

Care and Support for Organ Donor Families

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Abstract

This report describes the importance of perceiving brain death as “terminal phase of life in the acute stage” when medical professionals provide care and support to the donor family, while considering the significance for the donor family to overcome their grief and consent to organ donation when their loved one is unfortunately pronounced brain dead. From the terminal phase viewpoint, the basic treatment toward the patient’s family should be considered the same regardless of whether or not there is organ donation. Then, if organ donation is decided, the donor family must be treated with special considerations. This report points out the key points and problems involved when pronouncing brain death and presenting the option of organ donation during the entire process from the donation until leaving the hospital. In acute care that has no time to spare, it is important to repeatedly explain the seriousness of the patient’s condition including the possibility of death from a relatively early stage and to provide sufficient explanation and consultation when faced with difficult decisions, such as the diagnosis of brain death, the propriety of life-sustaining treatment, and the option of organ donation.

Key words Brain death, Organ donation, Donor family care, Terminal care in the acute stage

Introduction

The revised Organ Transplant Act enforced in July 2010 brought substantial changes in the organ donation system by brain-dead donors in Japan. More specifically, the following 3 changes were made: 1) organ donation became possible with consent from the family alone even without the patient’s donor card, 2) organ donation from children less than 15 years of age became possible, and 3) prioritized use of donor organs to the first-degree family members was approved. These important changes in the conditions of organ donation by the revised Organ Transplant Act have led to a prominent increase in organ donors in Japan while causing various repercussions in the areas that are involved in organ donation by brain-dead donors. As of December 2010, there have been 29 cases of organ donation by brain-dead donors since enforcement of the revised Act.

However, in Japan, only about 50% of the population accepts brain death as death according to a public-opinion poll, suggesting that national consensus has not yet been reached. Under these circumstances, a diagnosis of brain death is rarely made in daily clinical practice in medical institutions, except as a legal diagnosis for the purpose of organ donation. As an inevitable consequence, organ donation cases accumulate while doctors lack the experience to care and support the family of a donor (or a donor candidate) during the process of organ donation, which includes pronouncing brain death, presenting the option of organ donation, and the removal of organs. This fact deserves further attention because how grief care is provided to donor families, both during the process of removing organs and thereafter tends to be neglected. This report discusses proper care for families of organ donors (or donor candidates) during the entire process from the pronouncement of brain death until organ donation

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in the new era brought about by the revision of the Organ Transplant Act.

Relationship Between Brain Death and Organ Donation

The use of organs from brain-dead donors is a medical procedure that first emerged from the need of allogeneic organ transplantation medicine, which requires organs such as the heart, lungs and liver to be collected from human bodies with beating hearts. As a consequence, there is the view that the state of brain death itself began to attract attention on the premise of organ donation and transplantation. As a result, discussing brain death without referring to the issue of organ transplantation is questioned by some people.

However, from the viewpoint of medical professionals who treat patients with intracranial lesion, it is inevitable that some patients among many who have severe intracranial lesion will unfortunately fall into a state of brain death, and some of these brain-dead patients become donors after being so diagnosed or after cardiac arrest. The issue of organ donation accounts for only a small part of the overall care for brain-dead patients and their families. That is, medical procedures for patients who are in a state of brain death and have no chance of recovery with any treatments should be seriously discussed by physicians who are involved in the treatment of brain disease, such as neurologists, neurosurgeons, and emergency medicine specialists, regardless of whether there is organ donation or not. The issue of proper care for the family who is involved with organ donation is to be considered in such discussions as well. The opinion of transplant physicians should basically be the same, and some transplant physicians clearly state that the diagnosis of brain death is a part of medical practice and has no relation to organ donation.¹

The fact that making a diagnosis of brain death is not necessarily associated with organ donation indicates that a number of patients exist who are in a state of brain death and not related to organ donation. In actuality, such non-donating brain death (NDBD) patients are overwhelmingly greater in number than donating brain death (DBD) patients. For medical professionals who are engaged in the treatment of intracranial

lesion, care for NDBD patients and their families is the priority, and care for DBD patients is seen as an extension of this care. Needless to say, maturation of experience, knowledge, and ethics in the care for NDBD patients and their families form a basis of care for DBD cases. In brief, only through the experience of “the diagnosis of brain death and the care for the family” in NDBD cases that unfortunately happens, proper care for DBD cases can be achieved.

