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ORIGINAL ARTICLE

Effects of phased education on attitudes toward organ donation and willingness to donate after brain death in an Asian country

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Organ donation;
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Summary *Background/objective:* : This study aims to investigate the effects of phased education on attitudes toward organ donation and willingness to donate after brain death.
Methods: A survey was conducted using a questionnaire to examine attitudes toward organ donation of the families of patients admitted to a surgical intensive care unit (SICU) between March 1, 2014 and September 30, 2016.
Results: Ninety-two people voluntarily participated in this survey. Before reviewing the educational material, 75.0% had a positive attitude toward organ donation, 60.9% were willing to donate their own organs, and 38.0% were willing to donate a family member's organs. After reviewing the educational material, these figures increased to 92.4%, 80.4%, and 56.5%, respectively. Before receiving an education, there was a significant difference in consistency between people's attitudes and willingness to donate their own organs, versus donating a family member's organs (79.3% vs 54.3%, $p < 0.001$). With phased education, these percentages increased from 79.3% to 85.9% with regard to donating one's own organs, and from 54.3% to 64.1% with regard to donating a family member's organs.
Conclusion: Phased education was effective overall, but it had a limited effect on changing the willingness to donate a family member's organs. It increased the consistency between people's attitudes toward organ donation and willingness to donate their own, or a family member's organs.

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1. Introduction

The shortage of organs for transplantation remains a serious problem worldwide.[1–5] While the number of patients waiting for transplantation has grown rapidly, the number of organ donors has remained much smaller than the number of those on the waiting list. The waiting list in South Korea in 2015 contained 27,444 people, while only 2565 people (9.8% of the number on the waiting list) were registered organ donors.[6]

In order to increase the frequency of organ donation, it is important to identify potential donors and obtain informed consent to donate from their families.[7–11] Aside from some European countries, most countries use the "opt-in" system, in which obtaining consent is the most important factor for successful organ donation. The consent rate for organ donation in Europe has been known to range from 50% to 80%. Several studies have found that, while 85% of families that are asked to donate, only 50% end up providing consent.[12–17]

Screening for potential brain dead donors and approaching the families is one possible way to address the organ shortage.[18–21] While approaching a family, in order to ensure a rational and well-informed decision, the primary physician or the organ procurement organization coordinator must give the family information on the patient's medical status, the prognosis of brain death, and the social need or significance of organ donation. Most public educational promotions regarding organ donation contain similar contents. However, the studies on the effectiveness of this counseling or education in changing attitudes toward organ donation or willingness to donate is rare in East Asia. It has been blindly believed that Confucian traditions are the main barrier to organ donation in East Asia. Moreover, the consistency between attitudes toward organ donation and willingness to donate has also not been studied in East Asia.

This study aims to investigate the effectiveness of phased education in improving attitudes toward organ donation and willingness to donate.

2. Methods

The survey using a questionnaire was conducted on the families of patients admitted to a surgical intensive care unit (SICU) at a single institution between March 1, 2014 and September 30, 2016. Only voluntary participants aged 18 to 80 without cognitive dysfunction participated in the survey. The questionnaire was composed of questions relating to baseline characteristics, positivity toward organ donation (Q1), willingness to donate their own organs (Q2), and willingness to donate a family member's organs (Q3) after brain death. The questionnaire is presented in Appendix 1.

The medical staff, or nurses, asked the relatives if they were willing to participate in this survey, regardless of the cause and severity of the patients' illness, and only the relatives who participated voluntarily were enrolled in this survey. After enrollment, a transplantation coordinator conducted the survey in face-to-face interviews. Before conducting this survey, informed consent was obtained. While obtaining informed consent, the importance of frank responses without prejudice or psychological pressure was highlighted. And the participants were encouraged to respond according to only their own opinion, and not to be affected by any other factors. The participants were free to withdraw from the survey at any time. This study was reviewed and approved by the institutional review board (No. IB-1310-038).

The survey was performed in three phases. First, a baseline response to the questionnaire prior to phased education was obtained (Phase 0, P0). Next, the coordinator informed the participants about the medical aspect and prognosis of brain death, after which the participants responded to same questionnaire (Phase 1, P1). The education in this phase concerned the ultimate consequences of brain death and the differences between brain death and vegetative state. The education lasted 5 min, and its contents are presented in Appendix 2A. Next, a video clip promoting organ donation was shown to the participants, after which they responded to the same questionnaire again (Phase 2, P2). The video clip started with the story of a young woman who had donated her organs after brain death. Some statements from patients with organ failure and their families followed. The video clip ended with narrations about the value of organ donation. The contents of the video clip are described in Appendix 2B.

