

Revised Organ Transplant Act and Neurosurgeons

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Abstract

Cases of brain-dead organ donation have been increasing since the revised Organ Transplant Act took effect. While neurosurgeons routinely engage in the treatment of stroke and severe head injury potentially leading to brain death, those at organ donation facilities also take part in the processes from the legal diagnosis of brain death to organ donation. A questionnaire survey at the time of the enforcement of the revised Organ Transplant Act revealed that many neurosurgeons at organ donation facilities strongly felt burdened by the manpower, time, and psychological demands of organ donation. Furthermore, there are many new challenges such as organizational preparedness to deal with organ donation from brain-dead children. The Japan Neurosurgical Society announced its basic position regarding the provision of support to the legal diagnosis of brain death at organ donation facilities and the practice of organ donation. It plans to establish committees to support brain death diagnosis at the seven branches of the Society in the country.

Key words Neurosurgery, Brain death, Diagnosis of brain death, Organ donation, Law amendment

Introduction

After the revised Organ Transplant Act (hereinafter referred to as the revised Act)^{1,2} fully took effect on July 17, 2010, the number of brain-dead organ donations increased up to 29 cases by the end of December. The number in those five months far exceeded the highest previous record of brain-dead organ donation in one year (13 cases). There had been about 80 cases during the 12 years from the enactment of the Organ Transplant Act in 1997 to July 2010. As expected before the law amendment, this cumulative number may be surpassed by new cases within one year. As the Declaration of Istanbul (The Transplantation Society, May 2008)³ has effectively prohibited transplant tourism, the possibility of patients receiving organ transplantation abroad has become extremely limited. In this situation, the current development provides a glimmer of

hope for those patients who have no treatment options other than organ transplantation.

On the other hand, because brain death frequently results from stroke and severe head injury, neurosurgeons who are engaged in the diagnosis and treatment of these conditions are burdened by the heavy responsibilities and tasks relating to brain death diagnosis and organ donation in addition to their daily practice. As the revised Act permits organ donation from brain dead children based on the intention of family members, it is necessary to develop a system for the diagnosis of brain death in children and the appropriate response to possible cases of child abuse.

Based on the urgent questionnaire survey performed by the Japan Neurosurgical Society (JNS), this article discusses how neurosurgeons engaged in the treatment of cranial nerve disorders at organ donation facilities should deal with brain-dead organ donation, focusing on the

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problems after the enforcement of the revised Act and the response of the JNS.

The Urgent Questionnaire Survey on the Response to the Revised Act

Purpose and methods

The purpose of the survey was to identify the present state, problems, and requests regarding organizational preparedness and to provide input for the appropriate response of the JNS so that the specialist training facilities affiliated with the JNS and the members of the Society may properly participate in brain death diagnosis under the revised Act. Specialist training facilities affiliated with the JNS (385 Item A facilities and 739 Item C facilities; 1,124 in total) were subjected to the survey. Questions covered 1) the status of organizational preparedness for performing the legal diagnosis of brain death and organ donation after the enforcement of the revised Act (for adults and for children), 2) past experience in organ donation and the burden of brain-dead organ donation, 3) the reason for a lack of organizational preparedness, 4) the policy for proposing organ donation options, and 5) the need for support from the JNS. Questionnaires were sent via mail and answers were collected via facsimile. Answers were received during a 15-day period

from July 8 to 22, 2010.

Item A facilities among the JNS specialist training facilities are fully competent facilities performing many operations and are independently capable of providing specialist training. Item C facilities fall short of the requirement for Item A accreditation in terms of staffing and the number of operations, and cannot function independently as training facilities. Item A facilities are listed among the four types of brain-dead organ donation facilities recognized by the JNS.

Results

Answers were obtained from 720 facilities (response rate 64%). Of these, 233 facilities answered that they were Item A facilities and had been brain-dead organ donor facilities before the revised Act took effect. The following summarizes the results of analysis of answers from these facilities.

Organizational preparedness to perform the legal diagnosis of brain death and organ donation after the enforcement of the revised Act

Responding to the question as to whether they were prepared to perform the legal diagnosis of brain death and organ donation after the enforcement of the revised Act, asked separately for adults and for children, 206 of 233 facilities (88%) answered positive for adults and 39 of 233 facilities (17%) answered positive for children (Fig. 1).

Past experience in organ donation and the burden of brain-dead organ donation

Of the 39 Item A facilities that had established organizational preparedness both for adults and for children, 12 facilities (31%) had experience in brain-dead organ donation and 24 (62%) had experience in organ donation after cardiac arrest.

When these 39 facilities were asked about the burden of brain-dead organ donation, 92% answered very burdensome (20 facilities, 51%) or burdensome (16 facilities, 41%) (Fig. 2, left). The leading causes of burden were time (35 facilities) and manpower (34 facilities), followed by mass media relations (16 facilities), heavy responsibilities (14 facilities), and financial burden (11 facilities) (Fig. 2, right).

