

# Reconsidering Brain Death

## : A Lesson from Japan's Fifteen Years of Experience

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**Abstract:** The Japanese Transplantation Law is unique among others in that it allows us to choose between "brain death" and "traditional death" as our death. This paper reports the ongoing revision process of the current law (as of 2001. See the Note at the end of this paper).

\*Page numbers in the original are marked by [(preceding page) / (following page)].

Western scholars have recently been entertaining doubts about what had once seemed to be a settled consensus among them on the concept of death. In 1997, for example, Robert D. Truog pointed out several problems arising from the concept of whole-brain death and showed us three alternatives, namely, (a) returning to the traditional standard based on the permanent cessation of respiration and circulation, (b) recognizing the objections of particular religious views to the concept of brain death, and (c) giving permission to remove organs from brain dead patients, patients in persistent vegetative states, and anencephalic newborns whether they are alive or not (1). In 1999, Stuart Youngner and colleagues published a collection of essays titled *The Definition of Death* that featured reevaluations from various perspectives of brain death and its alternatives (2). In this book, Robert Veatch argued that we should permit patients to choose "an alternative definition of death provided that it is within reason and does not pose serious public health or other societal concerns" (3). Veatch insisted that whole-brain death should be the default definition of death, but that we should permit, in addition, traditional cardiopulmonary death and higher-brain death as reasonable minority views. Finally, in 2000, Michael Potts and colleagues published another collection, *Beyond Brain Death*, offering further objections to the concept of brain death (4).

This is a strange scene to a Japanese bioethicists. Japan has held nationwide discussions of brain death and transplantation since 1983, and the points that have emerged in the recent Western writings are very familiar there. But American and European bioethicists do not necessarily know of the recent Japanese debates, mainly because of the language barrier. Japan's Organ

Transplantation Law, enacted in 1997, permits people to choose between brain death and traditional death by writing their preference on a donor card (5). It is akin to the “conscience clause” found in New Jersey’s Declaration of Death Act, which Veatch identifies as an attempt to allow people to choose an alternative concept of death, and which Robert Olick said “signals a new direction for the [41/42] development of public policy governing the declaration of death in pluralistic communities” (6).

The Japanese transplantation law permitted organ translation in Japan, but it also generated new problems we had not anticipated.

### **A Brief History of the Japanese Debates**

Japan’s first heart transplantation from a “brain dead” patient was performed in 1968, several months after the world’s first heart transplantation in the Republic of South Africa. However, Dr. Juro Wada, who performed the operation, was accused of illegal human experimentation and also of poor judgment in the determination of death. This event engendered grave doubt about brain death among journalists and the public. The heart “heart transplantation” became taboo for fifteen years.

In 1983, the Ministry of Health and Welfare established an ad hoc committee on brain death and transplantation, which then started to establish criteria for brain death. At the same time, the Japanese Transplantation Society began to publicize the necessity and urgency of organ transplants. In 1985, criteria for brain death were announced. The committee distinguished “medical criteria for brain death” from “the concept of human death” and declared that the latter depended on the consensus of the Japanese people.

Two well-known journalists, Michi Nakajima and Takashi Tachibana, immediately published popular books that criticized the concept of brain death. Nakajima insisted in her book, *Invisible Death*, that ordinary people at the bedside of a family member could not accept brain death because the brain dead patient’s body was still warm and moist (7). She concluded that brain death is an “invisible death” that conflicts with everyday intuition. In *Brain Death*, Tachibana analyzed the medical aspects of the concept of “whole brain death” and concluded that the Japanese criteria for brain death could test only the cessation of the brain’s observable functions, not the actual death of all brain cells (8). He insisted that if some brain cells remained alive after the determination of brain death (which is unknown, since an electroencephalogram cannot detect the activities of cells deep inside the brain), some inner consciousness might exist inside the patient’s brain, just as in cases of “locked-in syndrome.” Their books became bestsellers. Tachibana’s book sold more than 100,000 copies, and more than one hundred other books concerning brain death and transplantation were published from

1985 to the early 1990s.

