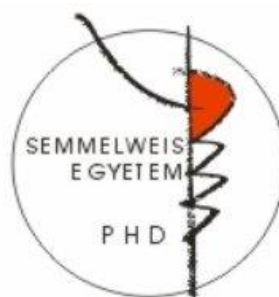


# Donation activity and donation attitude effects on each other in Hungarian intensive care units

PhD thesis

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Budapest  
2016

# 1. INTRODUCTION

Over the past 50 years organ transplantation has become an established practice worldwide, bringing immense benefit 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. It is a global challenge according to the data of the World Health Organization that the number and the report rate of suitable potential donors are low, meanwhile the number of patients on the waiting lists is continuously increasing. There were 118,127 solid organs reported transplanted worldwide in 2014, while the annual number of new patients on organ transplant waiting lists exceeded 200,000. Thus, the difference between supply and demand will grow, unless there are effective interventions to increase the number of cases or unless there are established new alternative therapies. Hungary has similar needs on the waiting list compared to the number of available donor organs, because 614 new patients were put on waiting list while 497 transplants have been performed in 2015. These features lead to a worsening problem, because if the number of waitlisted patients is increasing, for each recipient decreases the chance to receive an organ. The longer waiting time can lead to deterioration at certain cases, so the transplantation can be performed at worse physical and mental condition, or in other cases, the radical deterioration can lead to death occurring during the wait. For these reasons, it is important to identify all brain death cases suitable for organ donation and to analyse the causes of the loss of donor reports. One of the reasons of canceled procurements from deceased persons is family refusal in Hungary, because in case of the relative's objection the hospitals usually do not carry out the removal of organs. Despite the fact, that the relevant law did not mention the relatives' approval as a precondition for donation. The regulation is based on a right to self-determination connected to written forms to guarantee that people's decision is respected. The obligation to provide information does not equal to right for consent or protest. This means that often not the legal requirements are followed by doctors in case of family refusals. 30% of organ donations from deceased persons failed due to family objection, therefore we lose more than 100 transplants annually.

## 2. OBJECTIVES

Because family refusal is the most relevant obstacle to organ donation in Hungary, it is justified to examine this area, and then implement new methods based on the results. Hungary also made several donation attitude researches, but there was no survey on communication with relatives about brain death and organ donation led by the medical staff. The attitudes and opinion of professionals as well as the type of approach in these communicative situations were not investigated, the influential factors were not identified, neither we had surveys about donor relatives. **The subject of my study** was to investigate the knowledge and attitude of professionals who provide information to donor relatives, and to compare the results with other studies where the public was asked. I decided to assess the circumstances of these conversations, trying to find the factors that may influence the increase or decrease of refusal rate. **The aim of my study** was to improve the syllabus of medical and nursing training programmes and the content of the public information in order to focus on the current problems during the coaching of professionals, and to provide more precise information for the public. Having the results of the above-mentioned studies it was reasonable to create and implement a long-term follow-up which will let us to further modify those developments that were implemented according to the first two studies.

### **Hypotheses regarding the surveys:**

- Informing professionals raise the topic of brain death and organ donation not at the appropriate time, which may influence the family refusal rate.
- The approach of the donor family is not performed according to the legal requirements.
- The length of the meeting does not fulfil the needs of relatives, which may influence the family refusal rate.
- There is no preparation for the conversations, and the conditions are not always appropriate.
- There is no separate meeting for the communication of brain death and organ donation. There is no separate personnel to talk about the two different topics.
- The number of relatives, the type of their residence, the degree of their relationship to the patient, their gender and religion may influence the family refusal rate. The

deceased donors' education level, type of residence, marital status, gender and religion also might influence the family protest rate.

- Medical professionals at intensive care units have little practice on how to communicate brain death and organ donation.
- Hungarian medical doctors' willingness to donate their organs exceeds the Hungarian public's willingness regarding organ donation.
- Not all medical doctors who provide information to relatives agree on the concept of brain death or organ donation.
- The reasons behind family refusals are not always asked or discovered.
- Lack of understanding of brain death as death, fear of manipulation of the human body and distrust of the healthcare system are the main reasons for relatives to object the donation.

