

Natural Right to Grow and Die in the Form of Wholeness: A Philosophical Interpretation of the Ontological Status of Brain-dead Children

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**Masahiro Morioka**

Osaka Prefecture University, Japan

I. Preface

The development of advanced medicine has created a number of ethical issues over the past 40 years around the world. Japan is no exception. In the early 1970s, women's liberation activists began their protest against the government to protect their freedom to choose abortion, and disabled people began criticizing the government policy that aimed to stipulate a selective abortion clause in the eugenic protection law. The Japanese grassroots bioethics movement was launched by feminists and disabled people. In the mid-1980s, a nationwide debate on brain death and organ transplantation occurred. Many journalists, physicians, lawyers, and ethicists got involved in fierce disputes over whether or not brain death was human death, and whether or not organ transplantation from brain-dead patients was allowed. Japan's first heart transplant was performed in 1968; however, due to the scandals of that operation, heart transplants were suspended for the following 30 years. The Japanese transplantation law was established in 1997.

We can find unique and stimulating philosophical discussions in the Japanese bioethics discourse, some of which are now beginning to attract the attention of researchers around the world (Lock 2001; Kato 2009). I gave an outline of Japanese bioethical discussions in this period elsewhere (Morioka in press); hence, in this paper, I would like to concentrate on the debate concerning brain death from the mid-1980s to the year 2009, and try to propose a new philosophical concept, the concept of "natural right to grow and die in the form of wholeness."

2. Establishment of the organ transplantation law

The issue of brain death has been debated more fiercely in Japan than anywhere else in the world. More than 200 books on brain death have been published, and most of them were books for the

Corresponding author:

Masahiro Morioka, Osaka Prefecture University, 1-1 Gakuen-cho, Nakaku, Sakai, Osaka 599-8531, Japan.

Email: morioka@hs.osakafu-u.ac.jp

general public. Some books written by famous journalists became best sellers; however, all of them were skeptical about the concept. The important features of the discussions on brain death made by these skeptics were, firstly, that they tried to talk about brain death from the perspective of family members of a brain-dead patient, and hence, secondly, that they attached great importance to the protection of a brain-dead person's body when the patient had not expressed their wishes for organ donation. I called their arguments, "human-relationship-oriented approaches to brain death," because they repeatedly talked about the preciousness and importance of human relationships between a brain-dead patient and his/her family members (Morioka in press).

After a long and twisted political process, a law on organ transplantation was finally established in 1997. (Hereafter I will call this "the first organ transplantation law.") This law was unique because it stipulated the prior declaration of a brain-dead person in the form of a donor card or label as a necessary condition for the legal determination of brain death and organ removal. The law states that if a person wishes 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 would then be considered dead when brain death is diagnosed. Those who object to brain death and/or transplantation do not need to have donor cards. They are considered to be alive until the heart stops beating. The law additionally requires that family consent is necessary both for legally declaring death at brain death and for organ removal. This law was based on the idea of "pluralism on human death" and "the donor's prior declaration principle" on brain death and organ transplants (Morioka 2001; Zeiler 2009).

The donor's prior declaration principle in the first organ transplantation law created a difficult problem. The government issued a guideline for the law and stipulated that organ donation from brain-dead children under the age of fifteen was prohibited because their declaration should be considered legally invalid. This meant that under this guideline small children with severe heart diseases cannot be provided with hearts from brain-dead child donors.

Soon after its establishment, a discussion for the amendment of the law began. Professor Saku Machino proposed his amendment that defined brain death as human death, and enabled organ donation from brain-dead bodies by family consent only. His proposal was aimed to revise the whole structure of the first law by abandoning its "pluralism on human death" and "the donor's prior declaration principle." Opposing his amendment, and trying to protect the spirit of the first law, Morioka, the author of this paper, and Tateo Sugimoto announced another amendment proposal, which lowered the minimum age of the prior declaration down to twelve (Plan A) or six (Plan B) while maintaining the basic structure of the law (Morioka and Sugimoto 2001).

In 2009, four amendment bills were presented to the House of Representatives, and after a series of intensive discussions, the amendment basically based on Machino's proposal was adopted at the Upper House. (Hereafter I will call this "the second organ transplantation law.") Under the second law, organ transplantation from brain-dead children became possible by family consent only, and brain death became human death in the case of transplantation unless the brain-dead person had denied the judgment of brain death beforehand.

3. Long-term brain death

In the following chapters, I am going to defend the spirit of the first organ transplantation law, and show the readers a new idea concerning the ontological status of brain-dead children. First, let me talk about "chronic brain death," or "long-term brain death." This term was created by Alan Shewmon (1988) in his paper "Chronic 'Brain Death'." Not only lay people but medical specialists have long believed that once a person became brain-dead, the heart of that person would stop beating within a week or so, and this conviction has lent support to the idea, "brain death is human death."