The Prime Minister's special committee on brain death and transplantation presented its final report in 1992. The committee reviewed the brain death debates of the 1980s and concluded that brain death is human death and that the donor's prior intention to donate organs is necessary for organ removal. But the report also contained a minority opinion that brain death should *not* be considered human death. The objection to brain death was stronger than had been anticipated. In 1994, an organ transplantation bill was presented to the Diet to enable organ removal from brain dead patients if family consent was obtained, but it did not pass. In 1997, two organ transplantation bills were presented simultaneously to the Diet reflecting starkly opposed views of brain death. One, introduced by Rep. Taro Nakayama, stated that brain death is equivalent to human death. The other, introduced by Rep. Seiichi Kaneda, stated that a brain dead patient is still alive but that organs can be legally removed if two conditions are met ---- the donor has made a prior declaration of a desire to donate organs, and the family consents to organ removal. A harsh debate was provoked, and the Kaneda bill was rejected. Yet the Nakayama bill was completely revised, and a unique law passed the Diet (9). In 1999, Japan's second heart transplantation from a brain dead donor was performed (thirty-one years after the first). There have been fourteen transplantation cases from brain dead donors up to the present.

### **Japan's Organ Transplantation Law**

The law does not provide a uniform answer to the question, "What is human death?" Instead, it allows people to choose between traditional death and brain death. The law states that if a person wants to be an organ donor after brain death has occurred, he or she must record that intention on a donor card or label beforehand. That person will then be considered dead when brain death is diagnosed. Those who object to brain death and transplantation do not need donor cards. They are considered to be alive until the heart stops beating. Additionally, family consent is also necessary both for legally declaring death at brain death and for organ removal. Strictly speaking, "family consent" in this law means that the family does not express objections.

Thus in Japan we are free to choose which of two conceptualizations of death will be legally recognized at *our* death. Japan's transplantation law shares this "pluralism on human death" with New Jersey's brain death law, but while New Jersey considers brain death the default definition of death, Japan takes traditional death as the default.

It is illuminating to see how the law is to be applied. First, a patient is "clinically" diagnosed as brain dead in a hospital. It should be noted that a "clinical" brain death diagnosis is to be distinguished from a "legal" brain

death diagnosis. The clinical diagnosis is a tentative one. When a patient goes into a deep coma, for example, physicians try to reach a clinical determination of whether brain death has occurred. The determination does not require an apnea test (that is, a test to see whether breathing has [42/43] stopped) since the test might be detrimental to the patient's body.

If the patient does not have a donor card, or has declared against transplantation, then he or she is considered "alive" until the heart stops beating. Physicians are not allowed to reach a legal diagnosis of brain death (including an apnea test) on the patient.

If the patient has a donor card, and the patient has agreed to brain death and organ donation (and designated the names of transplantable organs on the donor card), then a transplantation coordinator comes and asks the family members if they also agree to legal diagnosis of brain death and organ removal for transplantation. If they agree, physicians start to make a legal diagnosis of brain death following the Japanese criteria for brain death, which include an apnea test. The transplantation team comes in. Organ procurement begins.

There have been long discussions since 1997 of the pros and cons of this law. The law is unique among contemporary brain death laws around the world, but it has created problems we had never thought of before its enactment. Three criticisms have been considered especially important.

First, many critics hold that the concept of human death should be one and universal. According to the law, a patient without any brain functions is "dead" if he or she carries a donor card and the family does not object to the legal brain death diagnosis, but "alive" either if he or she does not carry a donor card or if the family objects to brain death. Critics insist that this variability is inconsistent and irrational. A similar argument was made in the United States, where Alexander Capron called it the problem of a "bifurcated legal standard" (10).