The reason for lack of organizational preparedness and the plan for future improvement

Many of the 194 facilities that lacked organizational preparedness for adults or children identi-

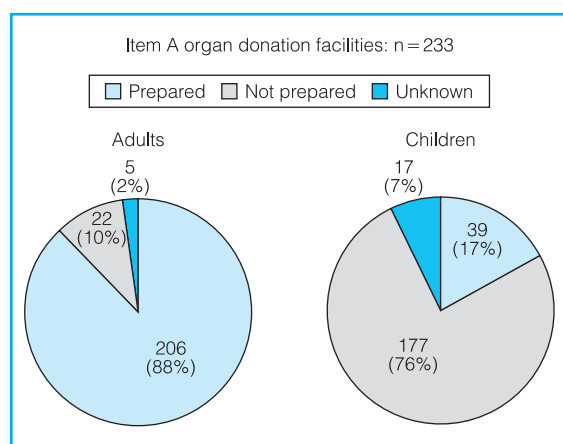


Fig. 1 Organizational preparedness to conduct the legal diagnosis of brain death and organ donation after the enforcement of the revised Organ Transplant Act (July 17, 2010)

The organizational preparedness for adult donors and child donors, respectively, was established at 88% and 17% of Item A organ donation facilities.

fied issues specific to children (diagnosis of brain death in children, response to child abuse) as the reason for not being prepared (Fig. 3).

With respect to the plan for future improvement, 75 (39%) of the 194 facilities lacking preparedness had improvement plans. Of these, 54 facilities planned to establish preparedness within half a year.

Policy for proposing organ donation options

An organ donation facility is required to propose organ donation options when a person without a donor card becomes brain dead. One question

asked how this proposal would actually be made. Answers showed it would be made by the patient’s attending physician (81 facilities, 35%), would be made by a separate team (13 facilities, 5%), would be made by somebody depending on the medical condition (76 facilities, 33%), and would not be made (38 facilities, 16%), while 25 facilities did not answer this question. Overall, 170 facilities (73%) answered they would propose options in some way (Fig. 4).

Need for support from the JNS

The question regarding what support should be

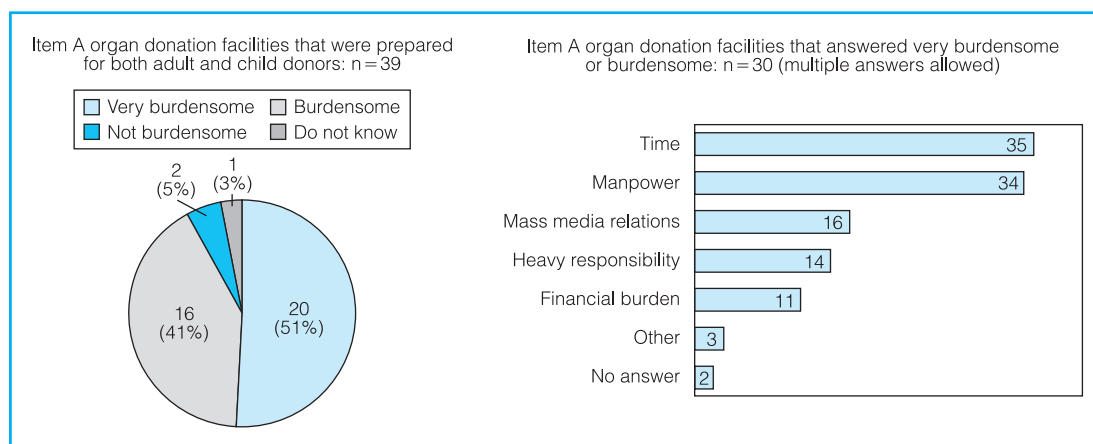


Fig. 2 Burden of brain-dead organ donation and its reasons

The answers from Item A organ donation facilities that were prepared for both adult and child donors showed that 92% of these facilities felt burden, including 20 (51%) that answered “very burdensome.” The leading causes of burden were time (35 answers) and manpower (34 answers).

