "After three–six months a professional of the intensive care unit, who had been in charge of the brain dead person and his or her relative, will phone the relative and ask how they are doing. Depending on the local circumstances this professional will be a nurse, a doctor or the head of the ICU. One purpose of the phone call is to ask the relative if he or she agrees or disagrees that a team-independent study group will contact them by sending them a questionnaire. The professional making the phone call explains the purpose of the study, which is to gain a better understanding of the feelings of relatives of potential organ donors and to learn from their experience to improve health care professionals' behaviour in dealing with grieving relatives and organ request."

With these revisions the ethical committee accepted the application.

In retrospective, the decision to abstain from asking immediately after the organ request was not only right on ethical grounds, but it also improved the feasibility of the study as the ICU profession-

als found it difficult to ask. In most cases, a local transplant coordinator ended up phoning the relatives six months after the organ request. Without the help of the transplant coordinators the study would not have been feasible.

Not one ethical committee but many

When starting the multicentre study we realised that not only did we need the approval of all ethical committees of the hospitals involved in the study, but also that the ethical concerns of the various committees differed substantially. Some were reluctant to the idea of contacting the bereaved relatives at all, as these relatives were considered too vulnerable and might be further distressed by a telephone call. The scientific literature demonstrating that most bereaved relatives are not distressed by post-bereavement research but on the contrary found being interviewed quite helpful changed their minds [6]. In the meantime, this issue had become the subject of an international scientific discussion after a proposed nationwide postal questionnaire to Swedish parents having lost a child due to cancer was denied by local ethics committees [7, 8]. However, a pilot study to assess the harms and benefits of the questionnaire was approved. 95% of the parents found the pilot study valuable [7].

Another unexpected obstacle was that each of the local ethical committees needed to be paid for their project evaluation, an item we had not included in the budget of the grant application.

Difficulties to get ICUs to cooperate

Multicentre studies depend on a practicable protocol and mutual trust in data collection and processing, as well as clear rules regarding who is publishing the results. When looking for cooperation with Swiss ICUs all over the country most agreed that a study about the experience of Swiss relatives asked for organ donation was important,

but they were concerned about the confidentiality of their data. We got the impression that dealing with bereaved relatives of brain dead, potential donors, and asking for organ donation is one of the most difficult jobs for ICU professionals. It is considered as one of the core issues of their job, but specific discussion about good clinical practice and how to improve performance is rare. The willingness of ICUs to participate in the study increased when it was made clear that the feedback of the

data was only given to the ICU who recruited the relatives concerned. This was seen as a quality control of their communication with bereaved relatives and a possibility to improve their skills. We agreed to abstain from a comparison between the different ICUs in the publication of results.

Finally, the following ICUs agreed to take part in the study: Aarau, Basel, Berne, Chur, Fribourg, Lausanne, Lugano, Luzern, Sion, St. Gallen, Uster, Zürich.

Findings

This is only a general overview of our findings as the detailed presentation of our results is given in papers submitted to other journals.

Questionnaire

Most relatives who consented or not to organ donation were satisfied with the quality of care. However, single cases were very dissatisfied. Most relatives perceived the information process concerning brain death as satisfactory, but a substantial minority did not understand the concept of brain death correctly (e.g. brain death as equivalent with coma).

Half of the relatives did not know the wish of the deceased one regarding organ donation.

Half of the relatives considered the request for organ donation as a considerable additional burden to themselves. Six months after organ request,

most would have decided the same way. About half of the relatives said that their decision regarding donation did not have an impact on their mourning process. A wide variety of suggestions how to improve the quality of care for bereaved relatives were made.

Interview

Long-term memories of the experience were influenced by the interaction of relatives' decision-making characteristics (clear *vs* ambivalent) and the perceived professional behaviour they encountered (person-focused *vs* organ/routine-focused). Person-focused professional behaviour and a clear decision resulted in non-traumatic memories. Organ-focused professional behaviour promoted traumatic memories in relatives both ambivalent and clear in their decision-making [9].