A second criticism has been that requiring the donor's prior declaration is too stringent a restriction. The most important characteristic of Japan's Organ Transplantation Law is that it makes the donor's prior declaration of intent to be an organ donor a necessary condition of organ removal. This means that when a brain dead patient does not have a donor card, physicians cannot remove organs even if the family members entirely agree to transplantation. This restriction may mean that the law does nothing to increase the number of removed organs. In many other countries, by contrast, organs can be removed even if the donor's wishes are unknown, as long as the family members agree to the removal.

The donor's prior declaration principle has a close connection to the law's pluralism on human death. If a brain dead patient lacks a donor card, then we cannot determine whether that patient thought of brain death as human death.

Thus if the physicians make a *legal* brain death diagnosis, they may violate the patient's right to determine his or her concept of human death. Further, such a violation would be a deep wrong: many Japanese think that a person's understanding of death is a very important and deeply personal thing that may be unknown even to a person's family members. This is the major argument for requiring the donor's prior declaration.

The donor's prior declaration principle created a third problem, the problem of qualification as a donor. In Japanese civil law, the will of a person under fifteen is legally invalid. This implies that the donor card written by a child under fifteen is also invalid; hence organ removal is impossible from him or her. Unfortunately, however, the heart of an adult is too big to be transplanted into a child's body. For this reason, small children with severe heart diseases are taken overseas to wait for brain dead child donors. Many people are sympathetic to these recipient children.

These problems notwithstanding, public attitudes about brain death and transplantation seem supportive of the basic framework of the present law. In contrast to the United States, there have been many public opinion surveys in Japan on brain death and transplantation since the 1980s (11). For more than fifteen years, about 40 to 50 percent of the Japanese people have thought of brain death as human death, and about 20 to 40 percent that brain death is not human death.

In May 2000, the Prime Minister's Office conducted a survey of the public views of the donor's prior declaration and family consent requirements (12). In this survey, about 21 percent held that the donor's prior declaration is sufficient for the legal brain death diagnosis and organ removal, and that family consent is not necessary. Seventy percent felt that both the donor's prior declaration and family consent are necessary. Only 2.1 percent felt that family consent alone is sufficient and that the donor's prior declaration is unnecessary.

### **Proposals for Revision**

A supplementary provision in the Organ Transplantation Law stipulated that the law would be [43/44] reconsidered three years after its enactment, in October 2000. Thus several proposals for revising the law appeared last year, and a hot debate started again.

In August 2000, a research group on brain death and transplantation, funded by the Ministry of Health and Welfare, submitted a report to the ministry containing a proposal that had been drafted initially by Saku Machino, a professor at Sophia University and a subdirector of the group (13). The proposal held that brain death is equivalent to human death without exception and that family consent is sufficient for organ removal unless the

brain dead person has previously refused to be a donor. In the case of a minor, the consent of persons in parental authority is sufficient unless the minor brain dead person has previously refused to be a donor. Most importantly, the proposal would deny pluralism on human death and reject the donor's prior declaration principle, both of which are basic to the present law. Moreover, the proposal goes on to assert that every one of us has already made an "inherent self-determination" to be an organ donor. Some diet members and recipient groups supported this proposal.

In December 2000, the Japanese Council for Transplant Recipients announced another proposal that would deny pluralism on human death. This proposal also held that brain death is equivalent to human death without exception, but it asserted that for adults, both donor's prior declaration and family consent are necessary for organ removal. For children under fifteen, the consent of persons in parental authority is sufficient.

Masahiro Morioka, the author of this paper, and Tateo Sugimoto, a child neurologist, officially announced in February 2001 a proposal that had been in the works for some time prior (14). The proposal held that for adults, both donor's prior declaration and family consent are necessary for the legal brain death diagnosis and organ removal, and it went on to recommend that for children under fifteen, similarly, donor's prior declaration plus the prior consent of persons in parental authority be required (15). Thus this proposal took pluralism on human death and the requirement of a donor's prior declaration seriously and tried to extend them to children under fifteen. The proposal came in two variants, one prohibiting organ removal from children under six, on grounds that children under six lack the ability to express their will consistently, and the other raising the age limit up to twelve.

