Doctoral Dissertation

Dynamics and Change of Bioethics in Japan

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CONTENTS

Introduction

The past several decades have seen dramatic advances in biology and medical technology. However, new questions regarding ethics and values have also been raised around genetic issues, organ transplants, determination of death, ethics committees, research on human subjects, care for the aged, among others.   I deal with these and other topics throughout this doctoral thesis.

I define “Bioethics" as a "supra-interdisciplinary" study that has emerged from various civic action movements aiming to analyze, research and integrate all spheres of "Life" related questions from various fields including biomedical sciences, nursing, religion, philosophy, politics, sociology and economics.

This is an entirely new approach to developing ethical and value standards and public policy, through ongoing public debates concerning "Life" questions. The notion of “Bioethics” was developed originally in the United States in the late 1960s. This was an era of enormous scientific and technological advancement but it also faced increasing problems of dehumanization. It is not surprising that various civic movements to reconsider the dignity and rights of the persons gained widespread public support during this period when health consumer activism, women's liberation, and minority rights was prevalent. People throughout the world began to realize that under these powerful forms of established social and professional systems, their rights and even their lives could be in danger if they were not conscious of their own lives.

I myself became very much concerned about the aggressive use of biochemical weapons harming human life and the human genome. When I was teaching at the University of Saigon in Vietnam, I had first-hand encounters with victims suffering genetic tragedies caused by herbicides used in the Vietnam War. This intentional misuse of scientific and technological achievement for the destruction of human life and the environment has led me into the new field of studies in genetics, life sciences, law and human rights. My career as a comparative family lawyer in Asia totally shifted to this area of study while I was in Vietnam and later, in Switzerland and the U.S.A.

These experiences have been integral in my own research works relating to human life and human rights, and in making a positive contribution to the emerging discipline of Bioethics as a pioneer in Japan.

In chapter one, I review the dynamics and change of Bioethics in Japan. Then, I address the topics of research particularly in the fields of genetic issues (Chapter two), organ transplantation and determination of death (Chapter three), ethics committees and research on human subjects (Chapter four), and care for the aged (Chapter five).

We, as people, became active when we realized that in order to protect and nurture our own lives, it would be necessary for us to have our own information and cooperate with one another to change the public policy and social system by our own efforts. Therefore, in the conclusion of this doctoral thesis, I focus on Bioethics as a prescription for Civic Action in Japan.

Chapter 1. Development of Bioethics in Contemporary Japan

Dramatic changes in Japanese social, political, and economic life have occurred since the 1860s, due in part to Japan's conscious desire to modernize and to rapid developments worldwide in science and technology.

In urbanized post-World War II Japan, the traditional nationalistic ethos of the Japanese people, based on a legally endorsed kazoku-seido (family system) as the social fabric of a kokka (state, literally, state-family) under the inviolable power of the emperor (Fukutake, 1981), has disappeared almost completely as a political system and faded as a social ideal. Some uniquely Japanese elements remain, however, especially in the realm of human relationship --- for example, in the mentality of amae (dependency or relatedness), resulting in a typically deferential and obedient response to seniors or those in authority; the striving for harmony (wa) with other people; and the socially reinforced mentality of thinking of oneself as a member of a group rather than as an individual (Doi, 1971; Hall and Hall, 1987). This article will discuss the contemporary Japanese approach to various issues and problems of bioethics, in light of the social, cultural, and historical milieu from which it arose. The account of bioethics in contemporary Japan will be chronological, highlighting events in what Rihito Kimura has interpreted as the three stages of development for bioethics in modern Japan.

It is important to note that owing to the character of Japanese society and its distinctive historical understanding of medicine, and the role and responsibilities of the physician, it was not until the 1960s that the bioethical and sociolegal concerns about the practice of medicine began to be deliberately reflected in Japanese society. Only during the 1980s that the notions of autonomy and rights in medicine, and of bioethics in general, became gradually influential (Kimura, 1979, 1987). In the long tradition of Japanese medical practice, the Confucian notion of jin (benevolence) has been one of the most important ethical elements; medicine itself is known as jinjutsu (the art of jin). Physicians, as conduits of jin, were required to act with benevolence toward their patients, and were responsible for the welfare of patients in a fiduciary (trust) relationship (Kimura, 1991a). It was obligatory to use medicine, a gift of benevolence, for the good of others even without payment. Physicians fulfilled their responsibility to-ward their patients and the patients' family members by acting in a paternalistic and authoritative way; the Japanese, nurtured in the Confucian ethos to respect law, order, authority, and social status, acquiesced without murmur to the superior knowledge of the physician.