### **3. METHODS**

#### **SURVEY ABOUT COMMUNICATION OF BRAIN DEATH AND ORGAN DONATION (2011-2012)**

Prospective data collection was made from 27<sup>th</sup> of May, 2011 till 14<sup>th</sup> of August 2012. The questionnaire contained 37 closed and 9 open-ended questions. 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. 188 questionnaires were filled out in collaboration with 140 medical doctors.

There were 14 common questions at first in order to identify the case, the hospital and the doctor who was involved in the treatment. The age, marital status, gender and religion of the donor, the diagnosis which led to brain death, the times of brain death identification and declaration were registered.

Questions from 15 to 25 had to be answered in one-meeting communications, when the brain death diagnosis and the organ procurement purpose were raised in one session. We asked about who initiated the donation, about the place, timing and duration of the meeting. We registered the gender, age, qualification and speciality of the involved medical doctors, and the date of their licence exams. The degree of relationship, gender,

age, religion, education and type of residence of the involved relatives were also investigated. In case of two or more communications the 26-43 questions were also filled out, which were similar than the previous group of questions. At the end of the query we asked the reason for refusal, the method used to handle family refusal if it existed, and finally whether the staff could successfully change the initial family refusal.

### **HOSPITAL ORGAN DONATION ATTITUDE SURVEY (2012)**

The 40th Congress of the Society of the Hungarian Anesthesiology and Intensive Therapy (MAITT) was organised at 3-4 May, 2012. We asked the participants to fill out our validated 48-item questionnaire. These 45 closed and 3 open-ended questions were based on the transposition of the “*Hospital Attitude Survey*” made by the *Donor Action Foundation*. We received back 329 valid questionnaires. This survey asks the service level of the hospital, the presence of neurosurgery facilities, moreover the education, qualification, job and position of the responder and the type of department he/she works for. After that we examined the personal willingness to organ donation with 12 questions. Among these questions the willingness of own and relatives’ organ donation seemed to be the most important. Three questions were related to general professional information, and then three more questions were about the represented donor hospital. We were interested in the availability of hospital protocols about brain death declaration and organ donation, while we asked the opinion about the activity of the individual hospital in four questions. Five items were focused on the real and believed practice at certain points during the organ donation procedure. The survey inquired the need for training and the age, gender and professional experience of the interviewed professionals.

### **ORGAN DONATION INFORMATION ATTITUDE SURVEY (2015)**

We had another survey at the annual congress of MAITT in 2015. WE used a 38-item validated questionnaire with 35 closed and 3 open-ended control questions. It was filled out by 105 congress participants. We asked the age, gender, years of work, position, qualification and type of hospital department of the responders. The organ donation attitude was repetadly asked with the same 11 questions from the previous survey, furthermore we asked the wording of presumed consent. The questions about hospital

protocols were completed with items to measure the acceptance and application of the presumed consent principle. The judgement of one's own professional experience was also expanded with questions about the type of approach with explanation. Additional important part was the examination of the method used to handle family refusal if it existed with questions about timing. Finally, we asked about the number of cases in which the interviewee actively participated.

## **SURVEY OF FAMILY REFUSALS (2015)**

Since 1<sup>st</sup> of January, 2015 questionnaire must be completed in every case, if the first signs of brain death were identified, the potential donor was reported, family communication was initiated and the relative expressed objection to organ donation. We asked the medical doctor in charge about the timing of this conversation, the circumstances of the meeting place, the number, the qualification, the work experience of the involved personnel and the number and degree of relationship of relatives, then the number and duration of the meetings. In case of refusal we asked the reason behind that, the applied method knowing the cause and the result of the communication phase. If the refusal was withdrawn by the next of kin, we were interested in the reason for that. Finally, we asked proposals from professionals involved in donor family communication based on their individual experience concerning the problem they faced with.

### **Statistical analysis**

The questionnaire data were analyzed with the use of the Statistical Package for the Social Sciences version 20.0 (SPSS, Chicago, Illinois) including descriptive statistics and test of significant differences. The significance level was set to 5% ( $p \leq 0.05$ ). We compared continuous variables with categoric variables (independent samples t-test), scale variables with nominal variables (ANOVA), two (dichotom) nominal variables (Pearson chi-square test), ordinal variables (Mann-Whitney U teszt) and Spearmans's rho nonparametric correlations were also used. Stepwise logistic regression model was used to analyze multivariate relationship.