Unexpected results

Educational issues

The Swiss European Donors Hospital Education Programme (EDHEP) was established more than 10 years ago in Switzerland. The one-day interactive workshop for staff members of ICUs is devoted to the improvement of communication skills in dealing with grieving relatives and asking for organ donation [10]. The lack of empirical data in Switzerland concerning the experience of relatives has long been lamented. The presentation of our results as a part of the workshop has improved the credibility of the workshop and improved the motivation for reflection and change of the individual communication style when interacting with grieving relatives.

Changed clinical practice in the long-term follow-up of relatives

In the beginning, transplantation coordinators were hesitant to contact the bereaved relatives six months after the donation request. However, as al-

most all relatives felt valued by the phone call and took the opportunity to talk about their experience, the task of contacting them became easier for the transplantation coordinators. With this experience, the steering committee of the Swiss transplantation coordinators decided to declare a telephone call six months after the donation request as standard practice. In Berne, the changed clinical practice includes the following elements: (1) written guidelines and a flow sheet when and how to address organ donation, (2) mandatory participation in the EDHEP course for all new staff members, (3) a telephone call to bereaved relatives six months after the organ request, (4) if relatives consented, feedback of how they experienced their interaction with the ICU staff to the staff concerned, (5) quality control and improvement if necessary based upon the individual feedbacks by bereaved relatives.

Usually, changing clinical practice takes time and is a process with different stages [11, 12]. What

tends to be overlooked is that health care professionals may change the clinical practice based upon personal experience by interacting with individuals. Although being the lowest level of evidence in evidence-based medicine (case histories), face validity may suffice as the necessity for a change in clinical practice is so obvious.

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References

- 1 Siminoff LA, Arnold RM, Hewlett J. The process of organ donation and its effect on consent. *Clin Transplant*. 2001;15(1):39-47.
- 2 Bonnet F, Denis V, Fulgencio JP, Beydon L, Darmon PL, Cohen S. Entretiens avec les familles de donneurs d'organes: analyse des motivations d'acceptation ou de refus du don. *Ann Fr Anesth Reanim*. 1997;16(5):492-7.
- 3 Noury D, Jacob F, Pottecher T, Boulevard A, Pain L. Information on relatives of organ and tissue donors: A multicenter regional study: factors for consent or refusal. *Transplantation proceedings*. 1996;28(1):135-6.
- 4 DeJong W, Franz HG, Wolfe SM, Nathan H, Payne D, Reitsma W, et al. Requesting organ donation: an interview study of donor and nondonor families. *Am J Crit Care*. 1998;7(1):13-23.
- 5 Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago, IL: Aldine Publishing, 1967.
- 6 Seamark DA, Gilbert J, Lawrence CJ, Williams S. Are post-bereavement research interviews distressing to carers? Lessons learned from palliative care research. *Palliative medicine*. 2000;14(1):55-6.
- 7 Kreicbergs U, Valdimarsdottir U, Steineck G, Henter JI. A population-based nationwide study of parents' perceptions of a questionnaire on their child's death due to cancer. *Lancet*. 2004;364(9436):787-9.
- 8 Burnell RH, O'Keefe M. Asking parents unaskable questions. *Lancet*. 2004;364(9436):737-8.
- 9 Kesselring A, Kainz M, Kiss A. Traumatic Memories of Relatives regarding Brain Death, Request for Organ Donation and Interactions with Professionals in the ICU. *Am J Transplant*. 2007;7:211-7.
- 10 Blok GA, van Dalen J, Jager KJ, Ryan M, Wijnen RM, Wight C, 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(3):161-7.
- 11 Grimes DA, Hubacher D, Nanda K, Schulz KF, Moher D, Altman DG. The Good Clinical Practice guideline: a bronze standard for clinical research. *Lancet*. 2005;366(9480):172-4.
- 12 Perleth M, Jakubowski E, Busse R. What is "best practice" in health care? State of the art and perspectives in improving the effectiveness and efficiency of the European health care systems. *Health policy*. (Amsterdam, Netherlands) 2001;56(3):235-50.