For reliability analysis, we scored the responses to the 3 items (Q1, Q2, Q3) in the questionnaire unidimensionally. These 3 items at 3 phases (P0, P1, P2) were analyzed using item-to-total correlations and Cronbach's coefficient alpha to determine scale unidimensionality and internal consistency reliability. Item-to-total analysis shows the correlation between the respective items and summated score (without the respective item), and the coefficient alpha if the respective item was deleted.

The consistency between attitude toward organ donation (Q1) and willingness to donate one's own organs (Q2), and the consistency between attitude toward organ donation (Q1) and willingness to donate a family member's organs (Q3) were calculated from the responses to the questionnaire. The consistency rate was defined as the sum of the percentages of responses showing agreement between the relevant attitude and willingness, whether positively or negatively. The inconsistency rate was the sum of the percentages of responses showing disagreement between the relevant attitude and willingness. For the comparison, a univariate analysis was performed with the

Table 1 Participants' characteristics (N = 92).

Variables	Number (%)
Age	36.1 ± 13.4
Sex	
Male	11 (12.0%)
Female	81 (88.0%)
Religion	
Catholic	21 (22.8%)
Christian	24 (26.1%)
Buddhist	11 (12.0%)
None	36 (39.1%)
Relationship to the patient	
Parent	2 (2.2%)
Spouse	12 (13.0%)
Descendant	26 (28.3%)
Not immediate family	52 (56.5%)
Education	
College graduate	77 (83.7%)
Non-college graduate	15 (16.3%)
Marriage status	
Yes	42 (45.7%)
No	50 (54.3%)
Trust of hospital staff	
Yes	69 (75.0%)
No	5 (5.4%)
Unknown	18 (19.6%)
Posthumous body disposal preference	
Cremation	81 (88.0%)
Burial	11 (12.0%)
Knowing about brain death	
Yes	60 (65.2%)
No	32 (34.8%)
Previous exposure to organ donation promotion materials	
Yes	55 (59.8%)
No	37 (40.2%)

chi-squared test or Fisher's exact test using IBM SPSS Statistics for Windows, version 21.0 (IBM Co., Armonk, NY, USA).

3. Results

Ninety-two people voluntarily participated in this survey. Their mean age was 36.1 years (SD = 13.4), and the majority of the participants were women (88%). Their characteristics, including religion, relationship with the patient, education, marriage status, and posthumous body disposal preference, are presented in Table 1.

Table 2 displays the details of participants' responses according to phased education stage, as well as the correlation between the respective item and the total sum score (without the respective item) and the internal consistency of the scale if the respective item was deleted. All item-to-total correlations at all stages of education were above 0.3, and the total Cronbach's alpha of 0.934 indicated an acceptable level of internal reliability.

Before education, the general attitude toward organ donation was positive, with 69 participants (75.0%) indicating a positive outlook (Q1). However, responding to the question about willingness to donate one's own organs, 56 participants (60.9%) were positive (Q2). This discrepancy between opinion and practice was even more obvious regarding the willingness to donate family members' organs, with only 35 participants (38.0%) giving positive responses (Q3). After education, including an explanation of brain death and a video clip, the positive responses increased progressively (Table 2). Fig. 1 shows the improvement of general attitude and willingness to donate with the phased education. Despite the improvements in general attitude (92.4% in Q1) and willingness to donate one's own organs (80.4% in Q2), the willingness to donate family members' organs (56.5% in Q3) remained relatively low, even after phased education.

The change in consistency according to phased education between attitude toward organ donation and

Table 2 Responses during phased education regarding attitudes toward organ donation (Q1), willingness to donate one's own organs (Q2), and willingness to donate a family member's organs (Q3).

