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To a Phenomenological Approach of the Problem of Organ Transplant after Brain Death¹

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An Introduction

The Act of Organ Transplant, which was established in 1997 after a long controversy, opened a possibility of organ transplant after brain death in Japan. This Act was revised in July 2009 and enforced in July 2010.

Concerning this Act of Organ Transplant in Japan before the revision in 2009 I wrote in my paper as follows: “I may appreciate the fundamental idea that organ transplant after brain death would be only legitimate if an expression in paper of the patient’ will of organ donation after brain death and an agreement of the family with it are presupposed and medical conditions of the legal judgment about brain death is cleared. As an attitude of medicine following Japanese culture I find it not bad that only on the ground of patient’s will (the first person) and of family’s agreement (the second person) the medical legal judgment of brain death (the third person) should be performed”³.

But, as said, this Act was revised in 2009 and the revised Act was enforced since last July. The most important point of revision is that organ transplant after brain death would be legitimate, even if the patient’s will is unknown, only if the family does agree with organ donation after brain death. It should destroy the condition of patient’s will (the first person) in the fundamental idea that I appreciated ever. In this presentation I would like to try to take this change and its new situation into consideration. Through discussion of this presentation I am going to prepare a phenomenological approach to the problem of organ transplant after brain death.

1. The problem of the first person

Scarcely a month has passed after the revised Act of Organ Transplant was enforced, according which judgment of brain death and organ donation are legitimate only with an agreement of

family, on the 9th August a young man in his twenties was judged as brain death and each harvested organs from him was transplanted in several medical institutions. Until today (March 2011) organ transplant after brain death has been performed in 18 cases⁴ for these four months according to the revised Act, whereas we had 86 cases for 13 years since the establishment of the Act before revision, i.e. about 7 cases for each year.

At the first case the Japan Organ Transplant Network (JOTNW) that controls all organ transplants in Japan explained that the patient didn't express his will in paper, and that the family agreed with judgment of brain death, because he said formerly: "In case of a emergency I may donate my organs". But, as to how he expressed his will of donation, the Network gave only a comment: "While we in family were looking at a TV program about organ transplant, he expressed orally his will of organ donation, therefore the family estimated his will". The Network didn't announce as to details of the time etc. of conversation, because it could not get any understanding of the family for publishing it.

Although the time of the conversation is important too (How about it, if it was 10 years ago?), there are other questions. When is the "case of emergency"? Is it after death (after stop of heartbeat) or does it include after brain death (during heartbeat)? Is the state of brain death included in the "case of emergency" just as in this case? Was his oral expression based on understanding of such a distinction? Was the decision of the family based on recognition of his understanding about it?

But, such questions are nothing but tied to the framework of the old Act where an expression in paper of patient's will was a necessary condition. As long as an expression of patient's will is asked, it matters whether its content is 1) donation after brain death, 2) donation after stop of heartbeat, or 3) no donation. Differently the changed point of the revised Act of organ transplant consists in that not only when there is an expression of donation, but also when there is no expression of patient's will, whether to donate or not to donate, only if there is an agreement of family, an organ transplant after brain death is legitimate, therefore that an expression of patient's will is not necessary, whether orally or written.

Since even family's supposition of patient's will is not necessary, even a confirmation of his having said that "In case of a emergency I may donate my organs", as above mentioned, is really not necessary. Even if his will is totally unknown, it is enough only if the total will of family in paper agrees with judgment of brain death and organ transplant: that is the point of the revised

Act. Of course, if we can confirm that the patient expressed even orally a will of organ donation after brain death, family's feeling could take a step forward easily to the direction that they want to respect patient's will. The point of the revised Act is that only the agreement of the total will of family make it legitimate even if patient's will is unknown. Just in above mentioned second and third cases it was the case. The reason why the family decided to donate when patient's will was unknown was as follows: "If there is no help, I'm glad only when a part of body is alive. I hope that vigorous parts would be helpful for people", "I would like to make a part of body useful for somebody. I'm glad when a part of body lives somewhere". I cannot help saying that it is an agreement of the total will of family that doesn't concern the patient's will.