## **4. RESULTS**

### **SURVEY ABOUT COMMUNICATION OF BRAIN DEATH AND ORGAN DONATION (2011-2012)**

#### **One-meeting communications**

Only one meeting was found with 106 donor relatives (56.38%). 6 families (5.66%) raised the question of organ donation before the doctor would have mentioned it. Most the medical staff interviewed was specialists mainly in the field of anaesthesiology and intensive therapy (95.24%). The average timing of approaching the relatives was 1 hour and 13 minutes before brain death declaration, but with relevant standard deviation (STDEV: 11 hours and 14 minutes). These conversations took 17 minutes in average (STDEV: 8.8; MIN: 5; MAX: 45).

#### **Family approach via more than one meeting**

Two or more meetings were necessary with 82 donor relatives (43.62%). 6 families (7.32%) raised the possibility for organ donation prior to the staff. Conversations needed 11-22 minutes. The first approach on brain death and organ donation were initiated 19 hours and 49 minutes before the official brain death recognition in average when more than one meeting took place. The timing of the last meeting was positioned 2 hours and 26 minutes before the recognition of brain death in average, so much earlier than the brain death declaration.

#### **Characteristics of the only one (1.), the first (2.) and the last (3.) meetings**

The meeting was located in a separate room (61%, 58%, 56%), the ICU department passage (16%, 11%, 6%), and right next to the patient's bed (14%, 28, 28%) or was managed through phone calls (9%, 3%, 10%). Usually 1 (1.09, 1.11, 1.06) doctor talked with 2 (1.87, 2.16, 1.98) relatives. The degree of relationship of informed relatives was diverse: (25%, 20%, 20%) spouse, (7%, 5%, 4%) companion, (37%, 31%, 30%) child, (12%, 24%, 24%) parent, (10%, 12%, 16%) sibling, (9%, 7%, 6%) other. We found various types of approaches, like brief information (73%, 76%, 57%), persuasion (22%, 19%, 35%) and asking for permission (5%, 5%, 7%). As a result of these meetings 9%, 11%, 14% expressed permission, 76%, 41%, 54% accepted the information without refusal, or 6%, 15%, 32% refused the donation.

There were more individual factors that showed statistical correlation (Pearson chi-square test) with the appearance rate of family objections:

- **incidence of family refusal is more frequent when the family is approached via more meetings, which indicates the purpose to influence the initial objection;**
- **raising the topic as soon as possible before determining brain death, the more often we meet the family protest;**
- **the higher the education level of the relatives, the less likely the occurrence of the protest;**
- **we find fewer objection, if the medical doctor does not provide the communication alone to the family;**
- **larger numbers of the relatives proved reverse correlation with the incidence of family refusals.**

Mann-Whitney U test revealed association between duration of donor family communication and occurrence of refusal ( $P = .021$ ; **a longer communication decreased the incidence rate of objection from the families**). We could hypothesize correlation between factors that collectively had influence, so it was necessary to create several (stepwise) logistic regression models to evaluate variables in the equation. It was found that there were 3 really important features regarding organ donor family communications, which together had an aggregated effect on the negative outcome (refusal) of the meetings. The first was the relatives' education level, **with higher education correlating with lower refusal rate**. The second was the number of staff who gave information to the family; **the more ICU personnel that were involved, the chance of family refusal decreased**. Third, a **higher number of participating family members seemed to reduce resistance against organ donation** in Hungarian donor hospitals. We found 19 initial family refusals in 188 involved cases, among them 10 could not be converted to acceptance by relatives. From the group of objectors finally 11 organ donations took place, which means that donation could be realized at certain cases in spite of family refusal, but 8 donations were canceled.

We proved, that previous personal experience of the family of organ donation or transplantation helped, in a way as one member of the family could mention it to another which contributed to change the rejective attitude. If the initial objection was followed by internal communication prior to the second meeting, the time spent by the



family dissolved the rejection. The reasons of refusals must be explored, that gives opportunity to dissolve them. It was proven that lack of information, doubts, and unanswered questions may also lead to objection, meanwhile the clarification of doubts and honest answers can help to gain the trust of the relatives. Doubts are connected to uncertainty about brain death declaration, therefore the examination of the missing brain stem reflexes in the presence of the next of kin seemed to be convincing and this procedure also helped to step back from previous reluctance.

