

## Information disclosure vs privacy protection

— Issue raised by the nation's legal organ transplantations from brain dead donors in Japan —

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### 要 旨

The Organ Transplant Law was enacted in 1997. When the first legal organ transplant from a brain dead donor was performed in February 1999, we had an issue never discussed before : how to balance the conflicting needs of disclosing information and protecting privacy.

Some people pursued transparency in medicine and others valued the privacy protection more objected to the argument. The nation's thirteen organ transplants performed up to March, 2001 posed an issue over information disclosure and privacy protection. In this article, it would be discussed how to balance these conflicting requirements as follows.

1. Timing to disclose the information : It seems that a real-time disclosure after the completion of the legal judgement of brain death is better.
2. Range of information to be disclosed : All the information necessary for medical and ethical verification should be disclosed but the specifics of the individual should not be.
3. Who discloses the information to whom : The medical institutes involved should be responsible for disclosing all the information except that which specifies the individual, to all competent persons older than 15 year-old, if they ask.
4. Ethics of Journalism : Journalism should weigh public benefits and human rights.

### Key words

organ transplantation, brain dead donor, recipient, information disclosure, privacy protection

### 1. Introduction

The Organ Transplant Law was eventually enacted in Japan in October, 1997 after many years of discussion on brain death. Due to people's strong reluctance to regard brain death as the end of human life and the haunting

memory of the nation's first heart transplant scandal by Juro Wada, few organ transplants from a brain dead person had been performed in Japan. With the background mentioned above, the Organ Transplant Law contains more strict regulations to donate organs of a person diagnosed as brain death than those of

any other countries do. Some requirements for organ donation ask for both the donor's determination written while alive and consent written by the donor's family.

As a result of strict regulations in that Law, in fact, no organ transplantation from a brain dead person was ever performed for sixteen months after the Law was enacted. It was February, 1998 when the first legal organ transplant from a brain dead donor was performed. A total of thirteen legal organ transplants from brain dead donors have been performed in Japan as of March, 2001.

However, the low number of organ transplant cases is not the main focus in this article. Here, the discussion is focussed on the issue, which had hardly been discussed before and was raised by legal organ transplants that were revived after a long absence in Japan, that is, how to find the appropriate balance between necessary information disclosure and privacy protection. When the first legal organ transplant from a brain dead donor was carried out, initially, the media covered this historical event in real time, which ended up outraging the donor's family. After the family protested, the content of the coverage was severely limited. In the subsequent organ transplant cases from the brain dead donors, the extent of information disclosure was left to the discretion of the donors' families. As a result, less and less information about those cases was provided.

With the bitter lesson learned from the heart transplant scandal by Juro Wada, ensuring that the organ transplant process is transparent is supposed to be the essential requirement for restarting medical care of organ transplantation from a brain dead person in Japan. In particular, transparency throughout the process to certify the donor's brain death and remove the donor's organs is regarded as most important condition in carrying out

ethical organ transplantations.

At the same time, the privacy of donor and recipient should not be invaded. How can this issue be solved? It will be considered specifically here how to balance these conflicting requirements.

## 2. Why is transparency required in the medical care of organ transplantation?

Organ transplantation from a brain dead donor is medical care that has more social aspect than other medical procedures. Therefore, to carry out this procedure, public understanding is necessary. The reasons for this are as follows.

(1) Transplantation from a dead person cannot be carried out without a donor of good will. This means this medical care is performed in cooperation with others. That is why the donor-card promotion campaign is being conducted. This kind of campaign will only backfire without public understanding.

(2) In addition, redefinition of death, or the brain death issue, is a factor. There are several opinions on this issue of the redefinition of death. Still some people show strong reluctance to consider brain death as the end of human life. In particular, it is called "invisible death"<sup>1)</sup>, and determination of brain death made behind closed-doors, as a rule, incurs people's distrust and concern. Therefore, even though there is the donor's will, it is very important to follow procedures clear enough to convince others and make every effort to gain understanding in the society before pronouncing donor's brain death and removing donor's organ for transplantation.

