

The psychological effects of cadaver organ donation and the possibilities of the development of communication with relatives in medical training

PhD thesis

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1. INTRODUCTION

Transplantation, which can save the life of terminally ill patients or can ameliorate their quality of life, makes part of the most prominent scientific achievements of the 20th century. Every year, the number of persons waiting for organs is growing faster than the number of transplantable organs.

In Hungary, despite the high level of social support, the number of organ recovery from deceased donors has not changed significantly. According to scientific data, the number of donations shows a positive relationship with the level of education of staff in intensive care units as well as with their attitude towards transplantation. In this respect, communication with donors' relatives is an important factor. Besides resulting in influencing the number of donations, informing about the diagnosis of brain death and donation also has long term effects which are manifested in the alteration of psychological reactions of the donors' family members.

In Hungary, surveys on transplantation examined society's knowledge and attitude towards donation; no research deals with family members of donors. The grief reaction of the donors' family members and its influencing factors are examined in very few surveys worldwide. These surveys pointed to the role of information, particularly to the way of communicating the diagnosis of brain death, to its understanding, to the amount of time given to accept it and to the importance of the competence of doctor. Nevertheless, there is no proven difference in the intensity of grief between the relatives of donors and those family members who did not support donation and did not consent to organ recovery.

The positive effect of the training of health care professionals on the transplantation program is proven by many surveys. However, no survey has been made to explore communication with the family members of donors from the point of view which of doctors which would make possible the elaboration of an educational plan meeting their needs.

One of the aims of my research was to examine the factors influencing psychological processes following donation among donors' family members. On the other hand, in knowledge of these facts and the qualifications and attitudes of intensive care unit workers, I aimed at working out a special educational program which develops the

communication skills of health personnel and makes possible the reduction of unfavourable psychological effects and the mitigation of loss and grief reactions.

2. OBJECTIVES

1. The aim of the “Organ Donation 2006” survey was to examine factors influencing grief reactions and depression symptoms 3-6 months after loss among family members of deceased donors. Hypotheses regarding the survey:

- Communicating of the brain-stem death and the denial of the fact of brain-stem death can intensify grief reaction and the seriousness of depression symptoms.
- Opinions about the usefulness of donation and the positive attitude towards transplantation can reduce the intensity of grief reaction and the seriousness of depression symptoms.

2. The aim of “MAITT 2011” survey was to analyse the knowledge and attitude of anesthesiologists and intensive care therapy specialists and nurses concerning transplantation and donation. Hypotheses regarding the survey:

- Trainings on organ donation enhance the knowledge of anaesthesiologists and intensive care specialist and nurses.
- Despite legal regulation, professionals at intensive care units find it necessary to request the consent of the family.

3. The aim of the third survey, the “VIDEO” model, was to discover the key points of informing as well as the typical errors of communication based on the analysis of communication situations in practice about brain-stem death and donation. Hypotheses regarding the survey:

- When communicating the fact of death, doctors cannot explain the pathophysiological and philosophical essence of brain-stem death.

3. METHODS

3.1 The “Organ Donation 2006” survey

Study population

In the prospective, quantitative survey, we examined the factors influencing grief reaction and depression symptoms 3-6 months following donation among relatives of Hungarian deceased donors. We involved family members concerned by donations which took place between 1st January 2006 and 31st December 2007. We analysed 29 questionnaires filled in by 7 men and 22 women. (ETT TUKEB, 230-11/2006-1018EKU)

Measurement of factors – „Organ Donation 2006” Questionnaire

The “Transplantation 2006” survey consists of four parts: (1) socio-demographic data; (2) the examination of relatives’ knowledge, opinion and attitude on donation and transplantation; (3) surveying relatives’ opinion on communicating brain-stem death and donation at intensive care units; (4) self-esteem scales to survey grief reaction and depression symptoms. To measure the extent of grief, we used the validated Revised Grief Experience Inventory (RGEI; Cronbach alpha 0.970), the 22 question of which can be divided into 4 factors: existential concerns (Cronbach alpha 0.922); depression (Cronbach alpha 0.930); feelings of tension and guilt (Cronbach alpha 0.827); physical distress (Cronbach alpha 0.900) (Lev 1993). To measure depression symptoms, we used the 9-question short form of Beck’s depression questionnaire (rBDI). (Beck 1972, Kopp 1995).

