Public Sphere for Brain Death and Transplantation in Japan

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Abstract: **"Brain death and organ transplantation" law was ratified in Japan in 1997 after a long debate on "brain death". On the one hand, it is difficult to make a political decision concerning the medical scientific issues such as "brain death" and "private issues" such as transplants. On the other hand, it is said that the "public sphere" in the context of Habermas would work to accumulate debates about even scientific and private issues in the process of decision-making. I would like to show that there were three dimensions of public spheres for brain death and transplants in the Japanese transplant history.**

In 1968 the first heart transplantation in Japan was performed. But this case was accused and since then heart surgeons became silent. Namely, even in medical journals heart surgeons had not talked about heart transplants. I would say surgeons left the "public sphere". However, the public sphere for brain death (Dimension1) grew later, when criteria for diagnosing brain death were established in 1983 and it brought on a lot of debate, which involved the general public and experts in the relevant fields. Dimension2 was built by patients. Instead of heart surgeons, patients built the public sphere by going overseas for transplants since 1984. Transplant abroad had been featured in the mass media. Doctors tried to rescue patients by transferring them overseas to places like the U.S.A. for transplants, since patients had no chance to survive as long as they were in Japan. This dimension functioned transforming the logic of dichotomy that a doctor was an evil. Dimension3 is "accusations." Kidney transplant surgeons had been accused of kidney transplants from brain-dead donors during 1984-1992 and this also stimulated discussions. Even accusations had grew a public sphere.

In conclusion, while heart surgeons had still been keeping silent, other actors had been building the public sphere in three dimensions which worked to ratify the brain death law.

Keywords: **public sphere, brain death, transplantation**

1. INTRODUCTION

"Brain death" law was legislated in Japan in 1997. The "brain –death problem" has a history of nearly 30 years in Japan and remains the most contentious of bioethical issues. A perusal of the well over 500 publications in Japanese on this subject since 1986 reveals a complex , often emotional discussion that leads to no conclusive answer as to why the country finds itself at this impasse.

There are many studies about the "brain –death problem" concerning the trans-domain issue which has the societal, bioethical and legal domains. Instead, I would like to analyze brain death problem in 1980's (from the time the patient participated in the public sphere to the time a special committee was set up)in the context of public sphere.

Edwards insisted that there is no adequate model available to picture the relationships between scientific expertise, public policy-making and the public. Quoting from Habermas's pragmatic model which provides for an active role to be played by the public, Edwards follows Taylor's definition of the public sphere as the common spaces in which the members of society meet (through a variety of media or face-to –face encounters) to discuss matters of common interest . This "public sphere" refers to a realm of social life in which citizens, scientific experts, and policy-makers communicate about public matters that need democratic control, agenda-setting, coordination, and societal learning(Edwards, 1999). Quoting this concept, Fujigaki insisted that the science arena and the policy arena should collaborate and couple together for problem solving in the "public sphere". Fugugaki, as to how to deal with the communication gaps between people who have different values and therefore impose different validation boundaries, for the purpose of problem solving, the validation boundaries would be required for integration of knowledge from different aspects .I would like to apply Fujigaki's concept to the process of accepting to the new definition of "death" in Japan. Before the legislation of the law, how had the "public sphere" functioned for actors? Had it provided not only the arena for social learning but also accumulated arguments by many actors such as surgeons(experts), patients, policy-makers, non experts and citizenry?

2. HISTORY OF HEART TRANSPLANTATION IN JAPAN

In 1968, just 1 year after the South Africa case, the 30th attempt was made in Sapporo, Hokkaido. The Sapporo transplantation initially was heralded as a dramatic medical triumph. However, several months later, the, surgeon in charge, Dr. Wada, was accused on a murder charge. Most Japanese believe, in retrospect, the patient whose heart was removed was not brain dead and that the recipient, who died 83 days after the operation, was not sufficiently in need of a new heart to have undergone the procedure(Lock, 1999,p.240.).

According to the report by the committee of the Japanese association for thoracic surgery, there were four questions concerning with this procedure, which were pathological findings of the recipient's heart, determination of the donor's death, resuscitation for donor and absent of anesthesiologist.