As mentioned previously, not many medical institutions diagnose brain death in NDBD cases of as a general rule. The review of previous organ donations from brain-dead patients in Japan revealed that, especially during the early years, some medical institutions that lacked in necessary experience with brain death diagnosis in NDBD cases and care for the families proceeded to organ donation and made errors unthinkable for experienced medical teams from time to time, which became the subject of enormous criticism. The guideline for operation of Organ Transplant Act,² which was presented at the same time as the Act, prescribes that the legal diagnosis of brain death be made by a physician with abundant experience in diagnosing brain death in a hospital where whole-hospital consensus has been reached. To begin with, the guideline strictly warns not to allow any organ donation from brain-dead patients in medical institutions that do not practice the diagnosis of brain death in NDBD patients.

Some institutions are under the false idea that the diagnosis of brain death is no longer allowed except for a legal diagnosis since Organ Transplant Act was enacted in 1997. However, the guideline clearly specifies that a clinical diagnosis of brain death that is not associated with organ donation from brain-dead patients is still allowed. Thus, only those institutions that practice the diagnosis of brain death in routine clinical practice would have physicians with sufficient experience in brain death diagnosis—and, that in turn means that other institutions do not satisfy the requirements of the guideline. In this sense, it can be said that many hospitals in Japan that are considered as donor facilities are not ready for organ donation from brain-dead patients.

From these aspects, this report focuses on the general diagnosis of brain death and care for the family in cases of NDBD, and as an extension of such cases, discusses care and support for the

family of DBD cases.

Terminal Care for Patients with Acute Disease

The most important issue when discussing the treatment of brain-dead patients may be consolidated into one key phrase, “terminal care for patients with acute disease.”

The 4 basic principles of in the past discussion of “terminal care” were: 1) to provide adequate information on the disease state and to offer counseling regarding treatment policies to the patient and the family (informed consent), 2) to allow adequate time to consider the provided information and treatment policies, 3) to respect the patient’s own will as much as possible (avoidance of paternalism), and 4) to provide grief care for the patient and family. However, in cases of brain death resulting from serious brain damage due to stroke or an accident, the patient and family are abruptly faced with the end of life in the situation where none of the aforementioned basic principles have been established. In such cases, it is not possible to provide information to the patient him/herself, and therefore, the family is usually given an explanation of the patient’s condition that severe brain damage is in progress, along with the information on emergency surgery and procedures. As the patient’s condition continues to deteriorate, the family has no time to fully consume the provided information and often unable to do anything but accept the treatment policies offered. When treatment progress is unsatisfactory, the patient usually falls into a state of brain death within 2 to 3 days. In such case, the family must also face the incomprehensible concept of “brain death” without sufficient time to truly grasp the concept.

Considering the common progress of acute disease as described above, the items 1 to 3 of the basic principles of “terminal care” must be abandoned when dealing with acute cases.³ Nevertheless, because the patient’s condition is steadily approaching the state of “brain death” from which recovery is impossible, awareness of “terminal care for patients with acute disease” is required. The only terminal care procedures available for physicians and nurses in charge of the patient’s treatment are to repeatedly discuss the patient’s condition with the family to help them understand the situation and provide grief care for the family

members. It is crucial to carry out these responsibilities with enough sincerity and faithfulness.

Care for Families of Brain-dead Patients

Being in the position to actually diagnose brain death and notify the family would reveal that it is not a simple process of medical practice composed merely of accurately presenting the result based on strict medical diagnosis to the family. The family repeatedly experiences stressful processes when their family member suddenly suffers severe brain damage—while they experience complex feelings of consternation, grief, dismay and anxiety, the family will have to listen to a series of explanations about the possibility of brain death, significance of the brain death diagnosis and giving consent to the diagnosis, the results of the diagnosis, and treatment policies. As mentioned previously, what is required here for medical professionals is to respond to the family with the awareness of “the terminal phase of life” in the acute stage, which in itself a unique situation. Medical professionals including physicians and nurses must not simply repeat medical information but make due consideration for the family throughout entire stages of explanations.

