

Title	Feminism, Disability, and Brain Death : Alternative Voices from Japanese Bioethics
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Editor(s)	
Citation	Journal of Philosophy of Life. 2015, 5 (1), p.19-41
Issue Date	2015-07
URL	<a href="http://hdl.handle.net/10466/14559">http://hdl.handle.net/10466/14559</a>
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# Feminism, Disability, and Brain Death

## Alternative Voices from Japanese Bioethics

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### Abstract

Japanese bioethics has created a variety of important ideas that have not yet been reflected on mainstream bioethics discourses in the English-speaking world, which include “the swaying of the confused self” in the field of feminism, “inner eugenic thought” concerning disability, and “human relationship-oriented approaches to brain death.” In this paper, I will examine them more closely, and consider what bioethics in Japan can contribute to the development of an international discussion on philosophy of life.

### 1. Introduction

In the early 1970s, Japanese women’s liberation activists and disabled people began a harsh debate with the government over the issue of abortion and selective abortion. This was the beginning of the Japanese grassroots bioethics movement. It is striking that Japanese bioethics was launched by feminists and disabled people.

In the mid-1980s, the debate on brain death and organ transplants emerged and developed into a nation-wide controversy. It lasted 15 years until 1997, when the Japanese Organ Transplantation Law was finally established.

The word “bioethics” was imported to Japan in the 1970s, via the translation of V. R. Potter’s book *Bioethics*,<sup>1</sup> as a science of survival in the age of global environmental crisis, and re-imported in the late 1980s as an academic discipline which dealt with the ethical issues arising from advanced medicine. The Japan Association for Bioethics was established in 1988. In the beginning, bioethics was accepted as a discipline imported from the United States and other European countries. Academicians ignored the grassroots bioethics movements in Japan, and tried to institutionalize bioethics as an academic discipline. After the turn of the 21<sup>st</sup> century, some leading universities established medical ethics

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<sup>1</sup> Potter (1971).

courses in their graduate schools. Today, the first stage of institutionalization seems to be complete. But today, while members of grassroots activists have opened up the lines of communication with academic societies, the gulf between them still continues to exist.

Japanese bioethics is not just a copy of American or European bioethics. We have developed our own discourses especially in the fields of feminist bioethics, the bioethics of the disabled, and the issues surrounding brain death. In the following sections, I will examine these topics more closely, and consider what bioethics in Japan can contribute to the development of an international discussion.

## 2. Feminist Approaches to Bioethical Issues in the 1970s

In Japan, abortion became legal in 1948, when the Eugenic Protection Law was established. However, in the late 1960s, the government began to seek to limit abortion rights, because it feared that increased abortions would result in a decrease in the population. In 1972, the Eugenic Protection Law Amendment Bill was presented to the Diet. One of the aims of this bill was to restrict women's access to abortion. The bill stipulated that the "economic clause" should be abolished because many women had used this clause as a reason to choose abortion. Actually, more than 99% of abortions were performed solely based on economic reasons.

Soon after the announcement of the government bill, Japanese women's liberation activists started a movement to abolish it, which was called "the Movement against the Eugenic Protection Law Amendment Bill." It is extremely interesting that while European and North American feminists were fighting to "acquire" the right to legal abortion in the early 1970s, Japanese feminists were fighting to "protect" their right to abortion they had already acquired in 1948. The assertions made by Japanese women's liberation activists can be categorized as follows:

- a) The state should not interfere with the sex and reproduction of individual women.
- b) It is a women's right (or freedom) to choose whether or not to give birth.
- c) We need a society where women can give birth in peace! We need a

society where women become inclined to give birth!

The first two assertions are familiar to readers, but the third might be new. Let us take a look at these three arguments one by one.

The first asserts that the state should not interfere with women's bodies and reproductive rights because these issues ought to be privately decided upon and claimed by women. This is an argument of women's self-determination against abuses of power. It was widely shared by women activists in that period. In this context, women's rights were claimed as a right of resistance against the state.

The second assertion is about women's right to abortion. Many women's liberation groups at that time talked about the importance of the freedom of abortion in their leaflets and articles. Among them, *Chupiren*, the activist group established in 1972 by Misako Enoki, proclaimed the most radical pro-choice opinions. *Chupiren* wrote in their magazine that it was women's fundamental right to decide whether or not to give birth,<sup>2</sup> and described abortion as follows.

A child is something that a woman has nurtured by giving her own blood and flesh. It is, in a sense, a part of the woman's body, hence, abortion is an act of self-destruction. Actually, it is we ourselves that are injured and suffered. Even if a woman cut off her hand, while trying to endure pain, nobody has a right to condemn her act. It is just as if a lizard cuts off the tail for its own safety. The woman should not be condemned by the establishment or men.<sup>3</sup>

However, we should note that an opinion like this was not necessarily the common view of pro-choice groups. If we take a closer look at the opinions of pro-choice women at that time, we can find a variety of ideas concerning women's right to abortion.