### **HOSPITAL ORGAN DONATION ATTITUDE SURVEY (2012)**

It was confirmed by Hungarian data collection that the potential for organ donation of hospitals with neurosurgery facility exceeds the hospitals potential without this type of treatment. Firstly, we measured the national data a year before our survey (2011) using the organ donation activity results at hospitals and combined indicators. Thereafter we used the data of our survey, and we found statistical correlation between the presence of neurosurgery and the organ donation potential of hospitals involved by Mann-Whitney U test. 99.08% of the responders support organ donation in general, 89.51% would offer own organ after death for transplantation purposes and 81.21% would give all transplantable organs. 46.18% shared their personal decision with relatives based on self-determination. 86.86% of professionals would offer their deceased relatives' organ, if it had been mandatory prerequisite, while only 53.25% knows the opinion of the family member on that issue. 58.33% would allow procuring organs from his/her existing child and the acceptance rate is 60.39% on the same question from currently childless participants. 43.38% of the responding persons believe that organ donation helps indeed to ease the grief, organ donation saves lives according to the majority (99.39%), organ transplantation gives additional healthy years for patients, but 7.12% said that we have sufficient number of donor organs according to the needs on the waiting lists. Only 6-12% was involved actively in 3 or more cases, meanwhile 38-41% declared themselves with adequate experience, which means that **the believed proficiency is higher than the real practice**. 55.63% of the answers stated that the organ donation activity of the represented hospitals is appropriate. 75.55% confirmed brain death as death of the individual which implies that **brain death is not a death of a patient according to one fourth of the Hungarian intensive care specialists**. We

investigated the opinion on the timing of family approaches. 25.32% prefer to communicate about organ donation together with the information of severe brain injury, 27.85% mention it with the recognition of the first signs of brain death, 12.34% give information with the declaration of brain death, and finally, 34.49% apply separate communication firstly about brain death and thereafter about organ donation. **One fourth of the relatives receive the first information about organ donation prior to the identification of brain death** according to the current practice.

### **ORGAN DONATION INFORMATION ATTITUDE SURVEY (2015)**

The medical professionals involved in this survey have 15.4 years of working experience in average at central or general intensive care units (MIN: 1; MAX:40; STDEV: 10.6). They (n=100) participated 2.7 times in the treatment of potential organ donor in average (MIN: 0; MAX: 35; STDEV: 4.5). They met 1.96 cases in average to inform the family about brain death (MIN: 0; MAX: 30; STDEV: 4.16). They were involved in meetings with relatives especially about organ donation 1.93 times in average (MIN: 0; MAX: 41; STDEV: 5.32). Only 0.28 family refusal for organ donation is experienced by one medical doctor in average (MIN: 0; MAX: 3; STDEV: 0.6). All the responders support organ donation in general, 94.34% of them would offer own organ after death for transplant purposes. 51.5% of doctors shared this personal decision within the family to express the wish after the death. 87.74% of responders would offer their relatives' organ, among them 34.91% with the permission of the relative expressed during lifetime and 52.83% without permission, meanwhile 59.8% know the relatives' opinion at the time of the survey. 51.87% would allow to procure organs from his/her existing child and the acceptance rate is 45.28% on the same question from currently childless participants. 54.4% of the responding persons believe that organ donation helps indeed to ease the grief, but 45.6% said no. Organ donation saves lives according to the majority (96.23%) and organ transplantation gives additional healthy years for patients (91.5%). 84.91% believe that we do not have sufficient number of donor organs, but 6.6% think we have, and additionally 7.55% did not know the right answer. **85.4% among the answers stated that brain death is equal to death, but 14.6% were reluctant on that.** The legal system based on the principle of presumed consent is appropriate by 73% of the answers, but it is feasible in

the daily practice according to 60% of the replies. 50% agrees that organ donation is canceled in case of refusal by the relative of deceased adult who was able to act during the life.

We could compare the results of the surveys of 2015 and 2012.

The willingness to donate organ is higher among medical doctors (94.34%) than for the public (73.9%), furthermore the doctors' willingness rate increased during the last 3 years. The professionals would offer more their deceased relatives' organs after 3 years and more positive answers based on the relatives' opinion, but one fourth of them would offer his/her loved one's organ without knowing the relatives' opinion. It is interesting, that both in case of existing or imagined child, the willingness to offer organs decreased. 11% more people thought after 3 years that the donation helps the mourning process. 79.8% considered themselves properly prepared for the communication of brain death, 76.1% about organ donation and 48.5% when consent request required in case of minor donor. 79.1% of respondents answered to be proficient in consolation to the bereaved families. By their own admission the doctors ask for consent to 48.8%, 51.2% of them give information about organ donation before. We prove by domestic survey that timing of donor family approaches has affected a significant impact on the incidence of protests, moreover to raise the topic organ donation in case of not brain dead patient is ethically questionable. Based on the results, the timing of first communication has improved during the last three years. Especially the early communications about organ donation rate dropped in favor of joint communication about brain death.

