



Practices Around Communication About Organ Donation in Hungary

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ABSTRACT

Background. One obstacle to organ donation is the high proportion of relatives who refuse consent in presumed-consent countries. The aim of this study was to survey the features of family approaches and to identify those that may have significant impact on family refusals.

Methods. A 46-item validated questionnaire was designed and used in 2011 and 2012 to investigate factors around all family communications about brain death and organ donation. The data of 188 cases were collected by telephone calls. We asked for the demographic data of donors; place, timing, duration, type, and result of approach; number, age, gender, and qualification of the staff; affinity, gender, age, education, and religion of the involved relatives; and finally the applied method to treat family refusal if it existed.

Results. Usually 1 physician talked with 2 relatives. Timing had significant impact on objection rate ($\chi^2 = 0.044$). Single-discussion meetings (56.38%) were an average 1 hour 13 minutes before the brain death declaration, and they were initiated an average 19 hours 49 minutes before brain death when more than one meeting took place (43.62%). Conversations lasted for 11–22 minutes. Mann-Whitney *U* test revealed association between duration of donor family communication and occurrence of refusal ($P = .021$). It was found that the relatives' education level, the number of staff, and the number of family members strongly influenced the occurrence of refusals.

Conclusions. The careful preparation, organized direction, and support by intensive care unit staff can decrease the number of family refusals.

OVER the past 50 years organ transplantation has become an established practice worldwide, bringing immense benefits to hundreds of thousands of patients. The use of human organs for transplantation purposes has steadily increased during the past 2 decades. Organ transplantation is now the most cost-effective treatment for end-stage renal failure, and for end-stage failures of other organs, such as the liver, lung, and heart, it is the only available treatment [1].

There were 114,690 solid organs reported transplanted worldwide in 2012, while the annual number of new patients on organ transplant waiting lists exceeded 200,000 [2]. The 8 Eurotransplant member states transplanted 6,896 organs from deceased donors in 2013, but the number of waitlisted new patients was 11,681 [3]. Hungarian organ transplant

activity increased by 37.7% in 2014, but this remarkable development still can not satisfy the actual needs [4]. The reasons behind organ shortage were clearly identified in those countries, where a continuous and systematic approach has been implemented to increase the number of donations in hospitals with the use of quality assurance program techniques [5–7]. Thirty-one percent of family approaches ended in refusal in the 6 countries with presumed-consent legislation [8].

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According to the prevailing law in Hungary, every competent person will become a potential organ donor after brain death, unless they explicitly refused this earlier. In absence of such refusal, the family can not refuse the removal of suitable organs from their deceased relative from a legal point of view (this is the so called “hard form” of presumed consent). Still, the consent of relatives is routinely asked for and their refusal is respected in everyday practice. Officially, 16 donations (6%) were cancelled due to family refusals in Hungary in 2014 [4], although the real rate is ~30%, according to assessment by the National Health Insurance Control Office [9]. The cause of difference is the nonreported events when hospitals do not initiate the process in case of family reluctance. The rate of donations that fail owing to family refusal varies by nations in Europe from 6% to 41% [10]. The biggest obstacle to improving organ donation rate is the high proportion of relatives (41%) who deny consent [8,11]. To decrease the loss of donor organs, it is important to examine the circumstances and reasons of family refusals, and to use these data to give appropriate information to donor families. Meanwhile we should try to avoid mistakes that led previous cases to deny consent. Organ donation performance correlates with intensive care staffs’ attitudes and knowledge [12]. On the other hand, the main modifiable factors on relatives’ reaction to deny or allow organ donation were the understanding of brain death, the specific timing of the request, and the how the relative was approached, according to real case studies [13]. Fear of manipulation of the human body, distrust of the health care system, and lack of information are the main reasons for unwillingness to donate organs among Europeans [14]. Seventy-three percent of the Hungarian adult population is altruistic regarding organ donation after death [14], but only 46% adequately know the existing presumed-consent legal system. All the elements of the process to approach the deceased donors’ family can not be examined owing to ethical reasons [15], but information regarding circumstances can be collected from critical care staff retrospectively, which may have correlation with consent rate.

The aim of the present study was to survey the features of the process to approach the family and to identify those that may have significant impact on family refusals and so to filter out unsuitable practices.

METHODS

The Organ Coordination Office, Hungarian National Blood Transfusion Service, is responsible for organ donor coordination in Hungary. The duty desk receives all donor reports and has the complete information of all cases, including initiated procedures that finally were cancelled owing to family refusals. A 46-item questionnaire (with 37 closed and 9 open-ended questions) was designed and validated to investigate factors regarding elements of family communications concerning brain death and organ donation. Inclusion criteria were all reported cases when the first signs of brain death were identified and the family was approached with the purpose of organ procurement. The data were collected in 2011 and

2012 from 140 medical doctors via telephone calls 24 hours after the end of each procedure. We found 188 donor reports, from which 128 donations were performed and 60 donations failed. There were common questions for all interviewees, and some specific ones for those cases when more than one meeting was carried out with the donor’s relatives.

We asked about the age, gender, marital status, and religion of donors, and the following features of the meetings:

- Who initiated the donation.
- The place, timing, duration, type, and result of approaching the relatives.
- The number, age, gender, and qualification of the staff.
- The affinity, gender, age, education, and religion of the involved relatives.
- The method used to handle family refusal if it existed.

There were 19 occasions when the family expressed refusal during the communication phase, and 10 of those families did not change their opinion. Altogether, 11 organ donations took place and 8 failed.

The questionnaire data were analyzed with the use of the Statistical Package for the Social Sciences version 17.0 (SPSS, Chicago, Illinois). Descriptive statistics and tests of significance (Pearson chi-square test or Fischer exact test) were used to evaluate the correlation of family refusal with categoric variables. Mann-Whitney *U* test was used to test the effect of meeting durations on refusal rate. Stepwise logistic regression model was used to analyze multivariate relationship.

RESULTS

One-Meeting Communications

Only one meeting was found to have occurred with 106 donor relatives (56.38%); 6 families (5.66%) raised the question of organ donation first. The majority of the medical staff interviewed were specialists mainly in the field of anesthesiology and intensive therapy. The average timing of approaching the relatives was 1 hour and 13 minutes before brain death declaration (SD, 11 hours 14 minutes), which took 17 minutes on average (SD, 8.8 min; range, 5–45 min). The meeting was located in a separate room (61%), the intensive care unit (ICU) department passage (16%), or right next to the patient’s bed (14%), or managed through telephone calls (9%). Usually 1 doctor talked with 2 relatives. The affinity of relatives was diverse: 25% spouse, 7% companion, 37% child, 12% parent, 10% sibling, 9% other. We found various types of approaches, such as brief information (73%), persuasion (22%), and asking for permission (5%). As a result of these meetings, 76% accepted the information without refusal, 7% mentioned that previous family conversations helped to cope with the situation, 1% actively promoted organ donation, 9% expressed permission, and 6% refused and thus prevented the planned procedure for organ donation. Finally, 1% would have required more meetings which were finally not realized.

Family Approach via More than One Meeting

Two or more meetings were necessary with 82 donor relatives (43.62%). Six families (7.32%) raised the possibility for organ donation before the staff did. We identified 2

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