(3) Organ transplantation from a brain dead donor is a very expensive medical procedure. Who must pay the bill is still undecided. If the recipient is to pay all the cost, only those who

can afford it will be able to receive this medical care, which could lead to discriminatory treatment of human lives. It is desirable that the cost should be covered by health insurance in the future. In that case, public understanding will become more essential than it is now because people won't pay for others' medical care if they are not convinced.

With the reasons mentioned above, public understanding is required to perform organ transplantation from a brain dead donor. It is necessary to keep all the processes, from pronouncement of the donor's brain death to the completion of transplantation surgery, as clear as possible to avoid raising any suspicions. For this reason, information disclosure is more essential than anything else.

In Japan, we had a bitter experience in the history of organ transplantation : the scandal of heart transplantation by Juro Wada at the Sapporo Medical College in 1968. At first, the nation's first heart transplantation was reported extensively as an emotional story. But, later, lots of doubts were brought to light. Even if it was overlooked that in those days, there was not yet a set of criteria to certify brain death in Japan, Juro Wada did not even conduct an electroencephalograph (EEG) test on the young donor. This means that no evidence remained to prove whether the young donor was diagnosed brain death or not. Moreover, Wada, who performed the transplantation surgery, pronounced the donor's brain death by himself. What's worse, the recipient boy was not necessarily fit for heart transplantation. Those doubts were left unclear because the people involved in the case had destroyed the evidence. The doctors involved in this transplantation were accused by the doctors of oriental medicine later, but they were not indicted due to insufficient evidence<sup>2)</sup>.

However, there is no knowing how much distrust of transplantation medicine this scandal incurred among people.

Wada scandal became the main obstacle for transplant surgery from brain dead donors in Japan. Thus, it was necessary to wipe away people's deep rooted distrust of organ transplantation in order to restart it from a brain dead donor in Japan. Japanese medical society, however, had not reviewed this scandal or made an apology for it. In the meantime, the Transplantation Law was enacted. The only relief is that we can see a reflection of the scandal in the strictness of this Law. Now this Law is being amended to soften the rules. Some people are afraid of such an amendment.

The Wada scandal, however, is not an exception. The idea of information disclosure has not been prevalent in other fields in Japan. Regarding medical society, this secrecy has often been pointed out. Doctors still are not making every effort to get informed consent from their patients. This secrecy in the medical society results in incurring people's distrust, which serves to slow down organ transplantation in Japan.

Not only for getting public understanding, but due to such a skepticism towards the Japanese medical society, it is required to ensure transparency, or disclose information, in the procedures of organ transplantation.

### 3. Privacy protection in organ transplantation

As already mentioned, transparency should be ensured throughout the organ transplant process. However, this does not mean that all the information should be disclosed at the cost of someone's privacy. In the first place, it is necessary to define the meaning of privacy.

According to Greenawalt, privacy is a complex concept, involving the following meanings :

(1) One's physical space or world protected from others' eyes

(2) One's informational privacy, which means that one's private information is not disclosed against one's will : "When one can control his or her own information by himself or herself, it can be said his or her privacy is protected." (Westin)<sup>3)</sup>

(3) One's decision-making right on matters relating to himself or herself—Right to privacy is now common awareness in the U.S.A.<sup>4)</sup>

In organ transplantation from a brain dead donor, the issue of privacy, particularly, informational privacy mentioned by Greenawalt should be respected. The individuals who fall under privacy protection in case of organ transplant will be the donor, the donor's family, the recipient and the recipient's family. Why it should be protected in this case ? Three reasons can be considered. First, if those individuals are identified, there might be a fear that the recipient might be watched by the donor's family throughout the rest of his or her life. It may be a possibility that a good relationship like friends can be established between both sides of donor and recipient. Still, in most cases, there is a fear that tensions are brought about to both sides by identifying the individuals.

Second, there is a particular environment that has produced the Japanese character in Japan's society. On the donor's side, knowing the praiseworthy meaning of organ donation fully, many donors' families hope not to be identified because they are concerned about people's negative feelings toward the notion of cutting up a dead body. On the recipient's side, many people will hope to keep things secret because they are afraid of people's cruel eyes. Actually, there is still antipathy to organ

transplantation among Japanese people. It can be said this is a problem embedded in Japanese culture.