Shewmon's paper cast a significant doubt on our understanding of brain death. He analyzed 175 brain death cases that appeared in peer-reviewed medical journals, and found that "approximately 80 survived at least 2 weeks, approximately 44 at least 4 weeks, approximately 20 at least 2 months, and 7 at least 6 months." He added that "the longest survivors (2.7, 5.1, and 14.5 years) were all young children, two of whom were newborns, and all nine survivors beyond 4 months were younger than 18 years." (Shewmon 1988: 1540). He showed that there were many patients who became brain-dead in their childhood and "survived" for more than a month. He called this phenomenon "chronic" brain death. In the case of the boy who had been brain-dead for 14.5 years at that time, "[m]ultiple EEGs have been isoelectric, and no spontaneous respirations or brainstem reflexes have been observed over the past 14.5 years." (Shewmon 1988: 1543). As Shewmon suggests, there is an inclination that the younger the brain-dead patients are, the longer their hearts can keep on beating. This means that long-term brain death cases might constitute a grave problem especially when a small child becomes brain-dead.

Long-term brain death cases were also found in Japan. In 2000, the Study Group for Child Brain Death Criteria, the Ministry of Health and Welfare, published the report "Brain Death Criteria for Children," and announced the results of their extensive research on brain-dead children (Koseisho Kenkyu Han 2000). They sent their tentative plan for brain death criteria for children to medical facilities across Japan in 1998, and collected information about the cases in which children under the age of six were considered to become brain-dead. They emphasized in their paper that their criteria was a very "strict" one in terms of the world standard. Surprisingly, among 20 cases which strictly satisfied child brain death criteria including two apnea tests,¹ the hearts of 7 brain-dead children (35%) continued beating for more than 30 days, 4 children more than 100 days, and 2 children more than 300 days.

We can find one of those actual cases in the paper, "An Infant Case in Which the State of Brain Death Continues More Than 300 Days," written by Kazutoshi Kuboyama et al (2000). This is a case in which an eleven-month-old boy became brain-dead, strictly satisfying the above tentative criteria for brain-dead children including two apnea tests. In this case, his heart continued beating for 326 days. It is striking that the height of the brain-dead boy grew taller from 74cm to 84cm, and moreover, the boy continued moving his hands and legs frequently throughout the period. The authors of the paper wrote, "his bodily movement looked as if he were dancing when it reached the highest point" (Kuboyama et al 2000: 342). This movement is called "Lazarus sign," a phenomenon that is well-known among brain surgeons, but not well-known among lay people (Ropper 1984).

The growth and movement of brain-dead children can be frequently observed. This is completely contrary to our intuition of "brain death." In the last couple of years, some Japanese newspapers and TV programs began to report on long-term brain-dead children. On February 17, 2008, *Yomiuri Weekly Magazine* published an article on child brain death. This article writes about the boy who was diagnosed as brain-dead when he was one year old, and thereafter "survived" for seven years in the state of brain death. He satisfied every test required for brain death diagnosis, except for apnea tests, which the doctors did not perform because they thought it might be harmful to the patient, and when he was seven, the complete cessation of the blood flow of his brain was confirmed. Now he is staying at home, intensively cared for by his parents. Over these seven years, his height has grown taller by more than 30 cm, and his baby teeth have been replaced by adult ones. When the parents of 14 children with severe brain damage (including long-term brain-dead children) were asked whether or not brain death is human death, up to 13 replied that brain death is not human death, with one saying they had not reached conclusions. Hina, a daughter of Chisen Kamei, became brain-dead when she was one year old, and "lived" for 4 years in the state of clinical brain death. Chisen and her family believed that Hina was alive, celebrating her birthday every

year at the hospital with attending physicians and nurses. Although Chisen had a clear understanding that her daughter's brain did not function at all, she could feel a torrent of life in Hina's body, and concluded that the four years time they lived together was truly meaningful to the family and brain-dead Hina herself (Kamei 2002).

The Ministry of Health and Welfare's report, mentioned above, suggests that there is no test that can distinguish long-term brain death from short-term brain death. This is to say, even if a child is diagnosed brain-dead, it is actually impossible for us to foresee when the heart of the child will stop beating. It might be tomorrow, a month later, or even more than a year later.

Let us stop and think about a heart transplant from a brain-dead child. In the operation, the doctors cut through the chest of the warm body which can urinate, excrete, grow, and move hands and legs, and then they remove the beating heart from the brain-dead body. If you remove the heart from the brain-dead child, he/she will soon become a cold corpse. But if you do not remove the heart, or any other organs, the child might continue to grow in the state of brain death for more than several hundred days. There have been a number of donor families who donated their beloved children's organs in the state of brain death, but still did not know the above facts. What do they think when they learn these facts? If they had not given consent to donation, they might have lived with their brain-dead child for more than a year at the bedside. This is possible at least in Japan because hospitals usually do not encourage us to remove a respirator from a brain-dead patient even when the parents do not give consent to donation.