The third assertion is that we should create a society where women can give birth in peace when they decide to have children. This opinion is based on the sentiment that while women ought to decide whether or not to give birth, something must be wrong with the word "right" in the context of abortion. Hence, they sought to protect women's freedom of choice without using the word "right." The appeal, "We need a society where women can give birth in

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<sup>2</sup> *Neoribu (Neolib)*, no.11, 1972, p.2.

<sup>3</sup> *Neoribu (Neolib)*, no.32/33, 1973, p.4.

peace! We need a society where women become inclined to give birth!,” was made in 1973 by the Ribu Shinjuku Center, the most important networking center for pro-choice women at the time. This appeal aimed to overcome the idea that “abortion is a women’s right” from the perspective of a pro-choice philosophy. An uncomfortable feeling about using the word “right” in the context of abortion was expressed by other women’s liberation groups as well. At the root of this resistance was the sentiment that abortion is nothing but the destruction of life, a life that has the possibility of developing into a human being.

Mitsu Tanaka, the founder of the Ribu Shinjuku Center and a charismatic leader of the women’s lib movement, published the article, “We Dare to Propose: Is Abortion a Vested Right?” in 1972, questioning the idea that abortion is a women’s right. I believe this was the most philosophically important document published in the feminist movement against the Eugenic Protection Law Amendment Bill in the 1970s. The year 1972 ought to be recognized as the birth year of Japanese feminist bioethics, for it witnessed the publication of not only this article, but Tanaka’s first book, *Inochi no On’na Tachi e (For Women Who are Inochi Themselves)*<sup>4</sup>.

In “We Dare to Propose,” Tanaka writes:

We know the expression, “It is a women’s right to choose whether or not to give birth.” Does this mean that a child in a woman’s belly does not have the right to live, when the woman exercise her right to abort!?! But if the child in the belly is a human being, it must have the right to live. **What** on earth does the woman actually conceive in her belly?<sup>5</sup> [Emphasis in the original]

At first glance, Tanaka’s words look like those of pro-life activists, yet, her intention is completely different. She continues:

Let me repeat to make sure what I mean. We must persistently condemn the evil of society as the evil of society. But even if we seek to justify abortion by a logic as this: “because we live in such a society” or “a fetus

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<sup>4</sup> Tanaka (1972).

<sup>5</sup> Mizoguchi et al. (1994), p.61. (The original Japanese of the last sentence is: On’na wa sono hara ni ittai **nani** o haramu no ka?).

is not a human being,” something uncomfortable still remains in us, and without persistently pursuing that “something,” we cannot conquer the idea of sanctifying the life of a fetus. This is the question of the meaning of life (inochi), which has nothing to do with ethics or pseudo-humanism.<sup>6</sup> . . . .

When I choose abortion on my own initiative, in the circumstance that women *are forced to* choose abortion, I want to consciously keep in mind that I am nothing but a killer. Since a fetus will die actually, if people call a woman who has an abortion a “killer,” I become defiant and say that yes I am a killer, and then I want to choose abortion. Staring at the chopped up fetus, I admit that yes I am a killer, and then I want to make every effort to denounce our society that makes women kill their fetuses.<sup>7</sup> [Emphasis in the original]

By the words “women are forced to choose abortion,” she accuses a society in which women are likely to be hesitant to give birth, and also accuses men who have created such a society. I want to stress that Tanaka was not a pro-life feminist; she admits that if she choose abortion she becomes a killer, and stresses that she should not turn her eyes away from the fact, but she does not mean by these words to condemn the act of abortion performed by women in general. Instead, she means to find fault with the power of the states, and the individual men who force such harsh and painful experiences on women and their bodies. This is the reason why Tanaka insists that while abortion is not morally justifiable, the freedom of choice must be given to women. (This point will be discussed again in more detail in Section 3.) This may sound like a contradiction, but living this kind of contradiction here and now is, for Tanaka, the basis of women’s liberation. She calls it “the swaying of the confused self (torimidashi).”

Tanaka believes that a woman who chooses abortion sways between two kinds of honest feelings (hon’ne), that is, the feeling that the freedom to choose abortion ought to be given to women, and the feeling that if she chooses abortion she becomes a fetus killer. She is thrown into a state of that oscillates between these two feelings. Tanaka says that women should begin from this swaying of the confused self, because it leads to encounters with other women

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<sup>6</sup> ibid. p.63.

<sup>7</sup> ibid. p.63.

who also move between other types of honest feelings in the midst of their lives. Real encounters are possible, Tanaka thinks, only between women who sway and suffer between honest, contradictory feelings. For Tanaka, the goal is not to solve the dilemma, but to embrace these contradictions in one's life. She writes:

Women's lib starts from two opposite honest feelings. It begins with the swaying between them. In a woman being confused and swaying between two honest feelings in the "here" and "now," we can find the real warmth of a flesh-and-blood woman who has been forced to get twisted in various ways as the result of the historical accumulation of considerable hardships.<sup>8</sup>

This idea lies at the heart of Mitsu Tanaka's women's lib movement, and was widely shared by feminists who were deeply influenced by her thought at that time. The following is an excerpt from a leaflet issued by their group, the Ribu Shinjuku Center, in 1973.