Statistical analysis

The questionnaire data were analysed by using the Statistical Package for the Social Sciences version 11.0 (SPSS Inc, Chigaco, Illinois) including descriptive statistics and test of significant differences. Continuous variables (RGEI, the shortened version of Beck Depression Inventory) were analysed by independent samples t-test for variables with two categories and by Spearmans’s rho nonparametric correlations for other continuous variables. Mann–Whitney U test was used for non-parametric statistical analysis between one continuous and one categorical variable. Pearson chi-square test

was used for statistical differences between two categorical variables. The significance level was set to 5% ($p \leq 0.05$).

3.2 The “MAITT 2011” survey

Study population

The cross-sectional survey has been made between 19th and 21st May 2011 at the 39th congress of the Hungarian Society of Anaesthesiology and Intensive Therapy (MAITT). The questionnaire was filled in by anaesthesiologists and intensive care specialist and nurses on a voluntary basis; we analysed 282 questionnaires. 179 anaesthesiologists and intensive care specialists (63.5%) and 103 nurses (36.5%) participated in the survey.

Measurement of factors

The questionnaire of the Hungarian Transplantation Society, the Hungarian Society of Anesthesiology and Intensive Therapy and the Organ Coordination Office consists of 20 items. Besides the epidemiological data (age, doctor's and staff member's qualification, type of workplace) the questionnaire asked for participation in organ donation training and the annual number of organ donations organized by the participants. We examined for what extent the legislation on strong form of the presumed consent is known, if it is agreed with, if it is known where a declaration on the prohibition of organ recovery from a deceased donor can be made. We examined opinions on practice contradicting legislation when the family is involved in decision making on organ recovery even in the case of major donors. We measured the attitude towards donation through the opinion on deceased donor organ recovery for transplantation. We measured on a five point self-esteem scale the knowledge on the legal, ethical and professional aspects of transplantation.

Statistical analysis

The questionnaire data were analysed by the Statistical Package for the Social Sciences version 17.0 (SPSS Inc., Chicago, Illinois) including descriptive statistics and tests of significant differences. Continuous variables were analysed with independent samples t-test for variables with two categories, ANOVA for more than two groups, Spearman's rho nonparametric correlations for other continuous variables. Mann–Whitney U test and Kruskal–Wallis test were used for non-parametric statistical analysis between one

continuous and one categorical variable. Pearson chi-square test was used for statistical differences between two categorical variables. Logistic regression models were created to analyse the everyday practice of the family being involved in decision making and to analyse factors influencing legal, ethical and professional knowledge on transplantation. The significance level was set to 5% ($p \leq 0.05$).

3.3 The „VIDEO” model

Study population

I analysed 32 situations in practice taking place on the second day of the organ donation training organized in 2008 and 2009 by the Organ Coordination Office, Semmelweis University and the University of Szeged. 192 persons participated in the situations 87 of whom were men and 105 women; the “deceased donor” was an underage in 16 cases and an adult in also 16 cases. In the 10 – 15 minute-long communication situations recorded on video both the “doctor” and the “psychologist” was played by physicians participating in the training; the spot of situations being the rooms of university clinics.

The method of analysis

I recorded the length of situations, the number of participants and the type of situations: “underage donor” (communication with parents) and “adult donor” (communication with parents of a major child; communication with a child on the death of a parent). I transcribed the situations, that are raw data registered on video by qualitative conversation analysis then, based on grounded theory, I created the categories such as communicating the fact of brain-stem death, informing about donation, types and frequency of communication errors and „family” stereotypes. The aim of the analysis was to identify typical patterns and fix their frequency of reappearance in the situations. Participants gave a written consent to video recording and the use of records for later analysis.