4. "Growing corpse"

Here we have come back again to the starting point: Is brain death human death, especially when a child becomes brain-dead? According to opinion surveys, 20%–40% of Japanese do not think brain death is human death. There are many parents who believe their brain-dead child is still alive. To them, their child is alive because they can perceive a fraction of "life" in every part of the child's body even if his/her brain has completely stopped functioning. For them, the brain is not the only essential organ for humans. They feel that the functioning of the heart, the arms, the legs, the skin, and every other part of the body are essential to human life. The arms and legs of a brain-dead child frequently move, and it is now clear that the child can grow taller in the state of brain death. If brain death is human death, it naturally follows that a brain-dead body is a "growing corpse" on the bed. This notion, "growing corpse," is completely contrary to our intuition of the "dead human body."

A proponent of brain death would argue that brain death is human death because a brain-dead human being has gone beyond the point of no return, and never regains consciousness in the future. However, the proponent would probably not be able to persuade the parents cited above, because they do not think that consciousness is the necessary condition for a human being to be considered alive. Although they are all well-educated citizens, they do not necessarily share a consciousness-centered concept of human life. Even if a brain-dead child has lost consciousness permanently, it is impossible for the parents above to regard their child as dead, as long as the child's body is warm, moves, and grows taller before their eyes.

In Japan, not only lay people but many scholars and journalists do not believe brain death is human death (for example, Takeshi Umehara, Yoshihiko Komatsu, Michi Nakajima, and others). Even in the United States, there are those who do not believe in brain death for religious reasons, such as some orthodox Jews and some fundamentalist Christians (Youngner and Arnold 1999; Potts, Byrne, and Nilges 2000). Inside the bioethics field, we should not forget the name of Hans Jonas, the exceptional philosopher who strongly denied the concept of brain death, supporting the idea that a brain-dead person should be considered alive (Jonas 1974). In recent years, there are a

number of bioethicists who deny the concept of brain death, and instead propose the higher brain definition of human death (Trough, Veatch, et al). In 2008, the President's Council on Bioethics, USA, published the report, *Controversies in the Determination of Death*. This report examined recent controversies on brain death, and concluded that the grounds for regarding brain death as human death are far from perfect, hence, our understanding of brain death should be theoretically reconstructed (President's Council on Bioethics 2008).

Let us move on to "organ transplantation" from brain-dead children. Think of small children who became brain-dead at the age of one or two. The children of this age do not have the ability to express their wish for organ donation even when they are alive and conscious. In such a case, what are the grounds that enable us to remove organs from those brain-dead small children? Removing organs from a brain-dead child is to forcibly stop his/her growth, and as a result, deprive him/her of an additional period of existence with a warm and growing body, which might have lasted for a month, a year, or more than several years if we had not removed organs. Why is this justified?

The first answer would be that because it is a dead body, it is justified. However, even if a brain-dead child is considered dead, it is still unclear why we can remove organs from the dead child. In many countries, the body of a dead child is not considered private property which the parents can freely dispose of. For example, the dismemberment of a dead body or selling the body parts by the parents is not allowed. This means that society does not regard a dead body as mere private property such as furniture or a pencil. The proponent would say it is justified because the removed organs will save the lives of other children. But again, I want to ask why saving other children's lives can justify the removal of organs from a brain-dead child who has not expressed any wish about removal. Some parents give consent in terms of love of humanity, and other parents give consent driven by the wish that the organs of their beloved children might survive in other people's bodies. However, we should remember that the parents are the guardians of their child, and hence what parents must do in the first place is to guard the body of their beloved child, especially during the stage in which their child has not yet had the ability to express his/her wish for organ donation. And moreover, I believe that parents should protect their brain-dead child even from "their own" desire, the desire to sacrifice the child for the sake of love for humanity, or the desire to make the organs continue surviving in other people's bodies. We have to keep in mind that this is the wish, or desire, of the parents, not of the brain-dead child him/herself. Of course, it should be accepted that parents decide to let their baby have surgery to cure his/her severe disease, because this decision is made for the benefit of their baby. However, in the case of organ removal, the parents' decision is made not for the benefit of their baby, but for the sake of other reasons. I think it is not justified to have invasive surgery against a child's body when it is not directly beneficial to the child him/herself. The only exception is the case in which the child has expressed his/her clear wish for organ donation beforehand.