But, it is already asked whether this point of revised Act, "It doesn't matter if patient's will is unknown", would go against the "fundamental idea" (the second article that is not changed after revision). This "fundamental idea" says that "the will of organ donation for transplant that the dead person had before death must be respected". It is certainly true that in the revised Act both wills to donate and not to donate are respected, but when a person who expressed nothing about her/his will comes to donate with an agreement of family, does it mean that we respect patient's will? The second clause of the same article says that "organ donation for transplant must be voluntary". But, when patient's will is unknown, can we call this organ donation "voluntary"? Further, the third clause of the same article says that "organs for transplant are donated based on humanistic spirit". But, if patient's will is unknown, can we call it "based on humanistic spirit"? Although it must be said about patient's "humanistic spirit", I cannot help saying that it was transformed to family's "humanistic spirit" to "make organs useful for somebody".

2. The problem of the second person

This "fundamental idea" has a history. Namely, the report of the special research committee for organ transplant after brain death before the conclusion of the old Act for organ transplant in 1997 ended with opinions of both sides, pro and contra. In the situation where one cannot insist that everybody agrees with considering brain death as death of a person, in order to open a way for people who may donate organs by considering brain death as person's death, the concluded Act made it legitimate to donate organs after brain death, by the thought of the right for "self-

determination” that was influential on the background of those days.

However, even the old Act didn’t consist only of the right for “self-determination”. Because the conditions for organ transplant after brain death were not only an expression in paper of patient’s will, but also an agreement with it by family. Even if there is the former condition, if there is not the latter condition, the organ donation becomes illegitimate, then the right for “self-determination” in a strong sense will be violated. According to the guideline for performing the Act of Organ Transplant, the range of “family” covers in principle “one’s spouse, children, parents, grandchildren, grandparents and relatives living together”, and “the chief mourner should collect the total will of the family”. If the chief mourner cannot collect the total will, organ donation after brain death becomes illegitimate. In this point the revised Act has no change. In the old Act it is necessary to full both conditions, not only the right for “self-determination” of the patient but also the agreement with it by family, whereas in the revised Act the former condition became not necessary and organ transplant after brain death became legitimate as far as family agrees.

This change made the gravity of family’s decision totally new. Please imagine: “Even if your loved person (e.g. your daughter/son) lies because of a heavily damage at her/his brain, you and your family is shocked. In addition, the patient is linked to an artificial respirator, although she/he has a pulse, her/his body is warm and sweats. Nevertheless the doctor says that her/his brain is already dead and she/he will reach soon to stop the heartbeat, and that there is no help, but there remains a way of organ donation”. In such a situation, under the old Act, organ transplant after brain death was only legitimate with the first condition, i.e. an expression in paper of patient’s will. If there is such an expression, it would push the family to a decision of respecting patient’s will and to a proposal of donation. In contrast with it, under the revised Act, even the patient’s will is unknown, therefore the family doesn’t think of a proposal of donation, medical staffs will approach the family by considering the patient as a candidate of organ transplant after brain death, and only if the family agrees with it, they can advance from the judgment of brain death to organ transplant. If the family will donate organs, there remains no enough time. In such a situation the family is demanded to make a decision. Does a decision in such a situation leave no regret, in case of which decision they made? It is no exaggeration to say that the gravity of family’s decision became of a totally different nature.

I would like to add one more thing to the problem of family, i.e. the addition of another point

to the Act: “an expression of will about prior donation to a family member”. Also as to this it is pointed out that it would go against the “fundamental idea”: namely, “The organ transplant must be performed appropriately to a person who needs a transplant”, and, “The chance of getting organ transplant for a person who needs it must be so considered as to be distributed fairly”. Based on this “fundamental idea”, the Japan Organ Transplant Network make a waiting list of recipients’ candidates, then prior donation to a family member will be performed as a break of this fair rule. Besides, the family is restricted to “one’s spouse, children and parents”. The agreement for organ transplant after brain death in prior donation to a family member is also made by the family (and the range of both sides is subtly different). The idea that the so to speak ownership of corpse or organs belongs to her/his family is more estimated than the fair right of chances for organ transplant. It is said that this revision of prior donation to a family member increased the number of people who express their will of donation. But it seems to me that the revised Act has strangely changed the problem of family from taking care of dying family member to asserting ownership of organs of family member.

3. The problem of the first person seen from the outside

About such a situation that organ transplant after brain death become legitimate even without patient’s will only with an agreement by the family, mass media reported often very schematically that “brain death became uniformly person’s death” by the revised Act. These reports were not exact, but caused a misunderstanding.