4. RESULTS

4.1 The “Organ Donation 2006” survey

Legislation on organ recovery in lack of a declaration of protest independent of family decision in the case of an adult donor (the strong form of the presumed consent) was known by 37.9% of participants and 75.9% accepted it. 86.2% supported **hospital practice** which, contrary to legislation, required relatives to consent. At the time of our survey, 37.9% of family members would have protested to the recovery of their **own organs** for transplantation purposes. 24.1% of respondents did not find organ recovery of deceased donors useful. After donation, 27.6% of participants thought that doctors might not have done everything in favour of the patient before organ recovery.

After **communication at intensive care units** was examined, it turned out that 93.1% of family members thought they got a detailed explanation of what happened with their relative. Even so, 48.3% of respondents thought that a more detailed explanation could help understanding brain death; 27.6% suggested to use an information booklet, 10.3% thought that they would have needed more time to understand the situation and to decide. 3 -6 months after death, 41.1% of respondents thought that **the diagnosis of brain-stem death** cannot be stated reliable.

From 20 families, 5 mentioned the possibility of **donation** before the doctor could have, the motivation of which was the wish to help others or to see the loved person persisting in someone else. 58.6% of relatives thought that it can help to endure grief if the loved person persists through organ donation. 55.2% of participants talked about donation with someone else than the doctor performing treatment.

72.4% of family members performed certain **depression symptoms**. Based on rBDI, the symptoms of mild depression were found in nine (31%) and of moderate depression symptoms in three (10.3%) cases; serious depression was estimated in the case of nine family members (31%). The seriousness of depression (rBDI) showed correlation with the extent of **grief reaction** (RGEI) ($\rho=0.794$; $p=0.000$).

There was no justifiable connection between grief reaction and the extent of depression and the length of time passed since death, the age, sex, marital status and religion of the family member. Grief reaction and the gravity of depression symptoms were less severe in the case of relatives with higher educational degrees than of those who did not have a

degree: significant differences were found in the RGEI total ($p=0.022$), in the “depression” factor ($p=0.028$), in the “feelings of tension and guilt” factor ($p=0.007$) and in the “physical distress” factor ($p=0.038$).

According to the psychological reaction related with knowledge about presumed consent legislation previous to organ recovery, significant differences could be observed only in terms of “existential concerns” ($p=0.037$). We neither found differences in the results of psychological self-evaluation scales regarding the opinion on legislation and the contradicting everyday practice which involves the family in the decision process, nor in their opinion on the usefulness of organ recovery for transplantation and the offering of their own organs in case of death.

Among participants who thought that the fact of brain death can be confirmed with full certainty, a lower level of grief reaction was found (RGEI: $p=0.020$) 3 -6 months after the relative’s death and depression symptoms were less serious (rBDI; $p=0.002$).

In cases when the family mentioned the possibility of donation, more serious grief reaction (RGEI; $p=0.082$), depression symptoms (rBDI; $p=0.052$), and bad consciousness (“feelings tension and guilt” factor $p=0.029$) was observed. The fact that family members asked for information on donation from someone else than the treating doctor and the existence or lack of family consensus on supporting organ donation did not show a correlation with the extent of the psychological reaction.

4.2 The “MAITT 2011” survey

40.1% of the respondents participated in a *training on organ donation*. 59% of doctors and 65.1% of nurses did not even want to participate in such training. The average age of those who participated in training was significantly higher among doctors ($p=0.002$); there was no difference in the case of nurses. Physicians who has not yet participated in training but would like to were younger by tendency than those who were negative about participation ($p=0.93$).

Doctors participated in training for a significantly higher rate ($p=0.000$) than nurses, but this difference could not be observed in the willingness of participating in training. The majority of doctors participating in training came from county hospitals (64.7%), the lowest rate of doctors participating in training came from capital hospitals (44.9%).