Some people say we are obliged to dedicate ourselves to social solidarity, and organ donation is a way of expressing solidarity with people with severe illnesses. Saku Machino insists that every human being is considered to have made a self-determination to donate his/her organs at the time of birth (Machino 2000). However, to express solidarity or to make a self-determination is possible only when the person has the ability to express his/her solidarity, which does not hold in the case of a small child. Others say human bodies become common property when they die. But even if they are considered common property, it does not necessarily justify the medical use of their bodies, because it is still possible for us to decide to protect that common property from the invasion to satisfy our own desire. This resembles the argument by ecologists that our primeval forest (which is considered to be a kind of common property) should be protected from exploitation by our industrial civilization. It is very interesting to see that bioethics and environmental ethics share a similar argument on the protection of common property.

5. “Holy being” and “principle of wholeness”

In this section, I would like to make my own argument on the ontological status of brain-dead children. This is my tentative conclusion as a philosopher who has been involved in this issue for more than 25 years. Before moving ahead, I would like to say that while I am going to use some words with “religious” connotations in the following sections, those words are not derived from my religious standpoint, because I am agnostic and do not believe in (or deny) any religion.

The basic idea is that since the body of a brain-dead child is a “holy being,” it should be protected in the form of wholeness from other people’s desires to utilize it. Even if it is performed to save the lives of other children, an invasion against a brain-dead child, without consent of the child him/herself, should be prohibited. A child has the ability to grow in the state of brain death. A growing human being, whether alive or dead, is an existence which should not be treated as a mere instrument for someone else. A brain-dead child has a natural right to grow in the form of wholeness and die in the form of wholeness. Actually, a brain-dead child can grow on the bed, supported by a respirator and other medical instruments, and cared for by medical staff and family members. The child takes in nutrition, excretes waste, moves the hands and legs, shares time and space with the people surrounding him/her, until the time the heart stops beating. The growing process should be protected and cherished. After the cessation of heartbeat, the body goes cold, and it is sent to the funeral and cremated in the presence of family members. This process should also be protected and cherished. Throughout the process the brain-dead child is treated cordially, and the wholeness of the body is protected, because the brain-dead child has the right to be treated as such, free from the other people’s desire to utilize the child’s body. I believe this is the way in which a brain-dead child should be treated during the period when the child has not yet acquired the ability to express his/her wish for organ donation. In other words, the body of a brain-dead small child is a kind of sanctuary we have to keep away from.

At the same time, when a child grows enough to be able to express his/her wish for organ donation, the situation fundamentally changes. If a child who has expressed his/her clear intention becomes brain-dead, the natural right to grow in the form of wholeness has to be overwritten by his/her wish. Although in this case the brain-dead child is still considered to be a “holy being,” the natural right to grow in the form of wholeness gives way to the brain-dead child’s prior declaration. In other words, the holy body of the brain-dead child is righteously put under the control of the child’s prior intention. A brain-dead child is a holy being, and has the right to grow and die in the form of wholeness; however, in the case of the child who has the ability to express clear intentions, his/her wish should be given priority, overriding the holiness of the brain-dead body. This is the basic argument of the “principle of wholeness” regarding the ontological status of brain-dead children.

Then, what about a brain-dead child who had the ability to express his/her intentions about organ donation before becoming brain-dead but has not expressed any clear wishes for it? I believe this child should also be considered a holy being, and his/her body should be protected from outside invasion, just as in the case of the brain-dead child who did not have the ability to express his/her intentions before becoming brain-dead. Then, what about a brain-dead adult who was competent before becoming brain-dead but has not expressed his/her wishes? I think there is no significant difference in the ontological status between a brain-dead child and a brain-dead adult when neither has declared anything about donation. Of course, in the case of an adult the height does not grow, but every part of the brain-dead body continues to renew itself at the level of organs, tissues, and cells. He/she sweats, urinates, sometimes moves the arms and the legs, gradually dismantles the bodily functions, and moves toward the cessation of the heartbeat. If growing is a holy process and should be protected from outside invasion, the same should be applied to the dying process of a brain-dead adult, because it seems to me that the dying process is as solemn and holy as the

growing process. My argument is based on the idea that growing is equivalent in value to dying because dying is as important as growing for human beings. Please beware that I am not comparing life and death. I am just comparing growing and dying. This is a crucial point for my discussion. (An incompetent adult can be regarded in this context as similar to a child who does not have the ability to express his/her clear intentions.)

In short, what I want to argue is as follows: 1) all brain-dead persons, including adults and children, are “holy beings;” 2) if they have not expressed any clear wishes for organ donation, their brain-dead bodies should be protected from any types of outside invasion; and 3) if they have expressed clear wishes for organ donation, their wish should be given priority over the holiness of their brain-dead bodies. And this argument is exactly the one which constituted the basic idea of the first organ transplantation law, which existed from 1997 to 2009 in Japan. I came to realize this fact when I was preparing my speech manuscript that was to be read to defend the first law in a witness interview at the Upper House in July 2009.