We were looking for the statistical correlation between different items of the investigation. We mainly seeked for factors, that may influence the attitude of professionals, practical communication and incidence of family protests. We found the following significant relationships:

- The older doctors with more working experience are more consistent in the implementation of the relevant legislation. The principle of presumed consent is feasible in daily practice in hospitals according to their view, so they prefer to inform about organ donation and they do not ask consent.
- Who had conversation about organ donation at home, not only told his own last will and testament, but also met relatives of opinion about organ donation after death.

Those professionals who discussed their willingness to donate organ after death at home rather believe that organ donation unburden the grief of the relatives.

- Those doctors who were involved more often in the treatment of potential organ donors and communication on brain death and organ donation, more frequently discuss the topic at home, and thus are more familiar with their relatives' will concerning organ donation. Conversations at home make doctors more confident in case of any consolation or support to the bereaved families, or request for consent from legal representative of the deceased minor.
- Our results showed that acceptance of brain death as death entails the adoption of the principle of presumed consent.
- Acceptance of presumed consent is stronger at those professionals, who participated at more organ donation, or consider their hospitals' activity appropriate. Doctors who are deeply committed to the Hungarian legislation, the more familiar to communicate brain death or organ donation to relatives, meanwhile they prefer to give information instead of request for consent. Of course, the opposite can be assumed between the two factors, as having experience in such communicative situations may strengthen the commitment to the principle of presumed consent.
- The working experience, participation in organ donor procedures and higher positions are associated with an opinion that the practice based on the principle of presumed consent is feasible. There are (more experienced) physicians, who believe that the current legislation is applicable in the daily practice, and they do it accordingly.
- Practitioners who are consistent to give information instead of request for consent accept less that family refusal may cancel the donation. Cancellation of donation is more common, when doctors expressly request for consent from the relatives of the deceased. This means that anyone who asks for consent, will withdraw the procurement in case of protest.

Finally, the correlation between self confidence and experience is clear.

## **SURVEY OF FAMILY REFUSALS (2015)**

We registered 20 cases in 2015 when the donor's next of kin protested following the information on organ donation. 10 donations canceled due to family refusal (among

them two minors), but relatives accepted the option for organ donation in another 10 cases. We had opportunity to fill out 19 questionnaires after the 20 registration. **Information about organ donation was initiated before the brain death recognition in 6 cases** (among them 2 cases canceled), but 13 meetings took place after the identification of brain death. 5 conversations happened at not separate room (corridor or next to the patient's bed), then 2 cases were canceled. 14 meetings were carried out without disturbing circumstances in separate room.

Conversations were provided by one physician in 8 cases, but 2-3 doctors were involved in 11 meetings. Half of the 10 canceled cases were managed by one professional. One-meeting communication was chosen in 4 cases, while 2-5 meetings were dominant, among them "continuous" family information was applied in 2 cases. We found one case only, when the cancellation was realized after one meeting. **The fear of manipulation of the human body was the reason behind the objection at 9 events**, but finally 4 refusals could be converted to acceptance. We registered the main arguments of doctors: "autopsy is mandatory due to the unusual death"; "*the loved one did not declare written objection during his life*"; "*how would he decide in this situation?*"; "*take leave of him*". We found a case when the doctor fully accepted the refusal without any intention to change or explore it. Distrust against the health care system was the reason at 3 cases. All 3 cases were successfully transformed to acceptance via detailed information about the whole procedure and empathetic conversation with the family. **Once the doctor did not ask the reason for refusal. Two cases have been traced to protest due to emotional reasons. The fact of brain death was not understood at two events**, however the following conversations dissolved the initial reluctance.

The asked colleagues suggested involving one more person to communicate in order to establish separate meetings about organ donation, to have personal discussions for informational purposes, to provide more time between the two meetings, furthermore to increase public awareness and to have communication trainings for medical doctors involved in deceased donor family approach.