Third, receiving any medical care is a private matter, as is a medical care of organ transplantation.

Based on the three reasons mentioned above, it comes to the conclusion that privacy protection of people involved should be respected as much as possible in organ transplantation.

#### 4. Privacy protection and transparency requirement

As mentioned above, information disclosure is necessary for ensuring transparency of medical care of organ transplantation. On the other hand, the privacy of people involved should be protected. This will bring about a serious dilemma. Is it impossible to find a way to ensure transparency as well as protect privacy ? It can be said there is a way to make these conflicting principles compatible. Then how can we find it ? The answers could be derived to this question specifically from the following four viewpoints.

##### (1) Timing to disclose the information

To meet the requirement of ensuring transparency throughout the organ transplant process, it is needless to say that real-time information disclosure from the beginning is desirable. There is a fear that people in charge will tamper with the data as they like if information is disclosed after the event. If that is the case, it will be very difficult to gain people's trust with such highly secretive medical care. Nevertheless, considering the feelings of the donor's family who are upset about their family's unexpected tragedy, they should be given some quiet time to care for their family member and make a crucial decision so that

they won't have regrets. If real-time news coverage makes the situation a "theater of a person's death", it will be too hard for the family to bear. Originally, it was thought that coverage of brain death should be real-time to ensure transparency, but now some people including the author of this article are inclined to think that the donor's family should be given quiet time to make up their minds, care for, and say good-bye to their loved-one.

When is the appropriate time to disclose the information? It would be better to disclose the information from the beginning upon completion of the legal pronouncement of donor's brain death. To get the consent of the donor's family on this matter should be advisable before information is disclosed.

As for the following procedures: process and result of recipients selection, removal of donor's organs, implant operation and its result and so on, it seems that real-time information disclosure will cause no problem, though the privacy of the recipient should also be protected. In addition, when a donor's dead body returns home, no picture-taking should be permitted.

In this case, how can we ensure transparency of diagnostic process by the time information disclosure on confirmation of brain death starts? Is it not important to keep the procedures in this stage more transparent than at any time? Regarding the details of process to pronouncement of a donor's brain death, a reliable third party should verify them as well as verification of other process after pronouncement of brain death, and publicize them. The verifiers of this third party should be chosen from nurses, caseworkers, lawyers, moral philosophers and citizen representatives as well as physicians. Even though real-time information in the first half of organ transplantation process will not be disclosed, it is possible to keep total process of it transparent by following

the carefully drawn-up steps mentioned above.

## (2) Extent of information disclosure

Here, it is considered how much information disclosure should be required. There are mainly two kinds of information: 1. Private information concerning either patients or their families and 2. Objective information, such as medical data, to be used for verification of the transplant process. These should be treated differently. Basically, the former must be treated as confidential since it involves information relating to identification of individuals. The latter must be disclosed. This applies to both donor's and recipient's sides.

In the nation's first legal organ transplantation in Japan, at first various information was publicized such as the age and sex of the donor, the type of disease and the name of the medical facility the donor was in. The donor's family was said to be outraged, especially because the name of the medical facility was disclosed. To make matters worse, some media began to report the district name where the donor's family lived, which panicked them. It was obvious that media went too far. In the author's opinion, it was not inappropriate to disclose the information concerning the donor's age, sex, type of disease and name of medical facility. Each person has his own view on privacy, so it may be difficult to draw a clear line between what invades one's privacy and what does not. With the lesson learned from the first transplant case, the extent of information disclosure was likely to be left to the intention of donors' families in subsequent transplant cases. This matches the definition of privacy by Westin: "One can control one's information by himself". Nevertheless, this manner should be reconsidered to keep transplant process transparent.

It is said that it is appropriate to decide the

content of information disclosure beforehand and get the family's consent of it. What kind of information is at least necessary? First of all, information identified each individual should not be disclosed. On the other hand, all information used to verify the medical procedures: age, sex, type of disease, medical facility's name, and medical data etc., should be disclosed except for identification of each individual. Though the disclosure of the facility's name made the donor's family outraged in the first case, this information was necessary to verify the transportation time of the organs to be implanted.