Women cannot rationalize the pain of their bodies when they *are forced to kill their fetuses*. Women must not rationalize it. ....

Condemning the evil of society where women cannot give birth, let us face up to chopped up fetuses. A society that forces women to kill fetuses does not let women live. The next victim is to be women. ....

Believing ourselves who have truly faced up to a human life, the life of a fetus, and bearing in mind the fear and seriousness of subjectively choosing one's own life course, our fellow women, let us cry now, "We need a society where women can give birth in peace! We need a society where women become inclined to give birth!" [Emphasis in the original]<sup>9</sup>

The above slogan became one of the most widely shared slogans among women's lib activists at that time. It is striking that many pro-choice women avoided using the words "the right to abortion" when fighting against pro-life people and the suppressive government.

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<sup>8</sup> Tanaka (1972), p.69.

<sup>9</sup> Mizoguchi et al. eds. (1994), p.178.

### 3. Disabled People's Approaches to Bioethical Issues in the 1970s

Let us turn to the political movements of the disabled in this same period. In the late 1960s, some disabled people with cerebral palsy (CP) joined the "Blue Grass Group (Aoi Shiba no Kai)," a friendship society for people with CP, and began living independency in the Kanagawa Prefecture.<sup>10</sup> Among them were Koichi Yokotsuka and Hiroshi Yokota, both of whom soon became the spiritual leaders of their group. As soon as they joined the group, they began protesting against discrimination toward disabled people, which was found in every part of our society. In 1970, a mother living in Kanagawa prefecture killed her CP child, an incident that was widely reported in the news. Surprisingly, the general public sympathized with the mother, not the murdered child. Yokotsuka, Yokota, and other disabled people were deeply shocked by this phenomenon, and harshly criticized the attitude of the general public. The public's attitude was driven by the idea that "life with disability" or "living with a disabled child" should be full of distress and unhappiness. Yokotsuka and Yokota called this idea "the egoism of the healthy people," insisting that this egoism among people served as the main source of discrimination against disabled people. They thought that what most strongly suppressed and bound disabled people was their parents, hence, it was necessary first and foremost for them to be liberated from their parents.

Hiroshi Yokota published the declaration of activity, "We Act Like This," in their journal *Ayumi* in 1970. The following is a translation of this epoch-making document.

#### *We Act Like This*

The Blue Grass Group (Aoi Shiba no Kai), 1970

\* *We identify ourselves as people with Cerebral Palsy (CP).*

We recognize our position as "an existence which should not exist," in the modern society. We believe that this recognition should be the starting point of our whole movement, and we act on this belief.

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<sup>10</sup> "Blue Grass Group" is a literal translation of the Japanese, "Aoi Shiba no Kai." In Japanese, "grass" is usually referred to as being "blue," not "green." Shoji Nakanishi writes. "It is true that Blue Grass Movement (Aoi-shiba) by people with Cerebral Palsy in Japan started in the 1960's and they fought against discrimination protesting 'Disability is one of the characters of a person.' This philosophy was very close to the Independent Living Philosophy." See Nakanishi (1997).



\* *We assert ourselves aggressively.*

When we identify ourselves as people with CP, we have a will to protect ourselves. We believe that a strong self-assertion is the only way to achieve self-protection, and we act on this belief.

\* *We deny love and justice.*

We condemn egoism held by love and justice. We believe that mutual understanding, accompanying the human observation which arises from the denial of love and justice, means the true well-being, and we act on this belief.

\* *We do not choose the way of problem solving.*

We have learnt from our personal experiences that easy solutions to problems lead to dangerous compromises. We believe that an endless confrontation is the only course of action possible for us, and we act on this belief.

(Translation by Osamu Nagase, italics by Morioka. See note<sup>11</sup>.)

In 1972, the Eugenic Protection Law Amendment Bill was presented to the Diet. As I have already noted, this bill aimed to restrict women's access to abortion, but at the same time, contained a clause for selective abortion of a fetus with severe disabilities. The Blue Grass Group strongly opposed this bill because in it they found a principle that leads to the denial of the existence of disabled people. In the leaflet, *Is It Natural that Disabled People Should be Killed?: An Objection to the Eugenic Protection Law Amendment Bill*, published in 1972, they wrote:

We “disabled people” are alive. We really want to live.

Actually, a number of fellows are struggling to survive their hardships.

And no one but disabled people themselves should judge whether their way of life is “happy” or “unhappy.” Much less can we admit the egoism

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<sup>11</sup> Aoi Shiba no Kai, *Ayumi*, no.11 (1970). Osamu Nagase's translation is found at < <http://www.arsvi.com/o/a01e.htm> >. His further commentary: “The following fifth point was added at a later date. <\*We deny able-bodied civilization. We recognize that modern civilization has managed to sustain itself only by excluding us, people with CP. We believe that creation of our own culture through our movement and daily life leads to the condemnation of modern civilization, and we act on this belief.> NB. Please note that this translation part was updated in March 2002.”

of healthy people which leads them to kill disabled fetuses because they are “defective descendents,” and moreover, leads them to justify their killing by saying that it was done “for the happiness of disabled fetus (people) themselves.”