This is my personal view, but the same thing must be applied to a heart-dead person as well, because a heart-dead person is still considered to be in the process of dying. That is to say, organ removal from a heart-dead patient should also be prohibited if the patient has not expressed a wish for organ donation. Heart-dead persons, as well, are considered “holy beings” in this sense. We find a similar sentiment in Chapter 190 of the Japanese criminal law, which stipulates that those who destroy or steal a (heart-dead) body should be punished. This is probably because ordinary people have long perceived a fraction of holiness in heart-dead bodies.

Hence, in my view, we could say that a human being comes into the world as a holy being, grows into a self-conscious subject, gets older, and becomes a holy being again, and goes back into nature. And unless there is a prior declaration, a holy being has the right to grow and die in the form of wholeness. Human life is nothing but a journey from a holy being to another holy being.

The result of my argument on organ transplantation is clear. Organ transplantation from brain-dead persons, whether adults or children, should be prohibited unless they have declared their wish to donate organs beforehand. This means that organ removal from brain-dead small children, who are considered to be incompetent, is prohibited without exception, and that organ removal from brain-dead adults who have not declared anything about organ donation is prohibited as well. You may be surprised to hear the conclusion, because my argument might sound intolerably heartless and ruthless. According to my view, the wishes of many children and adults who have been strongly longing for organ donation are to be destroyed without mercy. My argument has been heavily criticized by supporters of organ transplantation. I am a minority in Japan, because even many of those who are hesitant to accept brain death, surprisingly, agree to organ donation from a brain-dead patient if there is valid family consent. However, I can't find any persuasive grounds for removing organs from brain-dead patients without prior declarations, especially in the case of small children who do not have the ability to express their own wish for organ donation, no matter how many lives it can save.

It is important here to clarify the meaning of the words “outside invasion.” I mean by these words an act of destruction of the wholeness of the human body for the sake of fulfilling other people's desires. In other words, “outside invasion” is an act which does not benefit the invaded person him/herself. Organ removal from a brain-dead child is a typical example of this. On the other hand, an operation to save a baby is not an “outside invasion” because it is performed aiming to bring a great benefit to the baby.

Let us turn our eyes to a series of French laws on bioethics, which were established in 1994 and partially revised in 2004. These laws are quite interesting for our discussion because although their basic idea is similar to the principle of wholeness we have discussed so far, their conclusions about organ transplantation are obviously different from ours.

The French Civil Code stipulates in Article 16, Chapter 2, that “it guarantees respect for a human being from the beginning of its life,”²² and in Article 16-1 that “every person has the right to respect for their body. The human body is inviolable.”²³ The last phrase, “the human body is inviolable” represents almost the same idea as our “principle of wholeness.” An interesting point is that while it stipulates respect for a human being “from the beginning of its life,” it does not say anything about the end stage of human life.

Article 16-3 reads that “it is not allowed to impair the integrity of the human body unless there is the necessity for the medical treatment of that person, or unless it is an exceptional case performed for other persons’ medical benefit.”²⁴ This article implies that it is justified to remove organs for the benefit of other patients. Article L1232 of the Public Health Code stipulates organ transplantation from dead donors, saying that “organ removal is possible when a person has not expressed the refusal to the removal while the person was alive,”²⁵ and that “if the physician does not directly know the will of the deceased, the physician must try to acquire, from close people, by any means, the refusal of organ donation which might have been expressed by the deceased while the person was alive.”²⁶ This is the stipulation of presumed consent for organ transplantation from brain-dead patients.

Here a grave question arises. Why is organ transplantation from a brain-dead person who has not expressed his/her wish for donation justified? The answer would be that it may benefit other patients, which is stipulated as an exceptional case in Article 16-3. However, I do not understand why such a violation of integrity is justified if it is done for saving other patients, despite the fact that it does not benefit the brain-dead person him/herself. You might say that all of us have a sense of solidarity, hence, when a person has not expressed a refusal, it is highly probable that the person has carried a tacit sense of solidarity, that is, a tacit agreement to organ donation to fellow citizens. Concerning this reply, I would like to repeat my former argument and say that this theory cannot be applied to brain-dead small children, who have not had enough ability to think about solidarity, especially in the case of brain-dead babies of one or two years old. How can we say that even small babies have already developed a rationality that enables them to have their own opinions about solidarity in the form of organ transplantation?

Article L1232-2 stipulates that “if the deceased person was a minor, or an adult under guardianship, organ removal for one or several aims mentioned in Article L1232-1 is not allowed unless in the case where every person with parental authority or the guardian gives their consent in a written form.”²⁷ This is to say that in the case of a minor or an adult under guardianship who has not expressed anything about organ donation, the consent of persons with parental authority or the guardian is sufficient for organ transplantation. This way of thinking should also be criticized in terms of the principle of wholeness.