Although the proposers of the revised Act said that they didn’t insist that “brain death is uniformly person’s death”, their reason for it was as follows: “If the patient expressed her/his will not to donate organs, or also if her/his family doesn’t agree with donation, neither the judgment of brain death nor the organ donation is not forced, therefore the veto power of both of the patient and her/his family is recognized”. Certainly by estimating this point, in the “partly revision of guideline for applying the Act of Organ Transplant” it is clearly expressed as follows: “To the patient who expressed her/his will not to donate organs or not to follow the judgment of brain death a legal judgment of brain death should not be performed”. It is written clearly that to the patient who expressed her/his will of refusal neither judgment of brain death nor organ harvest would not be

performed.

But it was not without reason that mass media persisted in their expression that “brain death is uniformly person’s death”. Their point was as follows: “Whereas the old Act permitted ‘brain death as person’s death’ only under two conditions (patient’s expression in paper of her/his will and agreement of her/his family), the revised Act took off at least the first condition (the important requirement of patient’s right of self-determination related with the “fundamental idea”). Since the veto power is allowed, we can’t say that the revised Act abolished totally the first condition. Comparing with that in the old Act the first condition was only the case where the patient expressed her/his will to donate organs, in the revised Act the case where the patient didn’t express any will was added, consequently the case of no expression of patient’s will become to be treated as same as the case with an expression in paper of patient’s will. What mass media wanted to insist can be probably said in other words as “brain death is in principle person’s death”. It means: By excluding the case with an expression of no donation as an exception, brain death is in principle considered as person’s death.

It is called often as a conversion from opt in (contract in) as a system of *agreement* expression to opt out (contract out) as a system of *refusal* expression. Namely in the system of *opt in* only people who expressed an agreement become a candidate of organ transplant after brain death, whereas in the system of *opt out* only people who expressed a refusal is excluded from a candidate, i.e., except people who expressed a refusal all the others become a candidate. Shortly to say where the difference is, people who expressed nothing of their will would be treated differently. Namely, in the system of *opt in* they are excluded from a candidate, consequently they are treated as same as people who expressed a refusal will, whereas in the system of *opt out* they are put into candidate, so long as they expressed no refusal will, consequently they are treated as same as people who expressed a donation will. Before the revision people carrying a donor card were no more than ten percent of Japanese population and people putting a circle around the number of “no donation” was a very few. People carrying no donor card in 90 percent didn’t become a candidate from the beginning. On the contrary in the revised Act, except a small handful people who expressed a refusal in donor cards and a similar handful people who expressed a refusal orally all the other people would become a candidate. It was a great change of policy to increase the number of donor candidates.

In the system of *opt in* no donation is a principle (so to say “default”) and people expressing donation are treated as an exception and become a candidate for donation, whereas in the system of *opt out* a donation is a principle (“default”) and people expressing refusal of donation are treated as an exception and excluded from candidates for donation. Shortly it was a change from the old Act where no donation was a principle to the revised Act where a donation is a principle. Further to say in other words, because formerly organs were in principle patient’s possession, only people who renounced particularly the ownership and expressed a will of donation are treated exceptionally and become a donor. On the contrary, because now organs are in principle no patient’s possession and so to say a common property, only people who insist particularly the ownership and express a will of no donation are treated exceptionally and become no donor.

To tell the truth, with this revision of the Act of organ transplant a conversion from the thought “Organs are in principle patient’s possession” to the thought “Organs are in principle common property” was done. Although we think that the latter new idea is so unfamiliar that many people in Japan feel incongruity, if then we are asked whether the former idea is so familiar and natural that we can feel sympathy, we feel hesitation about whether I should affirm it. There is a logic of “self-determination”, “self-disposal” and “self-responsibility” from an attempter of suicide, a youngman with tattoo, a heavy smoker, a prostitute to a buyer of own kidney because of poverty who says often as follows: “Because my body (including organs) is my own possession, how to dispose of it is my own business”, “Since I will take responsibility for what I did, no others have right to meddle in my affairs”, etc. We are somewhat repulsed by this logic and feel the following idea also persuasive for us: “My body is not my possession that I got by my work, but a gift from parents, God, or Heaven”, “It is a gift that we inherited with DNA from the three thousand and eight hundred million years history of life, not my possession”. It can become a soil from which another logic arises as follows: “Although my body is my possession, as long as I am alive, I don’t care about that it becomes family’s possession after my death”. But now, I would like to seek another thought different from the logic of possession about body and organs.