All of you citizens, students, and workers.

We strongly oppose the Eugenic Protection Law Amendment Bill, which is based on the idea that fundamentally denies the existence of “disabled people” and seeks to totally eliminate “disabled fetuses” in their mothers’ wombs.<sup>12</sup>

Their objections to the bill were as follows.

First, the bill contained the idea of the “elimination of disabled people.” Adding a clause for selective abortion of disabled fetuses is equivalent to legally declaring that disabled people are not welcome in our society, which bears the implication that a disabled person is “an existence which should not exist.” As a result, their lives might be threatened much more than our times.

Secondly, the addition of this clause psychologically disempowers the disabled. If such a clause were to become implemented, in this age of biotechnology, many people would gradually come to think in front of them, “In this age of prenatal screening, why were congenitally disabled people like you born at all?” or “I wish you were not born.” Implicit in the question is the silent desire for the disabled to disappear. Surrounded by these kinds of unspoken words and glances, disabled people are gradually deprived of both the power to affirm themselves and the courage to live. In such a society, the majority of people would choose to abort severely disabled fetuses; to existing disabled people, this means that the majority of people do not wish to live with them. Even if this majority remains silent, their unconscious attitudes and glances would naturally express their inner thoughts about the disabled. Encountering such attitudes, disabled people will come to fully realize that they are unwelcome guests to society, and this consciousness deprives them of self-affirmation as people with disabilities.

Third is the idea that “people without productivity” are to be abandoned from society. Those who lack the ability to produce goods, for example, not only people with congenital disabilities, but those who became disabled by accident

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<sup>12</sup> Taken from the 1972 leaflet. The words “defective descendents” can also be found in Article One of the Eugenic Protection Law.

or disease, as well as senior citizens and physically weak people, are doomed to fall victim to discrimination and abandonment.

In 1972, both women's lib activists and disabled people formed a united front against the government, and struggled to abolish the amendment. At first, their united front seemed to be successful; however, the Blue Grass Group activists began to take issue with a "woman's right or freedom to choose abortion." They believed that if women were afforded such freedom, then it logically followed that women had the freedom to choose abortion even when their fetus is found disabled; this was exactly what the disabled had so harshly criticized. They then concluded that if "the right or freedom to choose abortion" includes "the right or freedom to choose selective abortion," then it must be rejected, and accused women's lib activists of having the "egoism of healthy people" inside their minds and hearts. Today, this incident is called "the conflict between women and disabled people."

The accusation was taken seriously by feminists at that time. Among them, the women's lib group, Kawasaki Women's Conference, published the following statement in a 1973 leaflet:

First of all, we have to criticize ourselves for the fact that we ourselves have been eroded by eugenic ideology, and have discriminated and suppressed disabled people. ....

We have been occupied with the logic of efficiency, and have considered rapidity as virtue. We have been wishing to have healthy and normal babies. In thinking about all these things, it is crystal clear that we have to start, in the first place, by confronting our own inner eugenic ideology.<sup>13</sup>

Women at the Kawasaki Women's Conference honestly accepted the criticism, and swore to confront their own inner eugenic ideology and transform their discriminative consciousness. After that, they believed, they would once again become entitled to fight against the government and discriminative power. This was one of the most sincere responses to the criticism made by disabled people.

Special attention must be paid to the words, "inner eugenic ideology." This

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<sup>13</sup> Aoi Shiba no Kai, *Ayumi*, no.19 (1973), p.14.

phrase strongly implies that the fundamental problem lies not outside, but “inside” us. The word “inner” was added to emphasize this. Later in the 1980s, activists began calling this notion “inner eugenic thought,” and this phrase became a keyword in contemporary Japanese bioethics.

Disabled people themselves found independently the same idea during their struggle against eugenic thought. Yokota wrote about a CP woman who, when she became pregnant, naturally wished her baby to be healthy and normal. He argued that this implied that she was occupied by eugenic thought, and that wishing a healthy and normal baby was equivalent to denying not only her own existence as a CP woman but also the existence of CP people in general. Yokota had to admit that “inner eugenic thought” (he called this “illusion toward healthy people” in his writings) was shared not only by a majority of people, but also by disabled people themselves. They found enemies both outside and inside them. This meant that their fight had to be twofold, both against the discriminative society, and against the eugenic thought within themselves. This was one of the deepest points reached by the Japanese bioethical movement in the early 1970s.

