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A Proposal for Revision of the Organ Transplantation Law Based on A Child Donor's Prior Declaration

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This is the translation of the so-called Morioka&Sugimoto proposal on brain death and transplantation. We proposed that the prior declaration of a brain dead child should be respected, and that when the child does not have a donor card the organ removal should be prohibited. Important material for understanding an unprecedented bioethics debate now occurring in Japan.

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

[Note: Japanese Organ Transplantation Law was established in 1997. Under this law before a “legal brain death diagnosis” and “organ removal” can occur, both the “donor’s prior declaration” and “family consent” must be obtained. While agreeing that the law allows a choice in defining when death begins, critics argue that the “donor’s prior declaration” principle is too strict. Moreover, donations by brain dead children under 15 years are prohibited. As required by a supplementary provision, the law began to be reconsidered in October 2000. Since then, several revisions have been proposed and have caused heated debates. The areas of greatest concern are the “donor’s prior declaration” principle and organ donations by children. An unprecedented bioethics debate is occurring in Japan. The following is an English translation of the proposal for revision of the Organ Transplantation Law by Masahiro Morioka and Tateo Sugimoto, announced on February 14, 2001. Information about the revision of the law is found on the page; <http://www.lifestudies.org/specialreport01.html>.]

1. Outline of the Proposal

(1) Concerning the “donor’s prior declaration” principle and organ removal from children under 15 years (revision of Article 6 of the current law)

With respect to organ removal from brain-dead donors,
(i) the current rules should be applied for organ removal from brain-dead donors 15 years and older (the words, “the body of a

brain-dead person,” and the definitions of these words should continue to be used); and

(ii) either Proposal A or Proposal B should be included in the revised text for organ removal from brain-dead child donors under 15 years.

Proposal A:

In children between 12 and 15 years, before a “legal brain death diagnosis” and “organ removal from brain-dead donors” can occur, written statements of the “donor’s prior declaration” and of the “prior consent of persons in parental authority,” as well as an admission that the persons in parental authority do not object to the procedure, are necessary.

In children between 6 and 12 years, in addition to the above conditions, the hospital’s ethics committee or the court must confirm that there was no sign of child abuse and that the child’s prior declaration was made of his/her own free will and without force.

In children under 6 years, neither a “legal brain death diagnosis” nor “organ removal from brain dead donors” is permitted.

Proposal B:

In children between 12 and 15 years, before a “legal brain death diagnosis” and “organ removal from brain-dead donors” can occur, written statements of the “donor’s prior declaration” and of the “prior consent of persons in parental authority,” as well as an admission that the persons in parental authority do not object to the procedure, are necessary.

In children under 12 years, neither a “legal brain death diagnosis” nor “organ removal from brain dead donors” is permitted.

(2) Concerning organ removal from heart-dead* donors (*the permanent cessation of respiration and circulation)

The same requirements as described above should be applied to organ removal from heart-dead donors. Words concerning “brain death” should be deleted from the text. Article 4 of the supplementary provision is abolished.

(3) Concerning organ removal from living donors

When an adult voluntarily requests the removal of one kidney, part of the liver, part of the small intestine, and/or part of lung, the excisions should be permitted, as long as organ removal does not harm his/her health. (A guideline that stipulates the possible organs for this provision will be written). Statements for the

protection of the donor's human rights and health should be included in the law.

(4) Concerning the extraction of human tissue

The requirements for the extraction of human tissues from brain-dead patients, from heart-dead patients, and from living patients should be the same as those for organ removal from brain-dead patients, from heart-dead patients, and from living patients, respectively.

2. Explanations

(1) "Brain death"

Under the current law, each of us may choose in advance whether to define brain death as death. If we want to be an organ donor after we are brain dead, we write our wishes on a donor card or label. Then, we will be declared dead when brain death has been diagnosed. If we object to brain death, we do not fill out a donor card. Then, we will be alive until our hearts stop beating.