30.9% of employees working at intensive care units have never participated in a donation process, while 61.3% participates in donation annually for 1 to 5 occasions, 4.3% 6 to 10 occasions, and 1.8% more than 10 occasions. **Donation activity** was not influenced by age and skill. Donor management is most frequent in county hospitals while it is less frequent in the capital ($p < 0.05$). Physicians who participated in training take part in donor management for a significantly higher extent ($p = 0.002$). At intensive care units where there are more donations, participation in trainings is planned for a higher extent ($p = 0.004$), but this was not characteristic for nurses.

98.3% of doctors and 87.3% of nurses knew **legislation** on the principle of the strong form of presumed consent in the case of a major donor and 91.1% of respondents agreed with it. 66% agreed with the **hospital practice** which requests the adult donor's family members to consent to organ recovery referring to tribute causes and/or because legislation on the subject is not known. In logistic regression model, the independent predictor of hospital practice referring tribute causes was the working at university hospital (OR: 2.48), and the predictor of hospital practice referring unknown legislation was younger age (OR: 1.39).

95.4% of participants would consent to **own organ recovery** for transplantation aims.

Examining **knowledge about donation and transplantation** both doctors and staff members have the most knowledge on donor management (3.70 points and 3.22 points), while they had the least knowledge on aftercare following organ transplantation (2.55 points and 2.83 points). The knowledge of participants evaluated on a five point scale can be examined as a dependent variable in the logistic regression model and can be dichotomised using the median. Independent predictors of knowledge about joining Eurotransplant were older age (OR: 1.90), the qualification of nurses (OR: 2.92) and participation in organ donation training (OR: 3.34).

Independent predictors of knowledge about donor management were higher age (OR: 1.37), medical degree (OR: 2.04), higher donation activity (OR: 2.69), and participating in training (OR: 6.27). The independent predictors of the knowledge about the legal and ethical references of donation were donation activity (OR: 1.90), working in a county hospital (OR: 2.34), participating in training on donation (OR: 5.78). Predictors of knowledge about both deceased and living donation were older age (OR: 1.50; OR: 1.33) and participation in training (OR: 4.62; OR: 1.98); nevertheless, while in the case

of deceased donation a medical degree signalled higher level of knowledge (OR: 1.99), knowledge about donation by living donors was predicted by professional staff degrees (OR: 2.52). The independent predictor of knowledge about aftercare was age (OR: 1.53) and the level of education of staff (OR: 2.31).

4.3 The „VIDEO” model

During situational practices, “physicians” explained *brain-stem death* to “relatives” by the termination of the personality and human individuality in 25% of the cases and in 12.5% of the cases a pathophysiological explanation was given. The termination of the personality and pathophysiological causes were both used for explaining brain-stem death in 21.86% of the cases. In order to show the process leading to brain death, imaging examination such as computed tomography was used in 31.25% of the cases. In 9.38% of the cases, the concept of brain death and coma were used as synonyms. It was defined two times as a state incompatible with life and fifteen times as an irreversible state; the two expressions were used together seven times. Four times (12.5%) a metaphor was used to explain that brain-stem death means real death and that it is possible to say about someone whose heart is still beating that he is in the state of brain-stem death. In 56.25% of the cases the expressions „dead” and „brain-stem dead” were used at the same time; in three of the cases (9.38%) the expression „dead” was used to communicate the death of a person whose heart was still beating.

The “doctors” told from the factors of the brain-stem death evaluation (the clinical examination by three physicians, the observation period and re-evaluation) none in five situations (15.63%) and all of them in two (6.25%).

The support by psychologist was proposed in twelve cases. The option of “saying goodbye” was suggested every time.

There was no situation where information about *donation* and brain death was handled separately, that is organ recovery was communicated before the fact of brain death could have been understood and accepted. Altruism, the helping of others as a motivating factor was mentioned in 93.75% of the situations; in six cases (18.75%) it was said that the deceased person could persist in someone else and in five cases (15.67%) both reasons were used.