In 1973, the Lib Shinjuku Center issued a leaflet for a gathering against the amendment bill, in which they used the phrase mentioned earlier: “We need a society where women can give birth in peace! We need a society where women become inclined to give birth!” The intention was to emphasize the wish to create a new society where women can really hope to give birth regardless of whether or not their babies are disabled. The Lib Shinjuku Center wrote in the journal *Lib News* that “the right to abortion does not contradict with the liberation of disabled people.” Feminists called for disabled people to form a cooperation, and the paradigm of a united front between women and disabled people was created once again. This paradigm prepared a firm basis for the development of the Japanese grass-roots bioethics movement in the late 70s and 80s.

Japanese bioethics was created by feminists and disabled people as a grass-roots movement. Their thoughts and discussions never took on an academic form, but in their discussions, we may find plenty of fruitful philosophical insights and contemplations.

#### 4. Inner Evil and the Fundamental Sense of Security

Here I would like to examine a couple of philosophical ideas that can be

found in the bioethical thinking of feminists and disabled people of this period.

First, I want to pay special attention to Mitsu Tanaka's words concerning abortion. In contemporary bioethics, especially in American bioethics, people's opinions about abortion are sharply divided into two camps: pro-choice, and pro-life. Those who take a pro-choice position insist that women have the right to choose abortion in certain circumstances, and in those cases abortion ought to be justified from a moral point of view. In contrast, people who take the pro-life position insist that women do not have such a right, and that abortion ought to be morally condemned.

However, Tanaka's philosophy does not adhere exactly to either of these positions. Remember her words: "if people call a woman who has an abortion a 'killer,' I become defiant and say that yes I am a killer, and then I want to choose abortion." Here Tanaka stays away from the moral justification of abortion. Of course, women are not natural born killers. As Tanaka puts it, women are "forced to choose abortion." In this sense, women who choose abortion are victims of a discriminative society. But at the same time, Tanaka stresses that when she chooses abortion, she wants to consciously remember that she becomes a killer. She goes on to state that the society that discriminates is to blame, not women themselves, and that our society must transform itself into one where all women who wish to have babies can give birth in peace. She believed that at the very least, until the coming of such a society, the freedom to choose abortion must be given to women.

Tanaka's reasoning is very unique. She affirms the freedom to choose abortion, but at the same time, denies abortion's moral justification. Her position unhinges the dichotomy between pro-choice and pro-life.

Tanaka's thought may reflect many people's feelings that while the freedom to choose should be given to women, the act of abortion itself cannot be seen as completely evil-free. But her position should not be considered as a mere compromise between pro-choice and pro-life. Instead, it should be regarded as a coherent philosophical thinking based on the fact that every human being has, or at least has the possibility to have, inner evil inside them. Tanaka's philosophy is a philosophy for those who commit, or are forced to commit, or are supposed to commit "evil" acts while clearly acknowledging that those acts are "evil" deep in their heart. They recognize at the bottom of their heart that the moral justification of abortion is nothing but mere deception. What is needed is to find a way to live life without regret as a human being who can never escape from

inner evil, and to find a way to create a society in which women become inclined to give birth, that is to say, a society where women are not forced to choose abortion. This is the direction in which Tanaka's thinking takes us, and the reason why she wrote, "This is the question of the meaning of life, which has nothing to do with ethics or pseudo-humanism."

Tanaka's voice resonates with those of the disabled at that time. As mentioned in the previous chapter, disabled people in the Blue Grass Group had to admit that "inner eugenic thoughts" existed not only within a majority of able-bodied people, but also within disabled people themselves. The discovery of the "fetus killer" and "inner eugenic thought" was the real starting point of the Japanese philosophical bioethics, which will provide, I believe, a fruitful soil on which future bioethics, or philosophy of life, will flourish.

Let's turn our eyes to one philosophy of the disabled on selective abortion. One of the most important contributions made by this movement to philosophical thought is the insistence that selective abortion could lead to the psychological disempowerment not only of existing disabled people, but many ordinary people as well. They believed that selective abortion and the future development of prenatal screening would systematically deprive the disabled of a sense of security and the joy of existence that we feel when we can exist without being imposed upon by anyone regarding any particular conditions. These disabled activists did not use the words "sense of security," but I believe that one of the messages they tried to express in their fierce activities can be fully grasped by using this term. If this kind of prenatal screening becomes prevalent, disabled people would come to think, "I would not have been born if my parents had undergone current prenatal screening tests," and come to feel that "my existence is not welcomed or blessed by my parents and other people who are accepting such technology in our society." As a result, they would feel they are utterly deprived of a very important sense of security that ordinary healthy people enjoy.

This feeling can be labeled as a "fundamental sense of security," the feeling that one's existence is welcomed unconditionally. This is a sense of trust in the world and society, a sense of trust that provides us with a solid foundation on which to survive. This is a sense of security that allows one to strongly believe that no matter if one had been unintelligent, ugly, or disabled, at least one's existence in the world would have been welcomed equally, and that no matter if one fails, deteriorates, or becomes a doddering old man, one's existence will

continue to be welcomed. This is the sense of trust that our existence was welcomed when we were born, and will never be denied when we become old or sick. This is a sense of security with which we can believe that we will never receive a glance that contains the unspoken words, “I wish you had never been born” or “I wish you would disappear from the world.” We require this basic security in order to stay sane in this society. Disabled activists argue that prenatal screening is “wrong” because it would systematically deprive us (not only disabled people but all of us) of this fundamental sense of security.