	Strongly Negative (%)	Negative (%)	Undecided (%)	Positive (%)	Strongly Positive (%)	Item-total Correlation	α if item deleted
Phase 0							
Q1	1 (1.1)	4 (4.3)	18 (19.6)	54 (58.7)	15 (16.3)	0.740	0.928
Q2	3 (3.3)	8 (8.7)	25 (27.2)	40 (43.5)	16 (17.4)	0.836	0.922
Q3	5 (5.4)	11 (12.0)	41 (44.6)	18 (19.6)	17 (18.5)	0.689	0.934
Phase 1							
Q1	1 (1.1)	5 (5.4)	12 (13.0)	64 (69.6)	10 (10.9)	0.783	0.926
Q2	2 (2.2)	8 (8.7)	17 (18.5)	52 (56.5)	13 (14.1)	0.822	0.923
Q3	2 (2.2)	12 (13.0)	33 (35.9)	37 (40.2)	8 (8.7)	0.765	0.926
Phase 2							
Q1	1 (1.1)	1 (1.1)	5 (5.4)	69 (75.0)	16 (17.4)	0.733	0.930
Q2	1 (1.1)	5 (5.4)	12 (13.0)	59 (64.1)	15 (16.3)	0.774	0.926
Q3	1 (1.1)	7 (7.6)	32 (34.8)	42 (45.7)	10 (10.9)	0.748	0.927

n = 92; Cronbach alpha = 0.934.

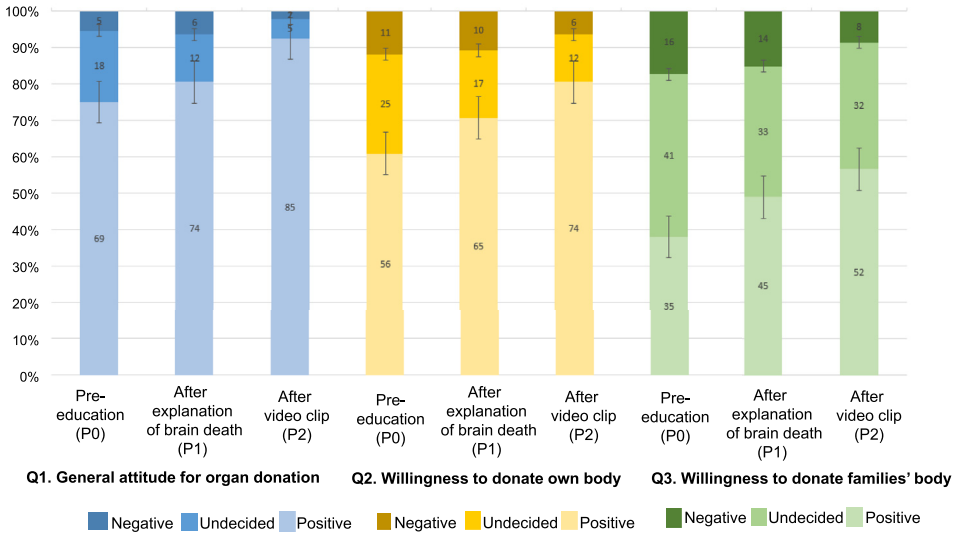

Figure 1 Changes in general attitude toward and willingness for organ donation after education (N = 92).

willingness to donate organs is shown in Table 3 and Table 4. Before education, the consistency in donating a family member's organs was significantly lower than in donating one's own organs (54.3% vs 79.3%, $p < 0.001$). With phased education, this consistency increased from 79.3% to 85.9% for donating one's own organs, and from 54.3% to 64.1% for donating a family member's organs. As such, even after phased education, the consistency in donating a family member's organs was significantly lower than in donating one's own organs (64.1% vs 85.9%, $p = 0.001$).

At the pre-education phase, only 35 participants (38.0%) agreed to donate their family member's organs, with the remaining 57 participants (62.0%) being either negative or undecided. Of these 57 negative or undecided participants, 21 (36.8%) changed their attitude after the phased educations. The other 36 (63.2%) remained either negative or undecided. The changing attitude of the initially negative or undecided participants on donating family member's organs as a result of phased educations is shown in Fig. 2.

4. Discussion

The public education program for the promotion of organ donation and counseling families of potential brain dead patients has various components; the fundamental ones being giving precise information, as well as explaining the social significance of organ donation, and the possibility of giving new life to someone. This study aimed to examine the efficacy of this traditional process of counseling or education and how it helps people make decisions that coincide with their beliefs about organ donation.

In the investigation of baseline characteristics, 88.0% of respondents preferred cremation to burial as a manner of body disposal, and 65.2% answered that they knew the meaning of brain death. About 60% had had previous experience with organ donation promotion materials (Table 1). These were fortunate findings about the general state of awareness about this subject. However, at the pre-education phase, despite the high proportion of people

Table 3 Change in consistency between attitude (Q1) and willingness to donate one's own organs (Q2).