3. SILENCE OF SURGEONS

The first heart transplant was strongly criticized and the subject little mentioned until the early 1980s . Finally surgeons became silent. Heart surgeons had strained themselves from discussing heart transplantation on even academic papers. For example, in "kyoubugeka" which is academic journal for heart surgeons, from 1970 to 1983 there was no word of "heart transplantation" published. Also in another Japanese journal for cardiac surgeons "nihon kyoubugeka gakkai zasshi(Journal of the Japanese association for thoracic surgery)", it revealed that surgeons had reduced the experiment heart transplants with animals and the discourse of heart transplant also became reduced until 1982. The first paper after the long silence was written by Hirose about the experiment of heart transplant . In 1970's the number of heart transplants reduced through the world, since the surgical outcome had been poor at that time. Even so, silence of surgeons was unnatural, while patients who had no treatments but transplant still existed. Applying Fujigaki's context, I noticed that relationship between experts and the media had been dichotomy, since the media criticized surgeons as if they were evils. In democratic society, it is thought that private issue should be solved by themselves but not by the administrator, since issues in the private domain are usually not related to public concern. However, defining death is public issue, although the issue concerned with transplant is not public one. For the purpose of rescuing the patients, transplant issue should be set the agenda in public. Silence of surgeons meant that transplant problem would not be set agenda in the public sphere. Only what patients were able to do had claimed to surgeons but not to public (Fig. 1).

In 1974, the Japanese EEG Society's Ad Hoc Committee on Brain Death published criteria for determining brain death only in cases of acute gross primary brain lesions. However silence of surgeons still continued. Some heart surgeon criticized the media that wrote that heart transplant was no worth of the experiment on a living human in 1976.

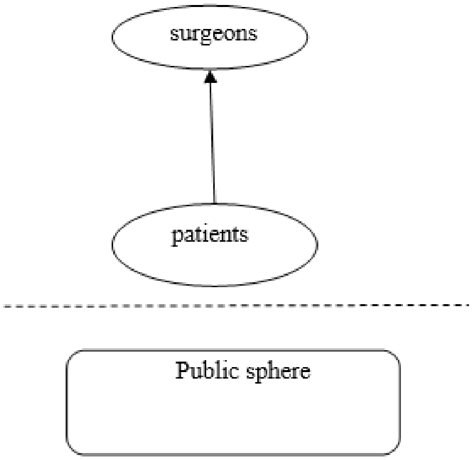

Fig. 1 Silence of Surgeons

4. DIMENSION FOR PUBLIC SPHERE: DEBATING BRAIN DEATH

In 1981 President's Commission for Study of Ethical Problems in Medicine and Biomedical and Behavioral Research drafted a uniform model death law in united states of America . Additionally the outcome of heart transplant became getting better because a new immunosuppressant had been innovated. Also in Japan a new brain death study group was organized to re-evaluate these criteria in 1983 and the new criteria of brain death was formulated by the Ministry of Health and Welfare's Brain Death Study Group in 1985 . Since then, public debating on brain death had come to arise. Newspaper article concerning brain death and transplantation had increased in number from 1984(10) to 1991(278).

Discussion “brain death” had been confused at some divisions such as medical experts, philosophical students, legal experts and so on. They had not noticed which should be first done. Should be practice first? Should be making law first? Or social consensus first? Some medical experts had believed that making law concerning brain death should be first. Responding it, some legal experts had believed social consensus should be first before making law. Some medical experts had believed practice should be first because the issue of brain death was not social issue but the pure scientific one. At the beginning of brain death debating, the relationship between expert and public had been paternalistic. Experts believed that the reason why public had not accepted brain death was public had been ignorant and so public should have learned it more. In the paternalistic context, there was only the one selection, whether public accepted or not and the problem had not able to solve (Fig. 2).

Other medical experts had believed “social consensus” should be first before practice. However it was also serious problem how social consensus had reached. Should all the people in Japan understand brain death completely? Before social consensus, some students had believed consensus among medical experts should be first. Some philosophical student insisted that brain death is not death and so we should not change the definition of death.

In the context of some of the media, there has been still scary diagnosing brain death by doctors because the organs could be harvested from the still living persons. This distrust has come from the first heart transplantation in Japan that was the accused case to investigate whether donor was diagnosed brain death. It indicated that there had been no patients in this public sphere.

We should consider how to deal with the communication gaps between people who have different values. Generally people including policy-makers had expected that it would have been possible to diagnose brain death precisely. However, as Fujigaki mentioned, scientific knowledge is contingent(Fujigaki, 2001). Even though the innovated procedure to diagnose brain death seemed to be perfect at that time, knowledge is always contingent on the conditions under which the data was gathered. For example, the diagnostic criteria of brain death has not been unification over the world in even 2002. It means that absolute true diagnosis may be illusion and so quality control and validation may be decided by citizens, advisory committees and other interested parties.