It is of course true that there are many patients who might die without organ transplants. They are desperately waiting for viable organs. Our position sounds too strict, rigorous, and harsh for those vulnerable patients and families. However, no matter how harsh it might be, organs ought to be removed only from people who have expressed their wish to save the lives of patients, and this should be the true meaning of “solidarity” in the context of bioethics.

6. Principle of wholeness and bioethical issues

The principle of wholeness prohibits organ transplantation from brain-dead patients, and in my view even from heart-dead patients, without prior declaration. This principle can be equally applied to other difficult bioethical issues. I would like to examine some of those issues one by one.

Experimentation on brain-dead subjects

Experiments on brain-dead persons, without their prior declarations, have been performed in some countries (Akabayashi and Morioka 1989). This kind of experiment ought to be prohibited. If a brain-dead person has given consent to the experiment, his/her wish should be deliberately and carefully examined by an ethics committee in terms of laws on organ transplantation and human experimentation.

Experimentation on small children

With regard to small children who do not have the ability to give consent (or assent), the experiments which are harmful and not beneficial to the children themselves ought to be prohibited, even if such experiments are considered to be beneficial to the health of the groups the children belong to. Alternative methods should be pursued in cases like these (Kurihara 2007).

Experimentation on fertilized eggs

Experiments on fertilized human eggs, or medical uses of them that involve the destruction of the eggs (for example, destruction to make ES cells), ought to be prohibited. In this connection, medical uses of the tissues or organs of aborted fetuses should also be prohibited.

Then, do fertilized human eggs have the right to grow in the form of wholeness in a petri-dish? If so, do we have the obligation to grow them as far as possible once we make them? It seems to me that according to the principle of wholeness, growing human beings have the right to grow in the form of wholeness, hence we have to continue growing as far as possible once we make them. Under current technologies, fertilized eggs will stop growing within a month in the petri-dish, hence what we should do is just to watch them grow and die in the liquid. Even in this situation, scientific observations are possible without invasion. And it is important not to throw them away until they stop growing and die.⁸

Termination of life-sustaining treatment

The principle of wholeness does not necessarily prohibit the termination of life-sustaining treatment, as long as the termination process does not constitute the destruction of the wholeness of the patient that is performed for the direct benefit of other people. For example, the cessation of an aggressive and extraordinary treatment for prolonging life of a terminal patient who has lost consciousness and has not expressed his/her wish for terminal care may be accepted from the viewpoint of the principle of wholeness. However, the artificial cessation of the respirator of a terminal patient for organ removal in the case of controlled donation from cardiac death (CDCD) should be prohibited (President's Council on Bioethics 2008). It goes without saying that it is extremely difficult to determine what treatments are considered aggressive and extraordinary in the context of terminal care.

Artificial abortion

Artificial abortion is nothing but an invasion from the outside to terminate the growth of a fetus, hence, at a glance it seems that it should be prohibited from the viewpoint of the principle of wholeness. But a fetus is a being which exists inside the womb, completely depending on the body of the mother, until 22 weeks from conception. A fetus is not an independent being during this

period. It cannot survive outside the mother's womb because it is physically connected to it. A fetus is, in this sense, a part of the mother's body. Hence, from a fetus's point of view, it should be that the mother is not a person who exists "outside" the fetus, and abortion is not an invasion from the "outside," because a fetus is inseparably incorporated into the mother's body. The principle of wholeness requires us to protect a fetus from "outside" invasion, but if our reasoning is right, abortion is not the invasion coming from the "outside." This means that abortion should not be prohibited because of the principle of wholeness. At the same time, it should be noted that the problem of abortion cannot be solved only by the principle of wholeness. More vigorous research on the philosophical aspect of the relationship between the fetus and the mother is needed.

Death with dignity and suicide

If organ transplantation from brain-dead persons based on their prior declaration is allowed, then it naturally follows that withdrawing life-sustaining treatment from terminally ill patients, based on their advanced directives, can also be justified in terms of the principle of wholeness, if it is performed with dignity, that is to say, in a gradual and deliberate manner. If this argument is right, we have to keep in mind that we should be very careful so that severely disabled patients or the elderly may not be forced to choose death, yielding to the surrounding pressure.

Then what about suicide? Since I hope all people will be able to live and die happily and without regret, I truly wish that the number of people who commit suicide from despair will radically decrease. However, if asked whether or not we have the right to commit suicide, I have to say suicide as a last resort should not be condemned in terms of the principle of wholeness. Of course, suicide is nothing but the destruction of the living human body, but this destruction is to be made by the prospective victim him/herself. At least from the perspective of the principle of wholeness, suicide should not be condemned, although it is not positively accepted or recommended. The relationship between suicide and the principle of wholeness will have to be discussed elsewhere in depth.

7. Conservative bioethics and the personhood argument

At first glance, my argument may look similar to that of proponents of conservative bioethics (Cohen 2006), but if we take a close look at the two arguments we can easily find the fundamental differences between them. The same can be said about the difference between my argument and the personhood argument, which many liberal bioethicists take for granted in their discussion (Singer 1993; Engelhardt Jr 1996).