4. The problem of the third person

The inexact schema of mass media “Brain death is uniformly person’s death” included another

misunderstanding as to the relationship between judgment of brain death and organ transplant. An impression was extended that in the old Act a judgment of brain death will be done only under the precondition of organ transplant, whereas in the revised Act “brain death is person’s death” without the precondition of organ transplant. But there was not no reason for such an impression.

One important point of the revision of the Act for organ transplant lies in the second clause of article six that states “definition of brain death”. In the old Act it is stated: “a body of brain dead person” means “the body of the person from whose body organs would be harvested for the use of transplant and who has been judged that the function of the whole brain including the brain stem has irreversibly stopped”. But in the revised Act, since the underlined part of the sentence was deleted, “a body of brain dead person” means plainly “the body of the person who has been judged that the function of the whole brain including the brain stem has irreversibly stopped”. Formerly the definition of “brain death” has the condition related to the person “from whose body organs would be harvested for the use of transplant”, therefore it has to fill the two conditions, i.e. an expression in paper of the patient’s will and an agreement of family, moreover the third condition, i.e. a legal judgment for brain death that “the function of the whole brain including the brain stem has irreversibly stopped”. Consequently, if first two conditions are not filled, the judgment for brain death would not be done from the very beginning. The deletion of the above-mentioned part in the revision seems to allow an interpretation as if a judgment for brain death would be done without to fill the two conditions, consequently only if the result of the judgment would show brain death, it would mean person’s death.

In this point, the proposers of revised Act explained: “Because this Act is persistently the Act for Organ Transplant which defines conditions making legitimate an organ transplant and is put into force within the frame of organ transplant, a judgment for brain death without a premise of organ transplant would be never done”. And, as said above, “To the patient who expressed her/his will not to donate organs or not to follow the judgment of brain death, a legal judgment of brain death should not be performed”. Also that the condition for organ transplant (the first clause of article six) and the condition for judgment of brain death are separated (although this separation follows the description of the old Act), seems to leave a possibility of the alternative to judge brain death without organ transplant by separating both conditions.

Even if the possibility of judgment of brain death without the premise of organ transplant is

denied legally in the above-mentioned guideline, the second clause of article six is written, as if “a body of brain dead person” could be medically defined as “the body of the person who has been judged that the function of the whole brain including the brain stem has irreversibly stopped” and a judgment for brain death would be medically performed. Then, I would like to ask again: Can we medically (objectively) declare that brain death is person’s death?

If we look back the history, the first heart transplant in the world was done by doctor Bernard in the Republic of South Africa 1967. Since it was a transplant after stopping heartbeat, the recipient died after only 18 days alive. After that people discussed whether a heart could be harvested before stopping heartbeat to transplant it freshly or in which point in time a heart may be harvested. In the next year 1968 the special committee for brain death of the medical faculty of Harvard University in U.S.A. defined death of the whole brain (in the expression of the report of the committee “comma dépassé”) as a new criteria for death. Responding to this, the Uniform Determination of Death Act in 1981 declared: “[Judgment of death] A person who fell into 1) irreversible stop of circulation and respiration, or 2) irreversible stop of the whole brain including the brain stem is dead. The judgment of death must be performed according to the approved medical criteria”. This is an Act that considers brain death as person’s death besides cardiac death. This made heart transplant after brain death legitimate, promoted by the development of immune restraining medicines, so that in U.S.A. since 1990 more than 2,000 heart transplant were performed every year. Compared with such a situation in U.S.A., in Japan since the Act for Organ Transplant was enforced in 1997, and from 1999 up to 2010 only 86 organ transplants after brain death in all, among them 70 heart transplants, were performed. There is no comparison between the two countries, so we notice that U.S.A. is a greatly advanced country with organ transplants.