Examining altruism, there were further parts to be stated. As part of the organ focused behaviour, the reason that „organs can help others” was used in eleven cases (34.38%). Person focused behaviour: as part of the behaviour focusing on the family and the deceased person during communication about organ donation, the idea of the deceased or the family helping others was emphasized (16 cases; 50%). The expression „the organs can be used” is considered as organ focused behaviour; it was used in 11 cases (34.38%).

Protest against organ recovery was explained by the „family” in two cases (6.25%) by stating that „the deceased would not have wanted it” and in nineteen cases (59.38%) the explanation was fear from losing the integrity of the body.

In the case of the sixteen minor donors, in accordance with legislation, the consent of the parents was requested. In the case of the sixteen major donors, in one case, in accordance with legislation, the family was merely informed (6.25%); legislation was described in ten cases (62.5%) but the consent, support or decision of the family was requested (6 cases) and/or they were assured that their objection would be considered (7 cases). In five cases (31.25%) the consent of the family was asked without legislation being describing.

Questions and stereotypes communicated by players of the „family” and their frequency is shown in figure 1.

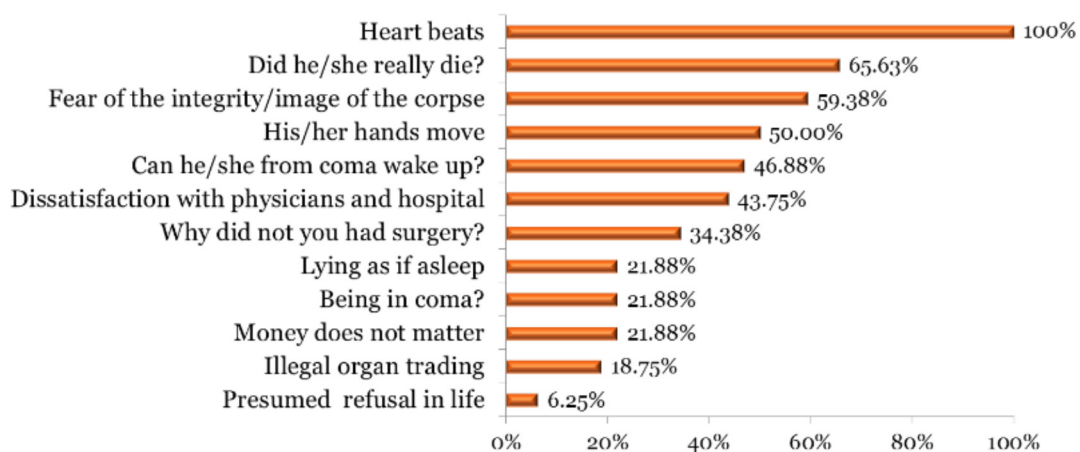


Figure 1. The reflects which can be faced in a family interview (n=32)

Doctors were using the present tense when communicating the fact of brain-stem death of the patient in ten cases (31.25%) form which present tense was used in seven cases

(21.88%) when speaking about organ recovery. In 59.38% of the cases a contradiction in meta-communication could be observed when the expressions of dead and alive were used at the same time referring to a person (e.g. „Unfortunately he/she is dead/brain-dead, we can keep him/her alive only with the machine”).

5. CONCLUSION

By 20th century organ transplantation, terminally ill patients suffering from organ dysfunction got a chance to survive. Transplantation became a widespread medical intervention with a growing demand for transplantable organs. An important step in the donation process is communication with donors' family members one of the aspects of which is the anticipation of the family's objection and the diminishing of the negative effects of the difficult situation on family members.

According to the surveys introduced above, the following conclusions can be stated, also taking into consideration the hypotheses listed when we stated our aims:

1. The symptoms of grief reaction and depression can be diminished if at the time of losing the loved person the family gets help, the first step of which is communication with relatives at intensive care units and its development which we call the „HELLP concept” (*Help Earlier in parallel with Loss of Loved Person*).
2. In the course of communication, the most important is that relatives understand and accept the fact of brain death, that they do not have any doubt about the reliability of the statement of brain death.
3. Among those who doubt the fact of brain death a more intensive grief reaction is probable thus the follow up of vulnerability family members is necessary.
4. Grief reaction and depression symptoms are not influenced by the late approval of the usefulness of organ donation and attitude to transplantation.
5. The training of staff working at different professional fields of donor recognition and donor management is crucial for a higher level of professional knowledge regarding donation.
6. Despite employees working at intensive care units agreeing with the legislation on the strong form of presumed consent in the case of a major donor, they found it necessary to involve the family in decision making.