To date, bioethics has not discussed this fundamental sense of security extensively, and yet I believe this is one of the most serious issues raised by selective abortion and prenatal diagnosis. Of course, prenatal screening is not the sole factor that erodes this fundamental sense of security; it has already been affected by a number of technologies and social systems. However, it is at least certain that current and future prenatal screening technologies will contribute to enhance the level of erosion of the sense of fundamental security. This is what I have learnt from the literature of disabled people and from discussion with them. Philosophical discussions about contemporary bioethical issues in Japan, including mine, have been greatly influenced, from the beginning, by the thoughts and actions of disabled people.

## 5. Brain Death Controversies in the 1980s and 90s

In the 1980s and 1990s, the most heavily debated topics in Japanese bioethics were brain death and organ transplantation. More than 200 books on brain death were published, most of which, surprisingly, were books for the general public. Not only medical specialists but also many journalists and lay people participated in the debate. A unique approach to the ethics of brain death emerged from their discussions, which I call “human relationship-oriented approaches to brain death.”

Japan’s first heart transplant from a “brain dead” patient was performed in 1968. However, Dr. Juro Wada, who performed the operation, was accused of illegal human experimentation and also of poor judgment in the clinical determination of death. This event engendered grave doubts about brain death and organ transplants among journalists and the public. The “heart transplant” became taboo for fifteen years.

In 1983, the Ministry of Health and Welfare established an ad hoc

committee on brain death and transplantation, which then began to establish the criteria for brain death. In 1985, criteria for brain death were announced. The committee distinguished “medical criteria for brain death” from “the concept of human death” and declared that the latter depended on the consensus of the Japanese people. As soon as the criteria was announced, journalists rushed to publish reports on brain death, and a fierce debate on whether or not brain death is human death began in the mass media. Books on brain death written by famous journalists, most of whom were skeptical about the concept, became best sellers.

The Prime Minister’s special committee on brain death and transplantation presented its final report in 1992. The committee concluded that brain death is human death and that the donor’s prior intention to donate organs is necessary for organ removal. But the report also contained the minority opinion that brain death should not be considered human death. Then, in 1997, Japan’s organ transplantation law was established. 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 transplantation do not need 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. The law was very unique, because it was based on the idea of “pluralism on human death” and “the donor’s prior declaration principle” on brain death and organ transplants.<sup>14</sup>

In the following section, I would like to concentrate on the bioethical and philosophical discussions that appeared in the debate on brain death during the 1980s and 90s.

In 1985, Michi Nakajima, well-known journalist, published the book, *Mienai Shi (Invisible Death)*. This was the first book that raised serious doubts about the concept of brain death, and established the basic argument that future Japanese criticisms of brain death would follow. Nakajima criticized brain death from the perspective of a patient’s family members. This point of view was very unique, since up to that time, most arguments had almost always been made from a doctor’s perspective.

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<sup>14</sup> For more on Japan’s organ transplantation law and its revision process, see my paper, Morioka (2001). The law was revised in 2009. Please contact the author concerning the details of the revision.



Nakajima wrote,

During a five-month period of observing brain-dead patients in an Intensive Care Unit, there was one thing that caused me to feel very awkward: nobody in the family took the brain-dead person's hands or shed tears when told that the husband, wife, or beloved child was deceased. At first, I tried to convince myself that I happened to have people who were cold-minded, and very rational. But I came to understand that nobody, in fact, could perceive the reality of the beloved one's brain death. ....

However, without exception, these people start crying intensely or shed tears calmly when the brain-dead person's heart stops beating and the respirator is taken off. At this moment, they finally realize the death of their beloved one.<sup>15</sup>

What Nakajima discovered in her fieldwork and interviews was people's bewilderment when faced with their beloved ones' brain death, the bewilderment that, while they could intellectually grasp the concept of brain death, they couldn't actually perceive the reality of their beloved ones' death at the moment of declaration of brain death. She repeatedly cast doubt on this new form of death which people found particularly hard to accept at the level of everyday reality. Nakajima's intuition was that regarding brain death as human death would deprive us of gentle sensitivity, and further "objectify" human life. She introduced two new concepts into the brain death argument, namely, "the perspective of brain death from family members" and "death in the second-person point of view," both of which would greatly influence the subsequent debate over brain death and organ transplants.

In 1986, another important book appeared, Takeo Sugimoto's *Kitakamo Shirenai Seifuku (A Uniform He Might Have Worn)*. Sugimoto was a pediatrician specializing in child neurology who experienced the brain death of his six-old son. When rushed to his bedside in a hospital, Sugimoto's son was already nearly brain dead. As a specialist in neurology, Sugimoto clearly understood that his son's brain would never recover, however, as the father of a dying child, he could never believe that his son was going to die. Even after the declaration of

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<sup>15</sup> Nakajima (1985), pp.12-13.

brain death, he could not accept the death of his son, for his son's body was still warm, and his arms and legs continued to make small, continuous movements. Sugimoto was torn between "the reality of a physician" and "the reality of a father."