Nevertheless in such an advanced country in organ transplants, U.S.A., in these years a little different movement appeared, namely controversies are very active about the definition of death that has already come to a social consent. On such a background, *CONTROVERSIES IN THE DETERMINATION OF DEATH, A White Paper of the President’s Council on Bioethics* (Washington DC, December 2008) was published. In this report it is recognized that “judging person’s death with whole brain death became difficult” from cases such as “long-term brain death”, and “come back alive from brain death”. The report pointed out at the beginning that the term “brain death” is problematic, that in the controversies about whether “brain death is person’s death” the term

including the word “death” let have a prejudice, so that they propose here the term “total brain failure” or more clearly “irreversible total brain failure”.

Moreover, the report paid attention to the method of “Controlled donation after cardiac death”. In this method the artificial inspirator of a patient retaining a little function of a heavily damaged brain is removed in accordance with the will of patient or family. After confirmed the stop of heartbeat and waited two till five minutes, the blood circulation in the brain stops and the cells of brain would perish soon. Immediately the waiting team for transplant harvests organs from the patient. In a word, the patient who doesn’t arrive at brain death would be brought to the stop of heartbeat and to be harvested immediately. This method, named Pittsburgh Method, was established in 1992, and performed in 793 cases in 2007. The report said that it will be also supported by people who don’t consider brain death as person’s death, so that with the help of UNOS (United Network for Organ Sharing) it is now rapidly spread in all over United States.

This White Paper shows that the U.S.A where brain death was very early legally defined as person’s death and people pushed forward with organ transplants after brain death have nowadays turned their attention to the problem of regarding brain death as person’s death, so that they are now seeking a way to make heart transplant possible not after brain death but after cardiac death.

In Conclusion

My paper mentioned at the beginning of this presentation was written on the background of controversies about the terminal care in Japan when the Japanese Ministry of Health, Labor and Welfare was wanting public comments to the “guideline concerning medicine at the terminal stage (a tentative proposal)”. There I wrote also about the terminal care as follows: “Therefore people think in Japan that the three standpoints, such as the first person of advance directives of the patient, the second person of consent by family etc, and the third person of judgment by medical staffs, need to keep a communication and build a mutual agreement through dialogue. I find it not bad as a situation in Japan, so that the idea doesn’t face a bad direction.”⁵

After that, by adding a small revision to the tentative proposal, the Ministry announced the “guideline concerning the decision process at the terminal stage” on May 2007. We can say that concerning the policy of the terminal medicine and caring, the posture of seeking a mutual

agreement through communication or dialogue of the three as least as an idea. It would be better, if we could find at least a similar posture also in the problem of organ transplant after brain death.

In the revised Act of Organ Transplant, compared with the guideline concerning the terminal care, the viewpoint of the third person of medical judgment got more weight, the viewpoint of the second person was turned rather to the decision about whether to agree brain death and organ transplant than to the caring for the patient in “brain death” state, and the viewpoint of the first person, especially about most people not expressing the will of donation, seemed to be forcibly interpreted to the will to donation. Although there are already some bibliographies about the second person viewpoint of the problem of organ transplant after brain death⁶, there is seldom enough considered about the first person viewpoint. Keeping watch these three perspectives, a phenomenological approach to this relationship would be now expected.

Notes

- 1 The original Japanese version of this paper was published in *Machikaneyama-Ronso*, No.44, Philosophy, 2010 December. This arranged English paper was read at the 4th International Conference of PEACE (Phenomenology for East Asian Circle), December 9-13, 2010, National Sun Yat-sen University, Kaohsiung, Taiwan. The Conference topic was “Border-Crossing”. The former speaker of my speech, Prof. Lester Embree (Florida Atlantic University) gave his speech “Some Phenomenology of not Retiring” in connection with his retirement at the university, whereas I gave my speech in connection with death as “Border-Crossing”. When we, or I, cross the border of life and death, who does or can decide it, whether I’ve already crossed the border or not? Medical doctor, I myself, or my family such as my wife or my daughters?
- 2 cpshama@let.osaka-u.ac.jp
- 3 “Caring of Life and Death -- from Phenomenological Anthropology of Caring --” in: *Philosophy*(edited. by The Philosophical Association of Japan), No.58, 2007.4.1.
- 4 This is the amount up to the day of the conference in Taiwan, whereas it has increased to 36 by now when I’m correcting this paper in March 2011.
- 5 See my paper above mentioned at the note 3 of this paper.
- 6 E.g. Masahiro Morioka, *The person in brain death –from the perspective of life-science*, 1989; Kunio Yanagida, *Gisei (Sacrifice) – my son: eleven days in brain death*, 1995.