If physicians do not make a brain-death diagnosis in a presumably brain-dead patient, provide vague information and poor explanation on treatment policies to the family members, and reduce the level of intensive care arbitrarily merely at their own discretion, there is obviously no chance that grief care and other types of support for the family will be provided. Under such circumstance, we may see the tragic scenario, in which medical professionals do not talk to the family enough because it is also painful for them, the family in need of care becomes isolated and alienated with no one to share their unexpressed anxiety and dissatisfaction, and consequently, the family has no choice but to keep watching the gradually weakening patient despite medical treatment. To the patient’s family who are in extreme grief, words of comfort and encouragement from medical professionals will sound empty and may even increase their anxiety unless the family do not perceive their attitude as sincere and whole-hearted.

Brain death differs greatly from the terminal phase in other acute diseases. The functional fail-

ure of the target organ can be clearly confirmed to be irreversible, by following a strictly medical process based on the criteria for diagnosing brain death (disappearance of the brain-stem reflexes, respiratory arrest, electrophysiological findings including electroencephalograms (EEG) and auditory brain stem response, findings of cerebral blood flow tests including cerebral angiography and SPECT as needed, etc.). If necessary, the status of functional arrest can be clearly shown to the family through visual records of EEG or cerebral blood flow tests. Therapeutic limits can also be predicted for functional failure of other organs such as the heart, lungs, liver, and kidneys if examined professionally. However, only the diagnosis of brain death allows clear demonstration of irreversible failure of the organ in a combination of number of diagnostic tests. Because the diagnosis and the resulting prognosis are absolutely certain, physicians should make efforts to diagnose and explain the results as fully as possible in cases of brain death as the sincere care of medical professionals.

The faith of the family in the physician is strengthened through sincere conversations—for example, when the physician explains about “brain death,” the harshest reality for the family, or in some cases discusses the propriety of life-sustaining procedures after brain death is confirmed.⁴ In my own experience, there have been no families who showed feelings of discomfort with the brain death diagnosis and its explanation. Without conducting the brain death diagnosis, explanation to the family who clearly does not favor life-sustaining procedures becomes vague, and it was exceptionally difficult to build trust with the family. Shigemura et al.,⁵ who studied psychological changes in the families of brain-dead patients in specific, stated that explaining the harsh situation in an earlier stage allows many families to anticipate worst possible outcome and allow time to prepare. In other way of saying, the fundamental principle of grief care in an extreme state is to give an honest explanation of the reality, however harsh it is, and exhibit a good understanding of the family’s feelings.

As mentioned previously, infrequent meetings and vague explanations by the physician do not help build trust between the physician and the family. Instead, the family may develop sense of isolation or alienation and become offended by or feel critical of medical professionals. Their

hatred for the disease afflicting the patient or the person who caused trauma to the patient may become transferred to medical professionals.

Care and Support for Organ Donor Families

Before making the official diagnosis of brain death in a patient who is presumably in a state of complete brain death including respiratory arrest (note: the term “clinical death” was used for this condition before the revised Organ Transplant Act was enforced), the option of organ donation are to be presented to the patient’s family. Many argue that it is mentally difficult for medical professionals to change the focus abruptly from explanation and counseling about treatment to explanation of postmortem issues. However, the family will begin to trust the physician and accept the explanation that the condition is untreatable after going through the process of the brain death diagnosis and pronouncement of the worst condition. Although the psychological resistance is understandable, in most cases it is not an issue on the family’s side, but rather an issue on the medical professionals’ side. Considering that explaining the brain death diagnosis procedure already assumes the worst outcome by itself, the physicians’ hesitation of toward suggesting the option of organ donation may be the reflection of the fact that no explanation of the brain death diagnosis has been offered.⁴ In the real clinical settings, the physician can suggest the option of organ donation without causing an excessive burden on the family by merely saying to the family, “I don’t mean to offend you, but if you are interested in organ donation, let me know anytime and I will contact a transplant coordinator.”

As mentioned repeatedly, the physician should assume the responsibility of providing grief care for the family when explaining the disease status and discussing treatment options in the course of treatment from the state of brain death to organ donation. Medical professionals should keep in mind the fact that the more frequent the meetings with the family, the more relief they experience.^{6,7} Naturally, physicians, nurses and other medical professionals are required to treat the family with a good knowledge of changes in the psychological conditions of the family during the process. The family shows various psychological reactions when brain death is pronounced.^{5,6,8}

While pondering over certain degree of distrust and sense of alienation, the family may think of preserving the dignity of the patient, wonder if they are being obsessive about the patient's life, or think that they should accept the patient's fate—and, the family might be swayed between the thought that organ donation is a philanthropic act and the feeling that not donating organs is a sign of egoism.⁹ The actions of medical professionals should take into account the sensitivity of the family. First of all, arrange to meet the family as frequently as possible. Listening to their feelings without criticism, answering their questions courteously, always showing sympathies to the family, and allowing someone from the family to be at the patient's bed side as long as possible, are all important. Having a nurse to confirm that the family fully understands the physician's explanations is also advisable. Some institutions propose both the family and nurses care for the patient together and had some success.