## 5. CONCLUSION

One of the most difficult area of medical communication is, when relatives must be informed about brain death and organ donation. This is influenced by lack of information of the Hungarian public as well as the type of approach, the direction of the process, the preparation and preparedness for the meeting and the experience.

55% of EU member states apply presumed consent system by law, however cancelation of donation may appear due to family refusal in all these countries as well. It can be stated that the principle of presumed consent based on the lack of protest is not applicable in daily practice, which means that the law is not feasible in full.

Physicians will have experience over the decades to meet certain number of cases to ensure the acquisition of practice, therefore it is appropriate to invite junior medical colleagues to be present at such conversations, even as an observer.

It is proven problem in Hungary that the information of relatives of the potential organ donors is not in accordance with the legal requirements, but very often the family's consent is asked. There are a number of reasons behind that, like there is not enough time for these conversations unfortunately, not even to prepare and not all the doctors are dedicated to the topic.

If medical science insists that the brain-dead person is dead, it remains the task of health policy to provide an organized framework to inform the public. This information must be understandable, regular and extensive and it is necessary to have systematic measurement of consequences and results. In addition, the professional task requires the support of health policy in which those committed professionals must be requited, who shall be authorized to conduct conversations with deceased relatives after a special medical and communication training.

The low number of cases influences the type of implementation, and therefore should be considered the following division of tasks:

- hospital coordinators should be delegated and appointed in all hospitals with significant organ donor potential;
- the appropriate hospital coordinator is anesthesiologist and intensive care specialist, who regularly encounters the treatment of severe brain injury and brain dead

patients and so he formed professional experience in the conduct of the death process;

- special training programmes must be provided for these appointed professionals;
- hospital coordinators should receive alert when the donation procedure shall start inside the institute, but the notification is also justifiable, when nearby hospitals ask support for the communication with donor relatives;
- the physician in charge is responsible for the communication on brain death, meanwhile the hospital coordinator should talk about organ donation;
- 2 independent professionals should talk about the 2 topics of brain death and organ donation, preferably in separate conversations, but both should be present at both meetings.

This idea of training programme and implementation plan fits well the recently launched networking of the Hungarian National Blood Transfusion Service. Currently there are 18 appointed hospital coordinators.

Medical doctors responsible for donor family communication should know the following:

- less than half the population is familiar with the legislation in force, and even fewer Hungarians are aware of the fact of brain death as death;
- Two-third of our country's population would offer own organs after death;
- up to one-third of organ donation is canceled worldwide, even in countries applying the principle of presumed consent, because of family objections;
- the family refusal not legally, but ethically may be accepted, if they had not known the regulation in use, but it is not acceptable ethically, if not well managed approach may lead to protest, because it is no longer linked to the fundamental right of self-determination;
- the most common reasons behind family refusal requires explanation, which effort usually causes the elimination of the initial rejection, so it means that lack of public awareness can not be the ultimate cause of refusal;
- the most frequent reasons behind donor family refusals nowadays in Hungary are the fear of manipulation of the human body, the lack of understanding of brain death and the distrust against the healthcare system, therefore the following issues must be clarified prior to questions raised by relatives:

- after the admission and treatment of the patient all efforts have been implemented to save the patients's life and thereafter and nonetheless death occurred;
- detailed information provision is required, and professionals must be sure that relatives understood brain death as death of the human being, therefore can not remain doubts about the reliability of the determination of death;
- talking about organ donation is not applicable as long as the relatives could not understand the concept of brain death;
- it must be detailed, that organ procurement takes place at sterile operating room, with complete respect for the rights of the deceased's ornamental funerary,
- and at the end of the surgical procedure all the visible anatomical conditions will be recovered, so even an open casket funeral is possible;
- professional should serve by giving possibility, time and attention to the family to ask questions, doubts and to express their feelings;
- communication with the family starts at the admission of the patient, and it requires much time and many meetings;
- possibly one or few physicians lead the discussions, but in case of more conversation leader doctors' involvement, all the information concerning the family approaches – including the content – must be handed over;
- only those professionals should be allowed to talk about brain death, who also believe that brain death is death and who are also willing to donate their own organs after death;
- presumption of brain death only arises after the first signs of brain death has already been identified, consequently the topic of brain death may only be mentioned to relatives after these medical examinations;
- organ donation can only be mentioned in case of a dead individual, so only after brain death declaration;
- the duration of the discussions – taking into account the opportunities – is determined by the relatives' needs, but we must dedicate a minimum of 30 minutes for the meeting;