Current Japanese law is based on "pluralism on human death." New Jersey's brain death law, which is highly regarded by some American bioethicists, is another example of this pluralism. Now, the Japanese Organ Transplantation Law is attracting widespread attention. According to some bioethicists, true pluralistic and democratic countries must have laws that permit "pluralism on human death" within limits.

Reconsideration of brain death has become a major topic in worldwide bioethics discussions. Not only ordinary people but also bioethicists in the United States have begun to doubt the concept. The hearts of many brain-dead patients can continue beating for more than a month, 14.5 years the longest; and brain-dead patients sometimes move their hands toward their chest automatically and show a praying posture (Lazarus sign). In 1998, D. Alan Shewmon's paper medically refuted premises that "integrative function disappears from a brain dead body" and that "the heartbeat of a brain dead body stops shortly." With that paper, the opinion of the Japanese Medical Association and the majority opinion of the Prime Minister's Special Committee on Brain Death and Transplantation were also medically refuted. (See Morioka, c.)

The idea of life that answers the questions "what is life?" and "what is death?" is very important to us. About 30% of the Japanese people reject the idea that brain death is equivalent to human death. Similar percentages hold true in many foreign countries. We believe that the idea of rejecting brain death as a definition of death should be respected as well as the idea of affirming brain death as death. The law must not deny this idea [108/109] of life shared by 30% of the Japanese people. Fortunately, we have a law, based on "pluralism on human death," that allows us to choose beforehand whether to define brain death as human death. While many Japanese bioethicists doubt the concept of brain death, few doubt that heart-dead patients are dead. Therefore, we believe that, without a prior written statement otherwise, heart-death should be human death. In addition, we believe that, for those who consider brain death as human death, brain death should be human death. We are pleased that Japan has such a pluralistic law concerning human death. We believe that the framework of the current law should be maintained.

(2) Transplantation

If the “donor’s prior declaration” is necessary for organ removal and organ removal against the donor’s wishes is prohibited, what should we do when brain-dead patients have not expressed their opinions? If we remove organs when brain-dead patients have said nothing, we may cause a profound violation of human rights: the removal is a medical invasion of their bodies. We have to account for cases in which brain-dead patients have not written their wishes on donor cards. Perhaps these patients were undecided or had never had a clear answer to this matter. When brain-dead patients have said nothing, we must consider that these explanations may be possible. Hence, when brain-dead patients have said nothing, we must not remove their organs. All of us have the “freedom” to waver, to withhold our opinions, or to not decide on “transplantation.” We have the “right” to keep silent, to not be forced to express our ideas of life and death.

(3) Children under 15

We should give children an opportunity to express their opinions on “the idea of life” and “organ removal.” Their expressions must be made voluntarily, not by force. Only when children have agreed to “brain death” and “transplantation” in written documents and when persons with parental authority consent, should we be allowed to make a legal brain death diagnosis and remove organs. The Convention on the Rights of the Child stipulates that all children have the right to express their opinions and that adults have the obligation to hear children’s voices. We must not ignore this treaty when revising the Organ Transplantation Law with regard to children. If we base a “legal brain death diagnosis” and “organ removal” only on the wishes of persons in parental authority without the child’s opinion, we are in danger of judging the death of the child and removing organs against the unexpressed wishes of the child. This is a violation of the child’s human rights. (See Morioka, a.)

Japanese law provides that persons in parental authority must protect their children. If a child has not expressed an opinion, persons in parental authority have an obligation to protect the child’s “living” body from the invasion of “transplantation.” Under the current law, people without prior declarations are alive until their hearts stop beating.

At younger ages, children may not be able to make valid declarations about brain death and organ donation. Hence, we have presented two proposals, namely, Proposal A and Proposal B. After discussion, we can decide which proposal is more appropriate. Because brain death can result from child abuse and parents can coerce a child or forge a child’s donor card, a third party should investigate and confirm the declarations of children under 12 years. In children under 6 years, a legal brain death diagnosis and organ removal would be prohibited because these children cannot give a meaningful declaration. (See Morioka, b. Some corrections should be made to this literature.)