Whether the family accept or rejects organ donation, medical professionals should respect their decision and continue to provide grief care until the patient passes away. In particular, hospital staff often become too busy to properly care for the family during the period from organ removal to hospital departure, so a staff member should be assigned to care for the family during this period.

In caring for the donor family after sending off the patient, attention tends to focus on the special fact that organs have been donated. However, they are also individuals who lost a family member, and they should be treated with sufficient knowledge of the psychological process of bereavement. When excluding the psychological changes during the so-called times of bereavement and after death, Corr et al.¹⁰ showed that the acceptance of bereavement is achieved through 4 tasks: 1) accepting the reality of loss,

2) working through the pain of grief, 3) adjusting to an environment without the deceased, and 4) recognizing the continuing relationship with the deceased. They also stated that these tasks should be applied to the donor family as well.

Although care of the donor family after the send-off is usually provided by the donor coordinator to some extent, the results of a questionnaire survey revealed that some donor families request for follow-up care from hospital staff after the send-off. Medical institutions face many difficulties providing such follow-up care, but this matter remains as future issue since the number of brain-death organ donations is expected to increase. Proper care for the donor family, while considering their psychological changes after bereavement, deserves further consideration.

Conclusion

This report discussed the importance of perceiving brain death as “terminal phase of life in the acute stage,” and then described key points in the fundamental aspects of general care for the families of brain-dead patients, proper care when pronouncing brain death and presenting the option of organ donation, and necessary care for the donor family members around the time of donation and after the send-off.

I particularly wish to emphasize the importance of repeatedly explaining the seriousness of the patient's condition including the possibility of death to the family from a relatively early stage, even in an acute case that is subject to time constraints. Full explanations of complicated issues such as brain death diagnosis, the propriety of life-sustaining treatment, the option of organ donation, are also important. Care and support for the family should be provided based on a sufficient understanding of the significance of these issues.

References

1. The 15th World Congress of the Transplant Society 1994. Counterargument to criticism against organ transplantation. *Transplant Communication*. 1994;4(November 29 Issue). (in Japanese)
2. Study Group of the Organ Transplant Act in the Health Service Bureau, Ministry of Health and Welfare of Japan (ed). *Notices of Applicable Laws and Regulations Concerning Organ Transplantation*. Tokyo: Chuohoki Publishing Co., Ltd.; 1998. (in Japanese)
3. Sato A. Ideal aspect of the terminal phase of life: In terms of the education of students and clinical practice. *The Proceedings of the 40th Liaison Conference of Medical University Ethics Committees*; 2009:71–79. (in Japanese)
4. Aida K. Withholding and discontinuation of life-sustaining treatment: from the viewpoint of patients' benefit and psychological burden of doctors. *Journal of Clinical and Experimental Medicine*. 2008;226:809–814. (in Japanese)
5. Shigemura T, Yokota H, Kushimoto S, et al. A study of the

- mental process of the families of clinical brain-dead patients. *Brain Death & Resuscitation*. 2008;20:63–67. (in Japanese)
6. Takayama Y, Sakai A, Iwata H, et al. A study on the mental state of the donor families after making a decision to donate organs under the clinically brain-dead condition—the mental state by the intervention of others. *Brain Death & Resuscitation*. 2007; 19:123–130.
 7. Deeken A, Kunio Y (ed). “Sudden Death” and Grief Care. Tokyo: Shunjusha Publishing Company; 2005. (in Japanese)
 8. Bellali T, Papazoglou I, Papadatou D. Empirically based recommendations to support parents facing the dilemma of paediatric cadaver organ donation. *Intensive Crit Care Nurs*. 2007;23: 216–225.
 9. Long T, Sque M, Addington-Hall J. What does a diagnosis of brain death mean to family members approached about organ donation? A review of the literature. *Prog Transplant*. 2008;18: 118–125.
 10. Corr CA, Coolican MB. Understanding bereavement, grief, and mourning: implications for donation and transplant professionals. *Prog Transplant*. 2010;20:169–177.