Caring my son at the bedside, watching his body lying on the bed, I was overwhelmed by the powerlessness of myself as a physician. As a scientist brain death could be understood without any doubt, however, as a family member, or thinking about the dying child himself, I could not easily believe he was dead. ....

It is natural that I can't believe. Even those who say brain death is human death would not be able to straightforwardly believe the death of their family members when they actually experience their beloved ones' brain death at the bedside.<sup>16</sup>

Sugimoto stresses the importance of the human relationships between a brain dead patient and the person attending at his bedside. While Sugimoto was a physician, as a father, he was inevitably entangled in his close "human relationships" between himself and his beloved son. He could not be free from the influence of this relationship when judging whether his son was alive or dead. He argues that it is natural that human relationships play an important role when judging human death. Sugimoto's book eloquently describes the complicated realities people face when encountering the brain death of a member of their family.

In 1989, I published the book, *Noshi no Hito (Brain Dead Person)*, and further developed the idea that Nakajima and Sugimoto had proposed. I stressed that what ordinary people actually encounter in a hospital was not the "brain" of a patient, but the "person" whose brain had a severe damage. Hence we have to discuss, in the first place, the relationship between a brain dead person and his/her family members at the bedside.

Hence, discussions of brain death, if intended for the general public, should begin with the issue of the "brain dead person," rather than the explanation of the dead brain.

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<sup>16</sup> Sugimoto et al. (1986), p.41, p.47.

We, the general public, encounter “brain dead persons” for the first time in the ICU, they might be our parents, children, siblings, relatives, or friends. These are encounters between people, that is to say, encounters between a person whose heart and brain are functioning, and another whose brain has ceased to function, but whose heart is still beating.<sup>17</sup>

In this book I discussed the ethical and philosophical issues arising from the “relationships” between a brain dead person and people surrounding the patient. I used the words “brain death as a form of human relationships” and emphasized that the issue of brain death should be studied in this respect.

I proposed that family members of a brain dead person should be given sufficient space and time for caring their beloved one and for saying good-bye in the hospital, before the organ removal is performed. (Unlike many other countries, in Japan the respirator of a brain dead person remains connected until the heart naturally stops beating.) Physicians or coordinators should not interfere with family members until after they accept the death of their beloved one from the bottom of their heart.

As for the question of whether or not brain death is human death, I wrote the following:

Instead of asking whether or not brain death is human death, we should put forward the following three questions.

- 1) Is my brain death my death?
- 2) Is the brain death of a person familiar to me the death of the person?
- 3) Is the brain death of a person unfamiliar to me the death of the person?

We must be aware that these three questions are, from the very start, each of a completely different nature from the others.

It would be appropriate to refer to these three questions as, “the question of the first person,” “the question of the second person” and “the question of the third person” with respect to brain death. Another way of looking at this is that questions 1 and 2 are for someone directly concerned with the death, and question 3 is for an onlooker.<sup>18</sup>

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<sup>17</sup> Morioka (1989), p.17.

<sup>18</sup> Morioka (1989), p.144.

Brain death had long been discussed from the perspective of the question for an onlooker particularly in American bioethics, however, what is most important in terms of bioethics was to discuss it from the perspective of the question for someone directly concerned. This was what I emphasized in my book.<sup>19</sup>

In 1995, the well-known journalist, Kunio Yanagida, published the book, *Gisei (Sacrifice)*, which became a best seller in that year. Yanagida's second son, Yojiro, became brain dead after committing suicide. Yanagida stayed at his bedside and cared for his brain dead son until his heart stopped beating. As an experienced journalist, Yanagida had believed that he knew all about brain death, but when he actually experienced his own son's brain death, he was completely bewildered by the situation. When he shook hands with his brain dead son, called his name, and talked about their shared memories to him, Yanagida felt he could communicate with his son at the level of the body without uttering any words. He writes:

When Ken'ichiro [the oldest son] and I [the author] talked to Yojiro, though he was brain-dead, his body talked back to us. This was truly a mysterious experience. This was probably a sense that can be understood only by members of a family who have shared happiness and sorrows with each other. Despite the scientific explanation that a brain-dead person is literally a dead person who has no consciousness or senses, I became quite sure that a beloved one's brain-dead body means a lot to the family members who have shared a spiritual life with each other.<sup>20</sup>

Using his own personal experiences, Yanagida eloquently illustrated the core idea of "human relationship oriented approaches to brain death." Even in the state of brain death, the patient's life can continue to exist in the midst of human relationships between the patient and family members. Yanagida named his perspective "death in the second-person point of view," words which became central in the debate over brain death after his book was published. It is striking that after experiencing his son's brain death, Yanagida began to examine his past relationship with his son. After reading his son's diary, Yanagida became

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<sup>19</sup> The distinction of three categories in human death was firstly introduced by Vladimir Jankélévitch in his book *La Mort*, 1966.