Generally speaking, conservative bioethics insists that the life of a human being must be protected from the very start, that is, from the stage of a fertilized egg. They think that a fertilized human egg is a "holy being," hence it should be protected from outside invasion. As to this point, their argument is very similar to mine. And conservative bioethics and my argument share the attitude toward the termination of life-sustaining treatment of patients who have lost consciousness without expressing their wish for terminal care.

However, concerning other issues, their attitudes differ significantly from mine. The biggest difference lies in the attitude toward organ transplantation from brain-dead children. The majority of conservative bioethicists in Europe and North America seldom criticize it. While there are Christians and Jews who oppose brain death in those countries, they have remained a minority even in the circle of conservative bioethics.

Conservative bioethicists oppose abortion and suicide, but as we have already discussed, the principle of wholeness does not require us to condemn abortion or suicide. If we are asked whether the principle of wholeness denies them, we have to answer in the negative to that question.

Then what about the personhood argument? Generally speaking, the personhood argument insists that human beings who do not have a set of abilities such as self-consciousness, reasoning, and interests do not necessarily have a fundamental right to life. Many bioethicists who support the personhood argument show positive attitudes toward experimentation on fertilized eggs, termination of life-sustaining treatment, organ transplantation from brain-dead children, artificial abortion, suicide, and death with dignity.

They tend to think that human beings who do not have self-consciousness, the minimum ability of reasoning, or interests deserve a lower status than human persons who possess those properties.

On the contrary, the principle of wholeness requires us to regard those human beings as “holy beings” and protect them from outside invasion. It is extremely interesting that although both share the idea that those who can think, feel, or express themselves should be distinguished from those who cannot, the personhood argument and the principle of wholeness completely differ in their attitudes toward the latter people. For the personhood argument, human non-persons are beings that are allowed to be dealt with for the benefit of other human persons’ desires or wishes. For the principle of wholeness, human non-persons are “holy beings” and ought to be protected from outside invasion, unless they have declared their positive wishes for such invasion. We can find here a sharp contrast between these two arguments.

What we learn from conservative bioethics is the idea that the birth and death of human beings should be beyond our control, and that human life should be considered a holy being itself. What we learn from the personhood argument is that human persons are endowed with freedom to deal with their own life and body, as much as possible, by exercising their own free will. My argument aims to integrate the positive sides of these two ideas, by utilizing the concept of “the principle of wholeness.”

8. The principle of wholeness as a natural right

My basic idea was that growing human beings have the right to grow in the form of wholeness, and dying human beings also have the right to die in the form of wholeness; in other words, they have the right to be protected from outside invasion, unless they have declared their wish to abandon that right beforehand. I called this the principle of wholeness.

In contemporary bioethics, living human beings have the right to be protected from outside invasion, but dead human beings do not necessarily have such a right, hence it is possible, in many countries, to remove organs from brain-dead persons even when they have not declared their wish for organ donation. In this context the decisive line is drawn between being “dead” and “alive.” In contrast, the principle of wholeness requires us to protect growing or dying human beings from outside invasion, whether they are dead or alive. This is to say, regardless of being “dead” or “alive,” human beings in the process of growing or dying ought to be equally protected from outside invasion unless they have wished otherwise. This means that in our theory the determination of death or the determination of the stage at which a human embryo becomes an independent human being does not play a decisive role in the context of the justification of outside invasion. This is one of the important implications of the principle of wholeness in bioethics.

The principle of wholeness insists that the bodies of growing humans or dying humans are holy beings, and they should be considered inviolable. This is a very strong proposition, which is comparable to the concept of unalienable rights found, for example, in the US Declaration of Independence.⁹ The modern version of unalienable rights was first introduced by Thomas Hobbes, in the name of “right of nature,” and then developed by John Locke and others. I would like to take a brief look at their arguments and reconsider the principle of wholeness from the viewpoint of modern natural rights theories.

Hobbes writes in *Leviathan*:

The right of nature, which writers commonly call jus naturale, is the liberty each man hath to use his own power as he will himself for the preservation of his own nature; that is to say, of his own life; and consequently, of doing anything which, in his own judgement and reason, he shall conceive to be the aptest means thereunto.

(*Leviathan* Ch.14)

He says the right of nature means the liberty we have for the preservation of our own life, and this liberty is exercised by our own judgment and reason. And this right includes the right to defend ourselves. We cannot lay down the right of resisting people who are aiming to take away our life. Hobbes regards the right of defending our own life as an inviolable fundamental right in the natural condition. And in his theory, it seems that only living persons who have the ability of judgment and reasoning are entitled to have the right of nature.