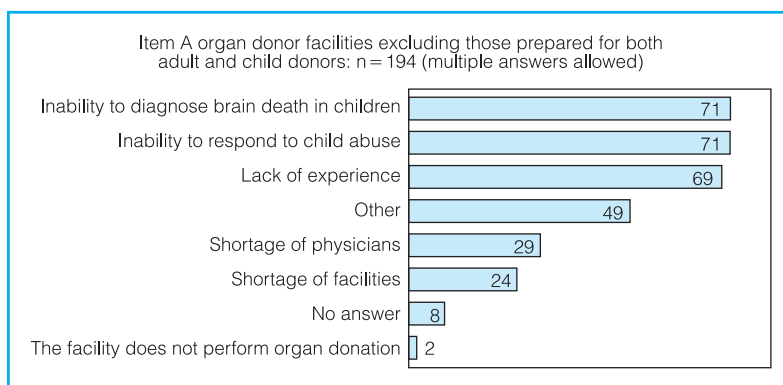


Fig. 3 Reasons for a lack of (or unknown) organizational preparedness for adult and child donors

The reasons for not prepared were mostly the issues specific to child donors (brain death diagnosis, response to child abuse).

provided by the JNS (multiple answers) identified the need for comprehensive support from JNS branches, technical support in brain death diagnosis including the dispatch of experts, support in Electroencephalogram (EEG) testing, and telephone consultation (Fig. 5).

Discussion of Survey Results

The organizational preparedness to conduct brain-dead organ donation under the revised Act was established for adult donors and child donors, respectively, at 88% and 17% of the facilities that had been registered as brain-dead organ donation facilities before the enforcement of the revised Act. This result highlighted a lack of preparedness for child donors. The reason for not being prepared for child donors included the inability

to diagnose brain death in children, the inability to respond to child abuse, and a lack of experience. However, 75 (39%) of the facilities lacking preparedness had plans for future improvement. They seemed to need time for establishing child abuse response committees and ethics committees, organizing procedures within hospitals, and developing manuals.

A large majority (92%) of the facilities with established systems for brain-dead organ donation from adults and children felt that brain-dead organ transplantation was burdensome. The reasons were most frequently related to time and manpower. According to past cases of brain-dead organ donation, the entire process from the first legal diagnosis of brain death to the completion of organ extraction takes 45 hours on average and requires much manpower. This fact seemed

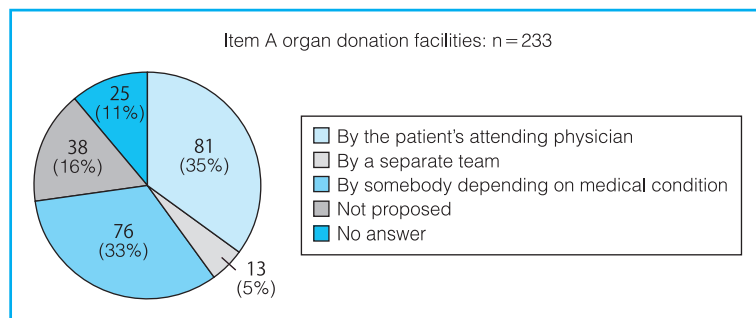


Fig. 4 Policy for proposing organ donation options

The question asked who would propose organ donation options when a person without a donor card becomes brain dead. While 170 facilities (73%) answered that organ donation options would be proposed to family members, only 35% answered that the proposal would be made by the patient's attending physician.

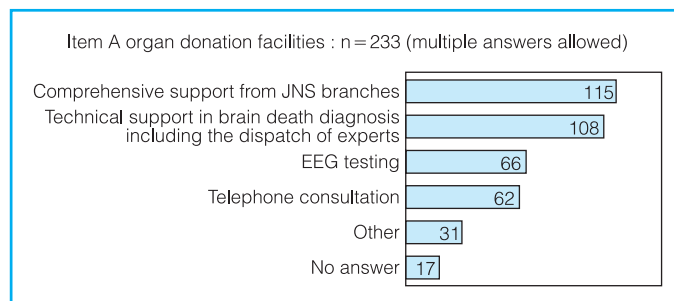


Fig. 5 Need for the support from JNS

Many answerers mentioned the comprehensive support from JNS branches, technical support in brain death diagnosis, support in EEG testing, and telephone consultation.

to increase the burden on organ donation facilities. Many of the facilities registered as brain-dead organ donation facilities felt the need for support from the JNS. In particular, they mentioned the need for comprehensive support from JNS branches, technical support in diagnosing brain death, support in EEG testing, and telephone consultation.

The Daily Practice of Neurosurgeons and the Problems of Brain-dead Organ Donation

In their daily practice, neurosurgeons strive to save the lives and brains of patients in critical conditions with stroke, head injury, brain tumor, etc., exerting their best efforts in performing operations and other treatments. Many neurosurgeons recognize that once a patient becomes brain dead (whole-brain death involving the cerebrum and the brain stem), it is irreversible, recovery never occurs, and cardiac arrest is inevitable. Therefore, when maximum treatment efforts have failed to prevent the development of extensive brain damage and clinical whole-brain dysfunction, leaving the patient in a condition close to brain death, the patient's attending neurosurgeon, although having a sense of loss and powerlessness, calmly explains the situation to family members and asks them whether or not they want life-sustaining treatment including intubation, the installation of a respirator, and the use of a vasopressor drug. For the neurosurgeon, brain death marks the end of efforts toward cure.