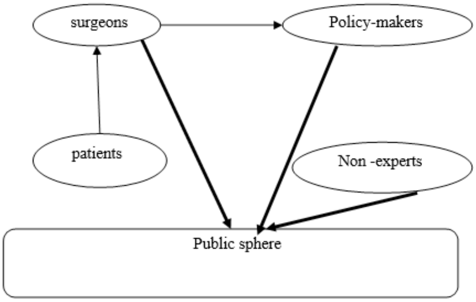

Fig.2 Dimension1: the public sphere for discussion

5. DIMENSION2 FOR PUBLIC SPHERE: PATIENTS ON THE PUBLIC SPHERE

5.1 THE PATIENT: AKEMI

After long silence, one patient(Nakata Akemi) described her feeling on the newspaper in 1983 , who had been waiting heart and lung transplantation because of heart failure (Eisenmenger syndrome). She had known that discussion of brain death had been getting hot recently in Japan but the possibility of transplant in Japan was still zero. She explained her sadness because while she could do nothing even concerning her life, brain death discussion had been hot among people that were unrelated to the patient(Goto, 1997). She also met Prof. Shummway who was a heart transplant surgeon in Stanford University in California and was invited Japan to have some lectures at the conference for surgeons. It was Prof. Manabe in Osaka who set the meeting between patient and Shummway in front of the media (Kawashima, 2009,pp.74-76). Nakata was the first Japanese patient on the waiting list in Stanford, though she died without transplant in 1988.

I would point out that Akemi was the first patient on the public sphere.

5.2 TRANSPLANT ABROAD

Although patients still has no opportunities of heart transplants in Japan, some of them went overseas for surgeries since 1984. When the patient had gone to USA in 1984, he told media that he was going to be a sacrificed stone and hoped other patients to follow. For this patient, a lot of money was raised. This fundraising in Japan was presented by media and so it gave opportunities people to think about transplantations and brain death. Other patients followed.

What the transplanted patients did was not only talking to media, but also publishing a lot of books about their experience. For example, the book was written by recipients, including the boy who unfortunately dead before going there, who had surgeries at the same hospital in UK

Many patients unfortunately were dead before transplants, though amount money had been raised for transplant abroad. The remained money were used to established another fund for other patients. Those actions were featured by media again. Consequently some networks among patients had been built like social movements, although those networks had been built by their families, since the prognosis of patients waiting heart transplant would be short such as one or two years . As long as patients remained in Japan, they would never survive. So all doctors could do was transferring patients to other surgeons abroad. Doctor's transfer worked for changing the situation with giving the pressure the government.

Citizenry became to realize that brain death problem was not only surgeon's problem but absolutely patient's problem. "Transplant abroad" helped to reform the relationship between experts and the media. Being released the dichotomy logic, communication gaps between experts and public got decreased (Fig. 3). This dimension functioned transforming the logic of dichotomy that a doctor was an evil (while a donor was a victim?).

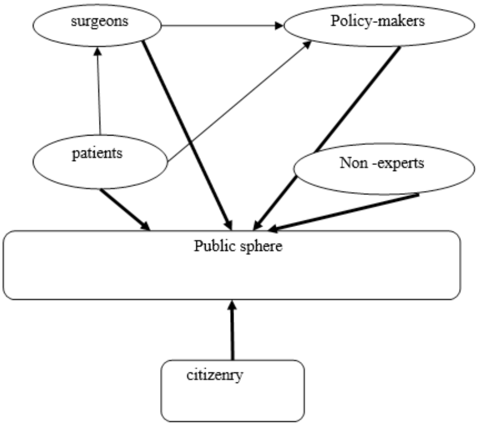

Fig.3 Dimension2: patients participate in the public sphere

6. DIMENSION3 FOR PUBLIC SPHERE: ACCUSATIONS

Some of kidney transplantations with brain dead organs had been accused from 1984to1992. In fact it was conflict between experts and other experts . Although it made surgeons frustrate a lot, media featured enthusiastically and played an effect role to make public sphere. Therefore the dispute by different type of experts had been opened to public. One of accused experts, Wakasugi professor of legal medicine, mentioned that debating brain death should be brought into court and so the prosecution would have to show the definition of death definitely.

However heart surgeons thought that transplants from the brain dead have come to be restrained even though no cases have been prosecuted. Also accusations lead some actors to do definite actions. For example, the directors of the Japanese Medical Association voted unanimously to accept brain death as the end of human life in January 1988(Lock, 1999,p.241.). Otherwise, In March 1990, a Special Cabinet Committee on Brain Death and Organ Transplants was set up.

7. CONCLUSION

In Japan, there had been long silence of surgeons since first heart transplantation in 1968. It was “takeuchi” criteria for brain death that was a breakthrough. Brain death discussion had come up, in which experts, non-experts and citizenry participated in 1983 through 1990. Public sphere for brain death had three dimensions, that dimension1 was brain death discussion by different actors who have different values, while there was no patients in the public sphere. Dimension2 was that patients had participated in. Transplants abroad and network of patients had affected different actors. This dimension functioned transforming the logic of dichotomy that a doctor was an evil Dimension3 was an accusation against surgeons. Although it was the conflict between experts, debating was opened and so public noticed that there was a dispute even among experts.

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