- Information of donor families is the right type of approach instead of asking for consent, because it would not be ethical to burden the relative with a decision, for which the relative is not entitled;
- thorough preparation of the place for the personal conversation is required;
- it is suggested to invite 2-4 relatives to the meeting;
- open-ended questions are useful to assess the relative's level of knowledge regarding the deceased patient's condition;
- in case of family refusal, the causes shall be assessed and detailed answers has to be given to all identified items;
- possibility of a last visit to see the deceased loved one should be offered, and even the possibility to look at the body after the procurement also should be provided if required;
- a religious person may be involved in the conversation, whose person's level of knowledge has to be checked at previous preparatory meeting.

These efforts require hours from physicians who were usually responsible for the treatment of patients at the whole intensive care unit. Therefore, it is appropriate to involve the supportive work of hospital coordinators, and thus continue the development of the network.

Conclusions for the daily practice:

- we update the content of the presentations and practical sessions of the organ donation trainings;
- we amend the guide for organ donation of the HNBTS, Organ Coordination Office, especially the part about family approaches;
- HNBTS will create and distribute separate leaflets about brain death and organ donation;
- 4 short video animations will be available about brain death, organ donation, relatives' perspective and organ transplantation;
- we are going to evaluate the effectiveness of this new type of public information;
- the completion of the survey of family refusals should be continued at least for 5 years in order to have eligible numbers of cases for statistical analysis.

# **BIBLIOGRAPHY OF THE CANDIDATE'S PUBLICATIONS**

## *Publications associated with the dissertation*

1. Mihály S, Smudla A, Kovács J. (2016) Practices around communication of organ donation in Hungary. *Transplant Proc*, 48: 2529-2533.
2. Kovács DÁ, Mihály S, Rajczy K, Zsom L, Zádori G, Fedor R, Eszter K, Enikő B, Asztalos L, Nemes B. (2015) Gerundium: A Comprehensive Public Educational Program on Organ Donation and Transplantation and Civil Law in Hungary. *Transplant Proc*, 47: 2186-2188.
3. Mihály S. (2014) A szervdonáció kérdésköre a szervező szemével. *FOCUS Medicinae*, 16: 14-20.
4. Teixeira JF, Maio R, Immer F, Dominguez JM, Papalois V, Mihály S, Paredes D. (2014) The Certification of Transplant Coordinators in Europe. *Transplant Proc*, 46: 1265–1273.
5. Smudla A, Mihály S, Ökrös I, Hegedűs K, Fazakas J. (2012) The attitude and knowledge of intensive care physicians and nurses regarding organ donation in Hungary-it needs to be changed. *Ann Transplant*, 17: 93-102.
6. Smudla A, Hegedűs K, Mihály S, Szabó G, Fazakas J. (2012) The HELLP concept - relatives of deceased donors need the Help Earlier in parallel with Loss of a Loved Person. *Ann Transplant*, 17: 18-28.
7. Smudla A, Mihály S, Hegedűs K, Nemes B, Fazakas J. (2011) Help, I need to develop communication skills on donation: the "VIDEO" model. *Transplant Proc*, 43: 1227-1229.

## *Publications not associated with the dissertation*

8. Nemes B, Mihály S, Asztalos L. (2014) Preface: the dawn of the new age. First experiences after being full member of Eurotransplant. *Transplant Proc*, 46: 2153-2154.
9. Mihály S, Márton J. Transzplantációs koordináció. In: Perner F, Petrányi Gy. Szervátültetés. Medicina Könyvkiadó Zrt, Budapest, 2013: 465-471.