	Q2, Pos (%)	Q2, UD or Neg (%)
A. Before education (P0)		
Q1, Pos	53 (76.8%)	16 (23.2%)
Q1, UD or Neg	3 (13.0%)	20 (87.0%)
Consistency rate = (53 + 20)/92 × 100 = 79.3%		
Inconsistency rate = (16 + 3)/92 × 100 = 20.7%		
	Q2, Pos (%)	Q2, UD or Neg (%)
B. After education (P2)		
Q1, Pos	73 (85.9%)	12 (14.1%)
1, UD or Neg	1 (14.3%)	6 (85.7%)
Consistency rate = (73 + 6)/92 × 100 = 85.9%		
Inconsistency rate = (12 + 1)/92 × 100 = 14.1%		

Pos, positive; UD, undecided; Neg, negative.

Table 4 Change in consistency between attitude (Q1) and willingness to donate a family member's organs (Q3).

	Q3, Pos (%)	Q3, UD or Neg (%)
A. Before education (P0)		
Q1, Pos	31 (44.9%)	38 (55.1%)
Q1, UD or Neg	4 (17.4%)	19 (82.6%)
Consistency rate = (31 + 19)/92 × 100 = 54.3%		
Inconsistency rate = (38 + 4)/92 × 100 = 45.7%		
	Q3, Pos (%)	Q3, UD or Neg (%)
B. After education (P2)		
Q1, Pos	52 (61.2%)	33 (38.8%)
Q1, UD or Neg	- (0%)	7 (100%)
Consistency rate = (52 + 7)/92 × 100 = 64.1%		
Inconsistency rate = (33 + 0)/92 × 100 = 35.9%		

Pos, positive; UD, undecided; Neg, negative.

with positive attitudes toward donating their own organs, only 38% indicated a willingness to donate their family member's organs. This willingness remained relatively low even after the phased education (56.5%). The relatively high proportion remained "undecided" on Q3 in all phases (Fig. 1). Without a family member's prior declaration about organ donation, the burden of family decision seems difficult to alter with education. This limited role of individual counseling in the family's decision highlights the need for strategic efforts such as the expansion of the donor card or the adoption of a "presumed consent" policy, known as an "opt-out" system.[22–31] The paradoxical increase of autonomy achieved by the adoption of an "opt-out" system in the UK is notable in this respect.[23]

The decision to donate organs depends on various factors, including the clinical situation, cause of brain injury, the characteristics of the decision-maker, and various perceptions on organ donation. While several studies have focused on the factors associated with the consent rate for organ donation, the effects of counseling or education have not yet been investigated in East Asia.[16,17,32,33] The number of participants willing to donate their own organs increased from 60.9% to 80.4% after education, and the number willing to donate from family members increased from 38.0% to 56.5%. Of the 36 participants who were undecided or negative about donating their own organs before education, 18 (50.0%) changed their minds after education. Furthermore, of the 57 participants who were undecided or negative about donating their family member's organs before education, 21 (36.8%) changed their minds after education.

Consistency between attitudes toward organ donation and willingness to donate is one of the important subjects in this study because a prudence or firmness of decisions is required to justify organ donation. The consistency increase in this study confirmed that education or counseling for organ donation is a supportive tool for a firm and informed decision. Many undecided or negative attitudes

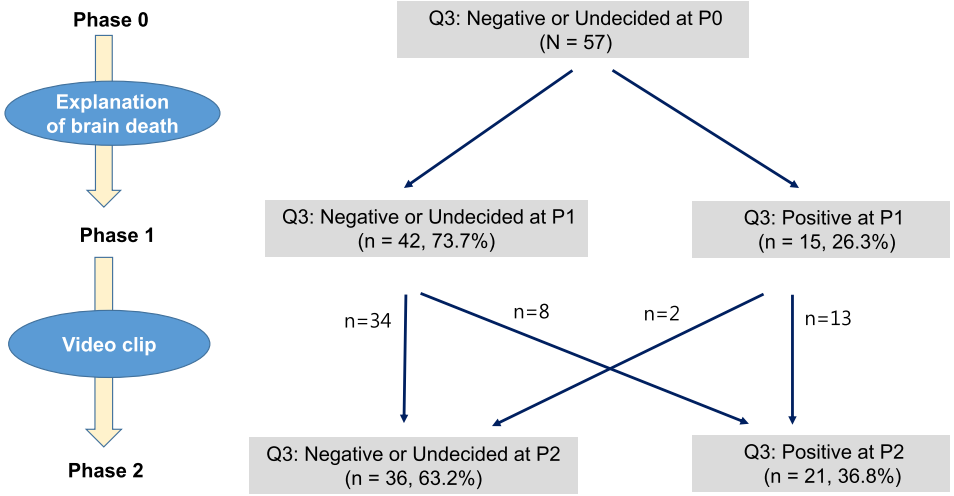

Figure 2 Change in willingness to donate a family member's organs according to education in participants who were negative or undecided at the pre-education phase (N = 57).