7. In order to prevent family refusal and to mitigate the seriousness of psychological reactions among family members of deceased donor, the communication training of doctors has a significant importance on the course of which the explain of pathophysiological and philosophical essence of brain death has to be emphasized.
8. In communication training, the „VIDEO model” is suitable both for individual training and the forming of and educational concept.
9. The obligatory education of anaesthesiologists and intensive therapy specialists and professionals integrated into the education before specialist exam in intensive care medicine and refresher courses is necessary to reach a higher number of donors and transplantable organs, the improvement of donor management and the mitigation of psychological effects in family members.

Based on our results, a program can be built up which is called „pyramid intervention” (figure 2), the basis of which being the education of health care employees. The method of this latter is influenced by their qualifications and their skills can be developed through education (“VIDEO model”: following the *V*isual presentation the participants discuss *I*nteractively the *D*onation situation and *E*xplore the video records in a retrospective way, by which teaching can be *O*ptimized) (figure 3).

The level of education influences communication techniques used with relatives of donors in the diagnosis of brain death which can be *H*elp *E*arlier in parallel with *L*oss of *L*oved *P*erson (“HELLP concept”) and also has an effect on psychological processes of family members after the loss. Training can be further modified by the follow-up of the family.

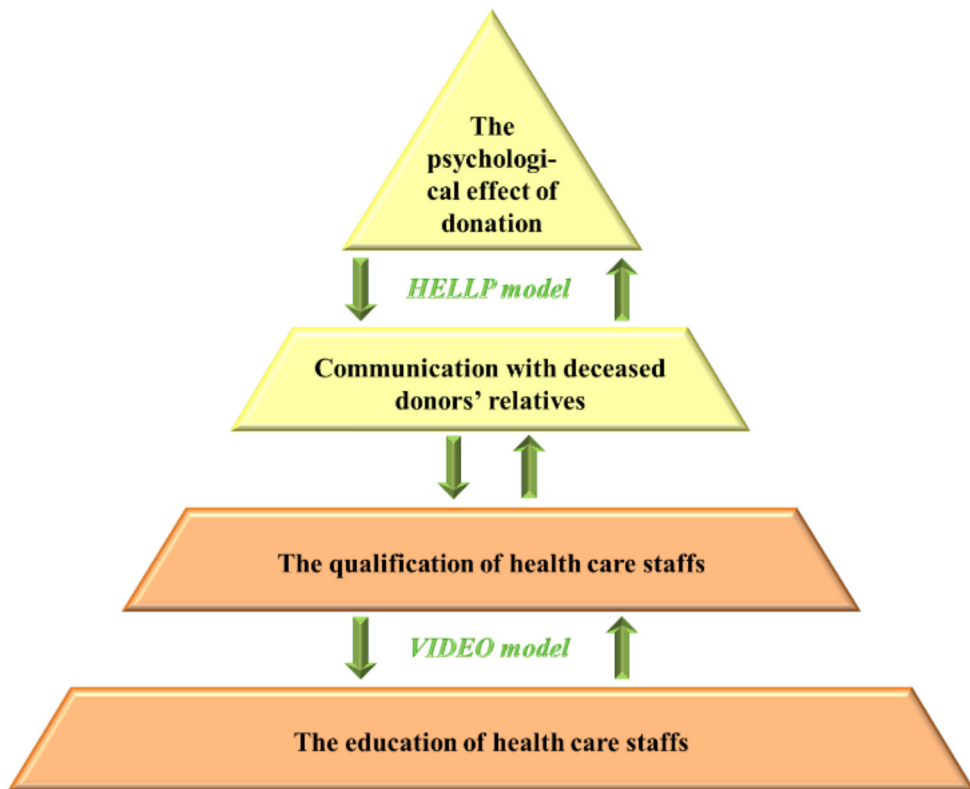


Figure 2. The „Pyramid intervention”