<sup>20</sup> Yanagida (1995), p.129.

familiar for the first time with the misunderstandings and disbeliefs his son had held against him, an experience which led Yanagida towards a “dialogue” at a deep level which was not possible while his son was “alive.”

In 1996, Yoshihiko Komatsu, professor of history of science, published the book, *Shi wa Kyomeisuru (Death Resonates)*.<sup>21</sup> He conducted extensive research on brain death and organ transplants in Japan, and wrote a groundbreaking scholarly book on the issue. Komatsu also cast doubt on arguments that did not take into account the human relationships surrounding a brain dead person. According to Komatsu, the death of a person is shared by those who surround the dying; death resonates around all who participate. Komatsu called this dimension of death, “resonant death.” Komatsu applies this concept to brain death, and concludes that brain death is never actual death. Komatsu published another controversial book called *Noshi Zokiishoku no Honto no Hanashi (The Real Story of Brain Death and Organ Transplantation)*, which again harshly criticized the concept of brain death.<sup>22</sup>

In 2001, I published the book, *Seimei Gaku ni Nani ga Dekiru ka (Life Studies Approaches to Bioethics)*<sup>23</sup>, and in its first chapter I provided an extensive analysis of the “human relationship oriented approaches to brain death” mentioned above. And I tried to explain, using such concepts as “intercorporality” and “presentation,” why family members sometimes feel that a beloved one is still alive in the state of brain death. In such cases they can understand that the brain function has ceased, and hence, the patient lacks internal consciousness, and yet they read a kind of existence on the patient’s body, the existence of someone who cannot exist. In other words, for them, a person who certainly should have disappeared now clearly appears before their eyes in the brain dead patient’s body. I argued that this is not an illusion, but something that can be explained by using the philosophical concept of “presentation.” This book discusses other philosophical issues concerning human relationship oriented approaches, and also extensively discusses feminist bioethics and disabled people’s bioethics mentioned previous sections.

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<sup>21</sup> Komatsu (1996).

<sup>22</sup> Komatsu (2004).

<sup>23</sup> Morioka (2001).

## 6. Conclusion

The biggest events in the field of Japanese bioethics in the 2000s were the establishment of The Law Concerning Regulation Relating to Human Cloning Techniques and Other Similar Techniques in 2000, and the creation of human iPS cells by Shin'ya Yamanaka in 2007. Here I do not talk much about Japanese bioethics in this period because I have published a paper on the Japanese law on human cloning elsewhere,<sup>24</sup> and because the public discussion concerning these issues has not become a heated one compared with that of abortion and brain death decades ago. I am not quite sure why this happened, but anyway, this might be another interesting theme for researchers. I have also published some papers that deal with the development of my own bioethical research in this period.<sup>25</sup>

I have had many opportunities to meet foreign researchers who came to Japan to study the attitudes toward bioethical issues here, especially those of brain death and abortion. I truly believe that comparative research is both important and stimulating, and yet, such research alone is not sufficient in order for Japanese bioethics to be able to contribute to the development of the international discussion. In order to accomplish that Japanese bioethics will have to recreate itself.

What we require most is a retrospective view into the fruitful discussions that emerged over the issues of selective abortion, brain death, organ transplantation, and the other central topics in the field of life and death in order to find a diamond in the rough. The philosophical basis of contemporary Japanese bioethics is considered to be made up of a mixture of American style of analytical ethics, Continental European philosophy, Buddhist and Confucian ideas, the Japanese traditional world view of life, death, and nature, and modern social philosophy based on humanism and democracy. This is pure chaos. For example, it has been argued that the leaders of the disabled group, the Blue Grass Group, namely, Yokota, Yokotsuka, and others, were deeply influenced by Jodo Shinshu Buddhism especially their emphasis on the importance of gazing at their own inner evil. However, it is unfair to reduce their philosophy solely to traditional Japanese Buddhism. The spirit supporting their radical movement was clearly that of modern man inspired by European concept of freedom and

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<sup>24</sup> Morioka (2006).

<sup>25</sup> Morioka (2013), Morioka (2015), and Kinjo & Morioka (2011).

equal rights.

One of the most interesting features of today's Japanese bioethics is this chaotic mixture, out of which future radical philosophical movements might emerge. And when that actually happens, our philosophical discussion will have been transformed into a new form of which we could previously only dream.<sup>26</sup>

\*This paper was first presented at the International Conference, *Cultural Power Asia: Producing Culture, Building Identities*, under the title "Bioethics in the Japanese Context: Its Past and Future," 13-15 November 2008, Goethe University, Germany.

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<sup>26</sup> I am now writing a book that enlarges this paper and makes an extensive philosophical analysis of the topics discussed here. The information of the book will be uploaded to my website: [www.lifestudies.org](http://www.lifestudies.org).

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