Recently, the families of patients at advanced ages and those who have been ill for many years often opt for a "do not resuscitate" (DNR) and allow death to occur in the natural course avoiding brain death. On the other hand, there would be an increasing number of cases where the family of a patient who became brain dead is told the fact that brain-dead organ donation is an option. The attending physician providing and the family listening to the explanation both enter a realm that is worlds apart from treatment discussion, and it may be difficult to propose organ donation options in some cases. Indeed, the questionnaire showed that organ donation options are proposed by the patient's attending physician at only 35% of facilities. It is necessary to avoid placing too much responsibility and burden on the attend-

ing physician. There should be help from other members of the care team, as well as actions and support appropriate for individual cases.

Once the case actually proceeds to brain-dead organ donation, the attending physician and the organ donation facility bear even more responsibility and burden, as the survey demonstrated. This is because the process from brain death diagnosis to organ donation requires much manpower and time (45 hours in average). If organ donation should hamper daily clinical practice and stop or compromise the function of the hospital, it is a serious problem for the healthcare system and needs to be corrected.

The Basic Position and Response of the JNS

In response to these survey results and other information on the actual situation, and also to be able to cope with the expected increase in the cases of legal diagnosis of brain death and organ donation, the JNS decided to clarify its basic position and response as an academic society involved in brain-dead organ transplantation. "The Basic Position and Response of the Japan Neurosurgical Society Regarding Brain-dead Organ Transplantation" was proposed at the Society's committee on brain death and the board of trustees, and was approved at the 69th Annual Meeting of the Japan Neurosurgical Society (October 27, 2010, Fukuoka). It is outlined as follows.

"The JNS supports the legal diagnosis of brain death and the practice of organ donation at organ donation facilities to ensure the fulfillment of their noble decision when organ donation is offered by patients who did not survive despite appropriate treatment and their families. For this sake, the JNS studies the measures to reduce the burden on healthcare workers and facilities involved in the legal diagnosis of brain death and organ donation, the improvement of organizational preparedness, and other issues; and also conducts scientific verification to help resolve the various problems relating to brain-dead organ transplantation. Furthermore, the JNS advocates toward the national government, administrative authorities, and the general public that correct understanding of and support to organ donation facilities are essential to the appropriate conduct of brain-dead organ donation without hampering

the daily clinical practice.”

Based on this basic position, the actions of the JNS were summarized in the following list.

1. Support to organ donation facilities
 - (1) The JNS and its seven branches jointly construct an organization to support organ donation facilities.
 - (2) Develop a system for dispatching experts in the legal diagnosis of brain death, supporters in EEG testing, etc. and for providing advice.
 - (3) Hold educational seminars and workshops and prepare manuals and other materials.
 - (4) Conduct a survey on the actual situation of organ donation facilities, examine problems, and consider solutions.
 - (5) Make proposals regarding the development of emergency care systems at organ donation facilities and the enrichment of personal and financial support.
2. Development of a system for organizational cooperation with the Japan Organ Transplant Network (JOT): A system is developed for cooperation between the JNS and its seven branches and JOT.
3. Cooperation with the national system for brain-dead organ transplantation
 - (1) Strengthen the cooperation with the Office of Organ Transplantation, the Ministry of Health, Labour and Welfare.
 - 1) Participate in the verification taskforce and in the conduct of appropriate transplantation medicine.
 - 2) Participate actively in study groups and committees relating to transplantation.
 - (2) Participate actively in conferences of academic societies relating to organ transplanta-

tion and make proposals as a representative member of the JNS.

- (3) Deliberate the accreditation criteria for organ donation facilities.
4. Academic cooperation
 - (1) Conduct a survey on the cases of brain death in children and examine pathological conditions.
 - (2) Study complementary tests (cerebral blood flow, evoked potential, etc.) for brain death diagnosis.

The Society has already been providing support in several fields such as EEG testing. To provide further support closely responding to the needs of local communities, the JNS plans to establish branch committees on brain death diagnosis at its seven branches in Hokkaido, Tohoku, Kanto, Chubu, Kinki, Chugoku and Shikoku, and Kyushu. Each of these committees will consist of 10 to 20 persons including experts in EEG and other procedures for brain death diagnosis and those experienced in brain-dead organ transplantation and verification procedures.

Conclusion

The increase in the cases of brain-dead organ donation expected from the enforcement of the revised Act is a godsend for patients waiting for transplant opportunities. Neurosurgeons are faced with brain death in their daily clinical practice. To ensure fulfillment of the noble intention of organ donation, they cooperate to the fullest and spare no effort. However, it is desired that a system is developed so that the increase in organ donation will not hamper daily clinical practice.

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