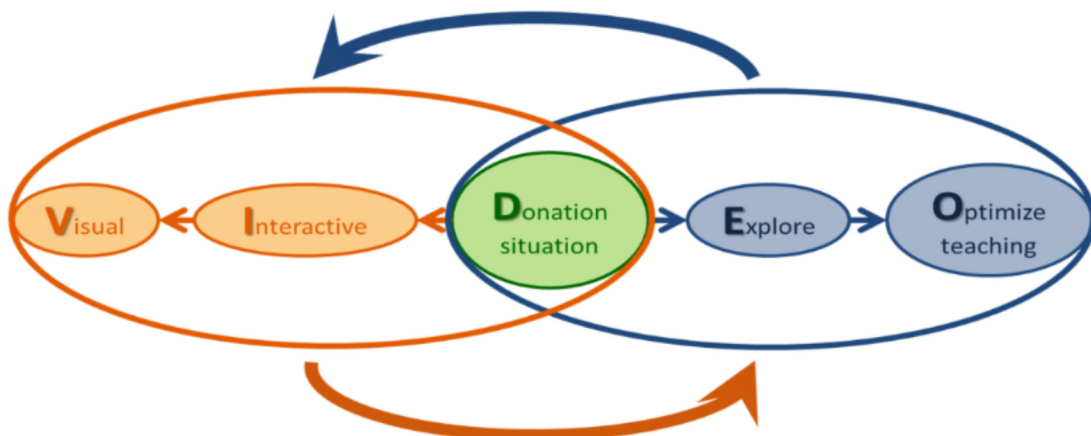


Figure 3. The VIDEO model

6. PUBLICATION

Publications associated with the dissertation

Original articles - international journals

1. **Smudla A**, Mihály S, Hegedűs K, Nemes B, Fazakas J (2011) HELP, I need to develop communication skills on donation. The VIDEO model. Transplantation Proceedings, 43(4): 1227-1229.

DOI: 10.1016/J.TRANSPROCEED.2011.03.073

IF: 1.005

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2. **Smudla A**, Hegedűs K, Mihály S, Szabó G, Fazakas J (2012) The HELLP concept. The deceased donor relatives need the Help Earlier in parallel with Loss of Loved Person. Annals of Transplantation, 17(2): 18-28.

IF: 2.020

Submitted manuscript – international journals

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Original articles - Hungarian journals

1. **Smudla A** (2006) A cadaver donorokból történő szervkivétel jogi, etikai és társadalmi vonatkozásai Magyarországon. Lege Artis Medicine, 16(5): 480-487.
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Chapter

1. **Smudla A**, Hegedűs K. „Mi sírva élünk, ők meg boldogok...” – A szervkivétel pszichológiai hatásai a donor hozzátartozóira. In: Kopp M (szerk.), Magyar Lélekiállapot 2008. Semmelweis Kiadó, Budapest,2008: 486-494.

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7. **Smudla A**, Hegedűs K (2007) The point of the relatives of dead donors in organ retrieval. *Transplant International*, 20(Suppl. 2): 338.
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Publications not associated with the dissertation

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1. **Smudla A**, Gerlei Zs, Gergely L, Varga M, Toronyi É, Doros A, Mándli T, Arányi Zs, Bán E, Sárváry E, Kóbori L, Fazakas J (2011) West Nile virus encephalitis in kidney transplanted patient, first case in Hungary: a case report. *Interventional Medicine and Applied Science*, 3(2): 80-83.
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1. **Smudla A**, Nyiri P, Somogyi P. (2003) Csípőtáji töröttek vizsgálata az osteoporosis és az életminőség tekintetében. *Magyar Traumatológia, Ortopédia, Kézsebészet, Plasztikai Sebészet*, 46(3): 258-267.
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