The Morioka and Sugimoto proposal would never force children to express their will concerning brain death and transplantation, however. It simply suggests that we must hear children's own opinions if we consider them potential candidates for brain dead donors. The proposal may be viewed as a compromise between the restrictions on organ removal in the current law and the impetus to make organ transplantation possible for children with severe heart diseases.

In *Invisible Death*, Michi Nakajima stated that transplantation might be accepted, but the idea of brain death was totally unacceptable. In 1991, a citizen group published a draft transplantation law that took up this idea. The group argued that we did not have to define brain death as human death in order to remove organs from brain dead donors. In 1997, Rep. Seiichi Kaneda presented a bill to the Diet stating that a brain dead patient is alive but that if the donor has made a prior declaration of intent to be a donor and the family consents, organs can be legally removed from the brain dead patient. Kaneda's bill was rejected, but many people who are skeptical about brain

death still support his idea. One proposal for revising the Organ Transplantation Law, developed in October 2000 by Yutaka Teruteru Nishimori, a graduate student, rejects brain death but insists that the donor's prior declaration to donate organs is alone sufficient for organ removal from a living brain dead adult (16). In effect, the Teruteru proposal pursues a limited version of one of Truog's alternatives, that of removing organs from brain dead patients, patients in persistent vegetative states, and anencephalic newborns even if they are considered to be alive. So far, however, there has been no discussion of organ removal from patients in persistent vegetative states and anencephalic newborns in Japan. There seems to be a tacit consensus that removing organs from them would be unacceptable.

Finally, some have proposed a complete ban on organ removal from brain dead patients. Through the 1980s and 90s, citizen groups that objected to the idea of brain death accused the physicians who removed organs from brain dead patients of homicide (17). This sentiment prompted Tomoko Abe, a Member of Parliament, and her supporters to call for abolishment of the law. The movement is supported by adherents of Oomoto-kyo, a new religion based on Shintoism, who are distributing "anti-donor cards" to the public.

### **Ongoing Concerns**

Japan's Organ Transplantation Law has three pillars, namely, pluralism on human death, the donor's prior declaration principle, and family consent.

*Pluralism on human death.* The significant proportion of the Japanese people who reject the idea of brain death usually say that a brain dead patient whose body is warm and moist cannot be seen as a corpse because the essence of humans exists not only in one's mind, but also in one's body. They reject the notion that the essence of humans lies in self-consciousness and rationality. They think that a warm, living body is an integral part of the person. This view seems to draw some support from the ongoing physical activities that brain dead people may engage in. Thus critics sometimes refer to a [44/45] pregnant Japanese woman who reportedly gave birth to her child while brain dead. They note that brain dead patients sometimes move their hands toward the chest automatically and show a praying posture (known as the Lazarus sign) (18). Even decerebrate posture (that is, an unusual extension and rotation of limbs) has appeared in brain dead patients, which implies the existence of some living neurons in the brainstem (19). And Alan Shewmon has reported that many brain dead patients' hearts continue beating for more than a month (and in one case, for 14.5 years) (20). We must admit that a brain dead person is completely different from a cold and pale corpse.

I think our right to choose which concept of human death will be applied to *our* death must be defended. How we understand death is very important

for how we understand life, and so for how we understand ourselves. It is a matter of personal philosophy and religious belief. And these different views of death are not irrational. But at the same time, we should confine the choice to traditional death and brain death. We must not enlarge death to include persistent vegetative states or anencephaly. Bioethicists in the English speaking world often speak of “cerebral death” as human death. But there are reports of exceptional patients in a persistent vegetative state who recover from it with intensive nursing care, and even become able to write and/or speak (21). The difference between brain death and a persistent vegetative state is that while the former never recovers, the latter has a slight chance of recovery. I believe it should be our rule that a human being who can voluntarily breathe is alive no matter what his or her condition is. Veatch emphasized that an alternative definition of death should be “within reason.” However, reasonable reasons might vary from one culture to another, and the “reasons” bioethicists recognize might be different from those of ordinary people.