When a transplant coordinator gets the consent of organ donation from the donor's family, he or she should also inform them of the extent of information disclosure and get their consent for it beforehand. It may be appropriate for a coordinator to persuade the family to give up organ donation if they cannot give their consent, because ensuring transparency in the transplant process is so crucial. But, the time that a donor's body returns home need not be publicized, as it does not influence verification of the procedures directly.

Additionally, the process to get the consent of a donor's family on diagnostic tests for confirmation of brain death and donation of organs, should also be disclosed. Specifically, what is most important here is to verify whether donor's family is forced to give their consent or not. To avoid any suspicion, how a coordinator works this process should be disclosed frankly. Information concerning the recipient's side should be also treated similarly to that of donor's side.

Furthermore, in the future, it may be a good idea to make a space in a donor-card to write the kinds of private information the donors themselves would allow for disclosure. Some

donors may hope for the public to know about who provides the "gift of life".

### (3) Who discloses to whom?

Third, It is necessary to consider who discloses to whom. Let's start with who should take a leading role in information disclosure. Medical facilities that carry out removal or implant surgeries of donor's organs, or a third party who verifies all the procedures should disclose this information. Publication of collective information by the Ministry of Health and Welfare is not desirable for fear of information control.

Next, information disclosure to whom? Information should be disclosed on request to anyone, except children younger than fifteen years old, who are regarded as incompetent legally, after screening their purpose. If there is a fear of improper information use, the information should not be disclosed to the individual.

Under the present law (Article 8 of Enforcement Regulations, the Transplant Law), only a donor's family, recipients and their families, and the organizations for organ transplant coordination can request to read the records of a case. However, when we consider the social aspect that organ transplantation has, this is far from satisfying.

### (4) Ethics of journalism

Final issue is on the ethics of journalism. Insensitive reporters who interview people in grief and behave rudely without considering others' feelings can be seen everywhere, not only in coverage of organ transplantation. Journalists are obliged to report important information correctly as soon as possible, and it is asked particularly in news of organ transplantation. However, this does not mean they can hurt others who grieve in their reporting.

It is required for them to behave with empathic understanding to patients and their families, along with the medical and health care staff, when they are on the site where the organ transplantation is carried out.

## 5. Closing

As the number of organ transplantation from a brain dead donor increases, the size of news coverage will become smaller and smaller inevitably. It is a situation where the role of organizations to verify the process becomes more important. Verifiers need to examine all the details in each case and disclose the results. The information should be accessible to all people who are fifteen years and older on request.

However, under the present circumstances, where public trust in medical care of organ transplantation is not fostered, it is necessary

for the media to cover as much detail as possible in each case. It can be said what has been offered in this article will be a useful reference in deciding the timing and extent of information disclosure.

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## 情報開示とプライバシーの保護

—日本における合法的脳死移植から新たに浮上した問題—

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### 要 旨

わが国で臓器移植法が施行されたのは1997年10月であった。それから16ヵ月後の1999年2月に最初の合法的脳死移植が実施された時、それまで論議されなかった問題が新たに浮上した。それは情報開示とプライバシーの保護に関する問題である。両者の間にどうバランスをもたせるのか。2001年3月までに13例の脳死移植の実施をみた。しかし、依然として本問題は解決していないように思われる。そこで本稿ではこの問題に焦点を絞って考察したが、本問題を解決するために筆者は次の4点を提言した。1) 情報開示の時期は法的脳死判定確定時にし、以後はリアルタイムで開示してゆくがよい。判定に至るプロセスは後の検証時に合わせて公表する。2) 情報開示の範囲は後の医学的、倫理的検証に必要な全項目とするが、個人を特定する情報は開示しない。3) 情報の開示は関連医療施設が求めに応じて、15才以上の判断能力を有する全ての個人に責任をもって実施する。4) 特に本問題に関しては、ジャーナリズムの倫理が強く求められる。

### キーワード

臓器移植, 脳死状態のドナー, レシピエント, 情報開示, プライバシーの保護