toward organ donation are based on ignorance or a lack of information. Without eroding autonomous determination, the phased education in this study reduced the discrepancy between people's attitudes and willingness to donate. However, the relatively low consistency with regard to donating a family member's organs compared to donating one's own organs remains a critical barrier to overcome. Our findings justify the need for routine use of public education or family counseling, especially in East Asian countries where the system for organ donation after brain death is not well-established.

One of the inquiries in this study states, "What is the appropriate target population of this phased education considering the effect on willingness to donate?" If this education is effective in changing the decision of organ donation from one's own body, but its effect is limited on organ donation from a family member's body, then the appropriate education target is the general population, not the families of patients in intensive care units. Although most potential donors are found in intensive care units, this seems to be an inappropriate situation for counseling and education of family members. Efforts to increase registered organ donors are more effective and education needs to be targeted at all levels of the population, from high school upwards, so that organ donation is regarded as a natural end of life decision. The less significant effect of education on the decision to donate a family member's organs in this study demonstrates how inefficient the system of East Asian countries is. However, the opinion of the public in East Asia was more positive than expected and the effect of education on own organ donation in this study suggests that a focus on public education and expansion of donor card system is the most effective strategy.

Traditionally, in East Asian cultures, especially in Korean, Japanese, Taiwanese and Chinese cultures, there has been a belief that the body should not be tampered with after death, which originates from a Confucian tradition. It is believed that this tradition may be the main reason behind the low consent rate for organ donation observed in East Asian countries. In addition to cultural differences, it is thought that widely differing opinions, perceptions, and concerns may be related to organ donation. According to the high proportion of positive response on donating their own organs in this study, the public attitude appears to be at a mature stage. Further study is needed to identify specific perceptional barriers against organ donation in East Asia. I do believe that the organ donation can be increased to the level of Western countries with systemic and strategic efforts in East Asia.

This study had several limitations. First, with only 92 participants, the sample size was small, so it is difficult to generalize the findings of this study to the general population. Second, there may be some bias in the participants' attitudes. Family members of patients who are admitted to SICU were invited to participate in the survey by either nurses or physicians. Some selection bias may have occurred during this process. Third, this study cannot account for the effect of emotional stress on families whose relative has been diagnosed with brain death. In real situations where such families have to make a decision about organ donation, the effect of education may be much more limited due to the state of emotional shock they may be in.

In conclusion, the phased education in this study was effective in increasing positive attitudes toward organ donation and willingness to donate one's own organs. However, it was less effective concerning the willingness to donate family members' organs. The phased education had a positive effect on increasing the consistency rate between attitudes toward donation and willingness to donate both one's own and a family members' organs.

Authorship

Ui Jun Park: data collection, data analysis, preparation of manuscript.

Sang Youb Han: data collection.

Kum Hyun Han: data collection.

Se Won Oh: data collection.

Hye-Yeon Jang: data collection, data analysis, data interpretation.

Hyoung Tae Kim: data collection.

Young-Nam Roh: study design, data collection, data analysis, data interpretation, preparation of manuscript, literature analysis.

Ethical approval

This study was reviewed and approved by the institutional review board (No. IB-1310-038).

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Conflicts of interest

The authors have no declared conflicts of interest.

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None.

Appendix 1. The questionnaire on attitudes toward organ donation.

Survey for Attitudes toward Organ Donation and Willingness to Donate after Brain Death

Thank you for your time.

The researchers of Ilsan-paik hospital transplantation center are conducting a survey for organ donation after brain death. This questionnaire was designed to identify attitudes and willingness about organ donation. Please read the question in the questionnaire carefully, and check the appropriate answer based on your perceptions and thoughts. During this survey, we will explain briefly about brain death and show you a short video clip about organ donation after brain death.