Some critics say that the opinions of children may be unreliable because very young children can be easily, sometimes deeply, influenced by their parents. If so, we must not diagnose brain death for these children and not remove organs from them.

(4) Other points

The above revisions to the law should be applied to removing organs from heart-dead donors, to removing organs from living donors, and to extracting human tissues.

In revising the law, additional ethical questions, such as family overrule of a donor's prior declaration, terminal care, "research on the human body," and "withdrawal of life support systems," as Jiro Nudeshima pointed out, should also be considered. These issues will require long academic discussion from many perspectives.

3. Criticism of other proposals

(1) Machino Proposal

"Brain death is equal to human death without exception. If family consent exists that is sufficient for organ removal unless the brain dead person has previously refused to be a donor."

This proposal has fundamental faults.

(i) The validity on medical grounds for saying that brain death is equal to human death "without exception" collapsed after recent neurological publications.

(ii) The idea that brain death is equal to human death "without exception" violates the opinion of 30% of the Japanese people who do not consider brain death the same as human death.

(iii) Machino's argument that everyone has already made an "inherent self-determination" to be an organ donor is based on faulty ethical theory.

(2) Proposal for adding an exception clause for children while maintaining the framework of the current law

This proposal has not been officially announced. This proposal states that, for children, family consent is sufficient for a legal brain death diagnosis and organ removal.

This proposal is legally contradictory.

(i) The current law defines heart-death as death and allows a "legal brain death diagnosis" and "organ removal" only when a patient has made a prior declaration to be a donor.

(ii) If a brain dead child has not declared an opinion, a "legal brain death diagnosis" for the child is prohibited.

(iii) If the revised law allows a "legal brain death diagnosis" without a child's prior declaration, the law will be inconsistent. In adults heart-death will be death, but in children brain death will be death.

(3) Proposal for legislation that enables organ removal from "living brain-dead donors"

"Human death should be the permanent cessation of respiration and circulation. A brain dead patient is still alive. If there are 'donor's prior declaration' and 'family consent,' organs can be legally removed from a 'living brain dead donor.'"

This proposal raises following questions.

- (i) If organs are removed, particularly the heart, from a living brain-dead donor, the patient dies from the procedure. According to this proposal, organ removal would appear similar to homicide or euthanasia.
- (ii) If the revised law allows organ removal from living brain-dead donors, the law may soon allow removing organs from living patients in a persistent vegetative state and from anencephalic newborns. It might further lead to organ removal from people who are disabled or who have senile dementia, from condemned criminals, etc. This revision could lead to a very slippery slope.
- (iii) Does not this proposal deny a personal idea of life and death to those who accept brain death as human death? [109/110]

(4) Proposal for the abolishment of the law itself

“Brain death is not human death. Organ removal from a brain-dead patient is a homicide. It must be prohibited.”

This proposal may ignore the wishes of many people.

- (i) This proposal denies an opinion to those who consider brain death to be human death.
- (ii) Abolishment of the law would violate the freedom of choice for those who hope to help others by organ donation.

4. Conclusion

We think our proposal, “A Proposal for Revision of the Organ Transplantation Law Based on A Child Donor’s Prior Declaration” (the Morioka&Sugimoto Proposal) is the best choice for the new law. We take seriously the lives of children who cannot live without organ transplantation. However, we must not violate the rule that the consideration of transplantation should begin after we finish protecting the dignity and human rights of children in a clinically brain-dead state. We present our proposal as the sole possibility that enables transplantation from children under the rule described above. We welcome discussions on every aspect of our proposal.

Medical knowledge and international decisions about brain death have changed over the past 10 years. Everyone interested in submitting proposals for revision of the Organ Transplantation Law should carefully discuss their ideas with their colleagues before presenting them to the Diet.

5. Proposal

We propose to the Diet members concerned, the organizations concerned, the associations concerned, and the persons in charge at the Ministry of Health, Labor and Welfare that they should prepare a bill for revision of the Organ Transplantation Law based on our proposal and the attached materials.

[Announced on February 14, 2001]

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