*Donor’s prior declaration and family consent.* The principle that there must be a prior declaration from the donor of a desire to donate organs is based on the premise that we have the right to determine our own idea of life and death, and also that we have the right to express our own will to donate organs after brain death. It may be interpreted as a kind of self-determination principle that protects the patient’s prior will from outside interference. The requirement of family consent is based on the idea that human death happens not only to the dying person, but also to the family members at the bedside. This idea might sound strange, since it is the patient that is dying, but it is the felt reality for many ordinary people in Japan that the dying person and the family share the dying process and the death itself, and that even after the diagnosis of brain death the family continues to share the dying process with the patient. I have elsewhere called this phenomenon “brain death as a feature of human relationships,” and Yoshihiko Komatsu has called it “resonating death” (22). This so-called “human relationship-oriented analysis of brain death,” which has become very popular in Japanese bioethics, suggests that the family has some right to say something about the legal brain death diagnosis and the removal of organs.

In my view, we should retain the donor’s prior declaration principle, even if it may reduce the number of removed organs. For one thing, the stipulation that donor’s prior declaration and family consent are required for brain death diagnosis and organ removal is necessary to introduce transplantation from brain dead donors to Japan, where many people are still skeptical about the idea of brain death. Further, as noted, people should be accorded the right to determine the criteria by which they will die, given its importance to their lives. And finally, the decision whether to diagnose legal brain death is also a

matter of terminal care. When a person is clinically brain dead and does not have a donor card, this may be a sign that we must keep away and leave the body to a less heavily medicalized dying process.

The requirement for family consent when the clinically brain dead patient has expressed a will to donate calls for further public discussion. It may be that in such cases, the family's objections should be ignored. This will be a delicate and controversial topic for the Japanese.

The remaining big problem is organ removal from brain dead children under fifteen. If we had not introduced the donor's prior declaration principle, we would never have faced such a difficult problem. Many Japanese seem to think that the family can decide these cases. It is my personal view, however, that children too should have the right to decide which concept of death they will die under (23). The United Nations Convention on the Rights of the Child stipulates that children have the right [45/46] to express their opinions and that adults are obligated to hear children's voices. In Japan, about 20 to 40 percent of adults reject the idea of brain death, believing that organ removal from "silent" children might well violate their unexpressed basic rights. At the same time, I also share the sentiment that children with severe heart diseases should be able to obtain heart transplantation. Thus the coming debate about the Organ Transplantation Law will be very difficult and complicated.

Commentators on organ transplantation sometimes ask why the Japanese continue to reject brain death while people in other countries have accepted it. And several answers have been proposed (24). I want first to confirm that most people in Japan accept brain death, according to opinion surveys. Roughly 20 to 40 percent of the Japanese people object to brain death, but recent studies show that roughly the same portion of the American population shares these doubts (25). And in 1997, 30 percent of the German Diet Members supported a bill declaring that brain death is not human death (26). These reports suggest that 20 to 40 percent of the population in every country might have some doubts about the idea that brain death is equivalent to human death. Interestingly, the countries in which strong objections to brain death appeared --- Japan, Germany, and Denmark --- were those that had something like a nationwide debate on brain death in the 1980s and 1990s. In these countries, the mass media covered the topic and ordinary people joined the debate. In contrast, in North America and in some European countries, the debate was restricted to the medical and bioethical spheres, and the views of ordinary people were not necessarily reflected. Why does Japan have the policy it does? In my view, it is because the country held a prolonged nationwide debate.

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**Note:** The Japanese transplantation law was revised in July 2009. "Pluralism on human death" and "the donor's prior declaration principle" were deleted from the revised law.