I would appreciate your cooperation if you give us your frank opinions. Your responses without prejudice, not affected by any other factors are critical for successful research. You are free to withdraw from this survey at any time if you feel uncomfortable about this subject.

We will use the survey data only for research purposes in accordance with relevant law, and we promise that all information will be kept anonymous so that you will not suffer any disadvantage to your personal information.

The following items are questions about your personal information. All content is for research purposes only and will remain anonymous.

Age:

Sex (Male / Female)

Religion (Catholic / Christian / Buddist / etc / None)

Education (College graduate / High school graduate / Middle school graduate / Elementary school graduate)

Relationship with the patient (Parent / Spouse / Descendant / Not immediate family) Marriage status (Yes / No)

Do you trust hospital staff now? (Yes / No)

What is your posthumous body disposal preference? (Cremation / Burial)

Do you know the meaning of brain death? (Yes / No)

Have you had any previous experience with promotional materials on organ donation previously? (Yes / No)

The following items are questions about your perception of organ donation.

Q1. Do you think positively about organ donation after brain death?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Q2. If you suffer brain death, do you have an intention to donate your organs?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Q3. If a family member suffers brain death, do you have an intention to donate their organs?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

After listening to the explanation about brain death, please answer the following questions.

Q1. Do you think positively about organ donation after brain death?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Q2. If you suffer brain death, do you have an intention to donate your organs?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Q3. If a family member suffers brain death, do you have an intention to donate their organs?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

After watching the video clip, please answer the following questions.

Q1. Do you think positively about organ donation after brain death?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Q2. If you suffer brain death, do you have an intention to donate your organs?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Q3. If a family member suffers brain death, do you have an intention to donate their organs?

1.Strongly negative / 2.Negative / 3.Undecided / 4.Positive / 5.Strongly positive

Appendix 2. Contents of phased education.

A. Verbal education about brain death (Content between phase 0 and phase 1).

"Brain death" is a state in which the entire brain including the brain stem with the heart temporarily supported by its automatic beating. This is different from the commonly known "vegetative state," which involves on the cessation of a part of cerebral function. It can allow spontaneous breathing, survival for months to years, and even clinical recovery. However, in the case of brain death, all brain functions are permanently stopped and there is no possibility of recovery. Inevitably, after a period of time (several days to weeks), the heart's automatic beating stops and the heart gives out. Brain death is regarded as a form of established medical death.

	Brain death	**Vegetative state**
Damaged area	Entire brain, including brain stem	Part of the cerebrum
Mental state	Coma	Unconscious state
Dysfunction	All brain functions	Memory, thinking, some brain functions
Respiratory condition	No voluntary breathing	Possible spontaneous breathing
Prognosis	Circulatory death (several days to weeks)	Possible survival and recovery (several months to years)

B. Educational video clip (Content between phase 1 and phase 2).

Title: The power of your gift can save a life.

Narration: Do you believe in miracles? This is the love story of a 22-year-old angel. She was strong, warm, and beautiful. But we cannot see her anymore. She taught us about hope, freedom, and dreams.

Statement of patient1's wife: "It is well over a decade ago since he was diagnosed with kidney disease. He did not know it at first. I took him to hospital, and he was already in kidney failure. He has been on hemodialysis for years. It was so hard to see him so sick. But, a hope came to us in the dark. There was a light. There are miracles in the world."

Statement of patient2 : "I was always tired. My arm and legs became swollen. One day, I suddenly collapsed in front of my house. The doctor said that I would not live unless I got a transplant. I was frustrated. But, one day, suddenly, a miracle happened, like in a dream. A donor appeared."

Statement of patient2's daughter: "My mom was healthy. She didn't even need glasses until she became sick. …..It was so painful to see her and my heart was so broken that I couldn't really do anything. But then, a miracle happened by the power of man. Thank you so much.

Narration: October 28, 2010. Emergency rescue. Ms. Oh Hae-jung was diagnosed with brain death after a traffic accident. Before leaving this world, she donated her heart, liver, kidneys, and corneas to give six patients new lives. Our emergency rescue. Our angel. Thank you so much.

Subtitle: A marvelous work that looked impossible…
A beautiful gift possible with human power.

Narration: The most difficult thing is to say goodbye to a family member. We support donors and families who create the miracle of saving a life.
The number of people on the transplant waiting list has reached 17,000. In 2009, 261 organ donors gave new life to 1135 patients. The organ donation agency will comfort and support the families of brain dead donors.

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