10. Mihály S. A magyarországi szervdonáció és transzplantáció adatok elemzése. In: Perner F, Petrányi Gy. Szervátültetés. Medicina Könyvkiadó Zrt, Budapest, 2013: 475-479.
11. de Graauw JA, Mihály S., Deme O, Hofker HS, Baranski AG, Gobée OP, Krikke C, Fehérvári I, Langer RM, Ploeg RJ, Marazuela R, Domínguez-Gil B, Haase-Kromwijk BJJM, Font-Sala C, (2014) Exchange of Best Practices Within the European Union: Surgery. Standardization of Abdominal Organ Retrieval. Transplant Proc, 46: 2070-2074.
12. Mihály S. (2014) A Szervkoordinációs Iroda rövidített Szakmai Beszámolója. Aneszteziológia és intenzív terápia, 44: 52-54.
13. Szentirmai Cs, Mihály S., Ablonczy L, Szőnyi L. (2013) Újszülött és csecsemő kadáver donáció kérdései Magyarországon 2013-ban. Gyermekgyógyászat, 64: 135-138.
14. Di Ciaccio P, Carella C, Procaccio F, Cozzi E, Mihály S., Kosieradzki M, Font-Sala C, Paczeck L, Rowinski W, Brezovsky P, Fryda P, Costa AN, on behalf of the COORENOR consortium. (2013) COORENOR: Coordinating a European initiative among national organizations for organ transplantation. Organs, Tissues & Cells, 16: 87-98.
15. Mihály S. (2013) Az Eurotransplant előzetes együttműködés első éves eredményei Magyarországon. Aneszteziológia és intenzív terápia, 43: 31-33.
16. Mihály S. (2013) A Szervkoordinációs Iroda rövidített Szakmai Beszámolója. Aneszteziológia és intenzív terápia, 43: 48-50.
17. Mihály S. (2012) A Szervkoordinációs Iroda rövidített Szakmai Beszámolója. Aneszteziológia és intenzív terápia, 42: 56-58.
18. Mihály S. (2011) Magyarország csatlakozott az Eurotransplanthoz. Aneszteziológia és intenzív terápia, 41: 200.
19. Mihály S. (2011. április) Transzplantációs és szervdonációs koordináció. Transzplantációs Továbbképző Szemle, 5-7.
20. Mihály S. (2011) Eurotransplant – új lehetőségek a hazai szervdonációs és transzplantációs rendszerben a szervátültetésre szoruló betegek érdekében. Aneszteziológia és intenzív terápia, 41: 27-29.

21. Mihály S. (2011) A Szervkoordinációs Iroda rövidített Szakmai Beszámolója. *Aneszteziológia és intenzív terápia*, 41: 43-45.
22. Mihály S. (2010) A Szervkoordinációs Iroda rövidített Szakmai Beszámolója. *Aneszteziológia és Intenzív Terápia*, 40: 66-70.
23. Mihály S., Bakos P, Márton J. (2009) Present situation of transplant coordinators in Europe. *Organs Tissues & Cells*, 12: 29-34.
24. Mihály S. (2009) A Szervkoordinációs Iroda rövidített Szakmai Beszámolója. *Aneszteziológia és Intenzív Terápia*, 39: 52-54.
25. Hanzély Z, Borsi JD, Deme O, Dudás N, Mihály S., Szakács É. (2007) Hungarian National Blood Transfusion Service takes over the tasks of Hungarotransplant after five years of service. *Organs Tissues & Cells*, 1: 50-52.
26. Mihály S. (2007) Donációs aktivitás Magyarországon. *Aneszteziológia és Intenzív Terápia*, 37: 23-24.
27. Borsi JD, Borka P, Tornai E, Mihály S., Deme O, Mina A. (2005) Results of a Multilateral Approach to Donation–Transplantation Process in Hungary in the Past 2 Years. *Transplant Proc*, 37: 3260–3261.
28. Mihály S., et al. (2005) Better result of donation and transplantation data for the 1st half year in Hungary. *Organs Tissues & Cells*, 8: 197-201.
29. Deme O, Tornai E, Mihály S., Németh E, Borka P, Borsi J. (2005) Time factors during the organ donation process. *Organs and Tissues*, 1: 17-20.
30. Borka P, Tornai E, Deme O, Mihály S., Mina A, Borsi JD. (2004) Short analysis of donation-transplantation numbers by comparison of eight-months activity in the last three years. *Organs and Tissues*, 3: 187-189.
31. Borsi JD, Borka P, Tornai E, Mihály S., Deme O, Németh E, Mina A. (2004) Impact of Hungarotransplant on organ donation and transplantation activity in Hungary, Current state of donation and transplantation programs in Hungary. *Organs and Tissues*, 2: 105-108.
32. Borsi JD, Tornai E, Mihály S., Deme O, Sáfrány É, Mina A, Borka P. (2003) Report on organ donation and transplantation activity in Hungary. *Organs and Tissues*, 2: 105-110.