John Locke writes in *Two Treatises of Government*:

Whether we consider natural reason, which tells us, that men, being once born, have a right to their preservation, and consequently to meat and drink, and such other things as nature affords for their subsistence. ...

(*Two Treatises of Government*, Book II, Chapter 5, Section 25)

Locke regards the right to preservation as a fundamental natural right, that is, something which is given unconditionally to everyone when we are born. And people have power (or a right) to preserve their lives against “the injuries and attempts of other men” (Chapter 7, Section 87).

Both Hobbes and Locke stress that people have a natural right to preserve their lives against violation or invasion from other people. The problem is that they seem to think that this right of preservation is given to rational adults, not babies or brain-dead persons. Locke, referring to the status of children, argues that parents “have a sort of rule and jurisdiction over them” (Chapter 6, Section 55) because children do not have understanding. Hence, parents must govern their children, and make a decision on their behalf. However, it is not still clear whether parents have a right to allow other people to invade the bodies of their children when they become brain-dead.

Anyway, we have to keep in mind that in the age of Hobbes and Locke, there were not brain-dead patients in a hospital or fertilized eggs in a clinic. Lives were given to human beings when they were born from their mothers, and they lost lives when they were deceased or killed to become cold dead bodies. The situation surrounding human life and death was completely different from our age. We have to keep in mind also that while in their age almost no value can be found in dead bodies, in our age dead bodies have come to possess much value, that is to say, they can be used as a resource for transplantation, and their tissues are utilized to create materials originating from human bodies for medical operations. In order to protect peripheral human lives, such as brain-dead patients and fertilized eggs, from the desires of outside people, we have to think a little differently from Hobbes or Locke, and try to figure out what kind of natural right is to be ascribed to such peripheral human beings. What is needed is to create a new way of thinking about the irreplaceable value of silent and vulnerable human beings in the age of science and technology.

Natural right is inviolable right, which is given to all human beings when they are born. According to contemporary knowledge, a biological human being is born when a fertilized egg comes into being. Hence, we have to think that a natural right to grow in the form of wholeness is given to a fertilized egg when it comes into being. A dying human being also has a right to die in

the form of wholeness, whether their brain is dead or alive, until all the activities of bodily cells stop functioning, because their each and every active bodily cell, which constitutes the integral function of the dying body, comes from the cells of a single fertilized egg to which a natural right to grow in the form of wholeness was given when it came into being. Just as the total sum of activities of living cells of a fertilized egg constitutes the wholeness of the egg, the total sum of activities of living cells of a dying person (including a brain-dead person) is also considered to constitute the wholeness of the person that should be protected from outside invasion. It is a known medical fact that the body of a long-term brain-dead patient maintains a kind of biological integrity without brain function.

In my opinion, natural rights have to be extended to include the right to grow and die in the form of wholeness in the age of scientific civilization, where peripheral human lives are being threatened by aggressive biomedicine and other advanced technologies. This is what I have learned from the debate regarding brain death and organ transplantation over the past 25 years in Japan.¹⁰

Notes

1. This is the test for confirming that the patient is in the state of no breathing.
2. Article 16: “La loi assure la primauté de la personne, interdit toute atteinte à la dignité de celle-ci et garantit le respect de l'être humain dès le commencement de sa vie.”
3. Article 16-1: “Chacun a droit au respect de son corps. Le corps humain est inviolable.”
4. Article 16-3: “Il ne peut être porté atteinte à l'intégrité du corps humain qu'en cas de nécessité médicale pour la personne ou à titre exceptionnel dans l'intérêt thérapeutique d'autrui.”
5. Article L1232-1: “Ce prélèvement peut être pratiqué dès lors que la personne n'a pas fait connaître, de son vivant, son refus d'un tel prélèvement.”
6. Article L1232-1: “Si le médecin n'a pas directement connaissance de la volonté du défunt, il doit s'efforcer de recueillir auprès des proches l'opposition au don d'organes éventuellement exprimée de son vivant par le défunt, par tout moyen”
7. Article L1232-2: “Si la personne décédée était un mineur ou un majeur sous tutelle, le prélèvement à l'une ou plusieurs des fins mentionnées à l'article L. 1232-1 ne peut avoir lieu qu'à la condition que chacun des titulaires de l'autorité parentale ou le tuteur y consente par écrit.”
8. Of course, artificially making fertilized eggs itself might be problematic. This needs further investigation.
9. “We hold these truths to be self-evident, that all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness.” Declaration of Independence, 1776.
10. This paper was written from the viewpoint of “philosophy of life,” which I have proposed in recent years with the help of my colleagues. Philosophy of life is a new academic field that encourages us to investigate, from a philosophical point of view, the ideas and concepts concerning life, death, and nature that appear in bioethics, environmental studies, and other humanities which deal with these topics. If you are interested in this project please contact the author at www.lifestudies.org.

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