Traditionally, the mentality of amae (which Japanese psychiatrist Takeo Doi has explained as having some analogy to children’s feelings of dependence on their parents; Doi, 1971) dictated this response --- the patient’s relationship to the physician was analogous to that between a child and the parent who acts to do what is best for the child. Rihito Kimura interprets the impact of amae in bioethics as a notion of “related-autonomy” or the making of decisions in relationship. This relatedness extends to all living beings and to one’s bond with the environment. These notions of jin and amae, along with that of wa, which will be discussed later, form the backdrop for the development of bioethics in modern Japan.

Confucian Virtues in a Paternalistic Medical Tradition (1868-1937)

In the early seventeenth century, the Tokugawa Shogunate closed Japan to foreigners. One small Dutch trading post in Nagasaki was tolerated, but, until the end of the Edo era (1840s-1860s), contact with foreigners was prohibited and the influence of Dutch medicine remained very minor, while traditional Japanese and Chinese medicine continued to flourish. However, as the era drew to a close, restrictions were eased and

Japanese physicians sought out texts on Western medicine, training themselves in Dutch methodology and practice (Rangaku) using texts available through the Dutch trading post and questioning its resident physicians.

To this end, a document by Christoph Wilhelm Hufeland, originally published in Berlin under the title Enchiridion Medicum (1836), was translated from German into Dutch by Hermann H. Hageman (1838). This translation became influential among the Ranpo-I or Dutch School physicians (those trained in Dutch medical techniques). An 1849 translation, Ikai (Medical Admonition), by Seikyo Sugita, of Hufeland's chapter on physicians' responsibilities, which asserted that physicians have a duty to take care of all patients regardless of their social or economic status, was widely read and accepted by Japanese physicians (Sugimoto, 1992). A thirty-volume translation of Hufeland's writing completed in 1861 by Koan Ogata, a great forerunner of Japanese modern medicine, established this thinking more firmly among Japanese physicians. In 1859, a book traditionally known to Japanese physicians as Ishimpo (Heart of Medicine), the oldest extant medical encyclopedia in Japan, was reprinted by the Tokugawa government and made more widely available. This popular Ansei-era edition, originally written on thirty scrolls in 982 C.E. by Yasuyori Tamba, stated in its preface that physicians should embody the spirit of Daiji-Sokuin --- Daiji, the great mercy of Buddha, from the Buddhist scripture, and sokuin, meaning sympathy or benevolence (also expressed as jin), from Confucian teaching.

In 1868, feudal samurai in particular han (local provinces), such as Satsuma, Choshu, Tosa, and Hizen, initiated the restoration of political power to Emperor Meiji after the Tokugawa shogunate's reign of 265 years (1603-1867). The Confucian ethical teaching, dominant among the samurai during the Tokugawa shogunate, was integrated into Kyoiku Chokugo (the educational Edict of the Emperor, 1890) as the basis for moral teaching in the elementary school curriculum; the classes were compulsory (This edict was not abolished until 1948). Confucian ethics, as embodied in this edict, attributes great mercy and benevolence to the emperor and affirms the importance of virtues such as loyalty to the emperor as the head of the "state-family, " and filial piety and respect for parents. It also emphasizes the importance of brotherhood and sisterhood, obedience to law and maintenance of order, the necessity of education, and devotion to the state (exemplified for men in military service). Grass-roots movements for liberty and civil rights in the political process (jiyuu-minken undo) were increasingly popular but were suppressed by the emperor’s proclamation of the Meiji constitution in 1889, which consolidated political power in the hands of the emperor and established the Diet (Parliament) in his name. Modern Japanese medical ethics cannot be isolated from this social and political milieu. The strong paternalistic nature of Japanese medical practice is the natural outcome of Confucian teaching, which calls for respect of the master and for his authority as a source of unquestionable wisdom and truth.

As Japan became more open to the West, the Dutch ceased to be the sole source of Western culture and other nationalities replaced them. The process of modernizing Japan began in the second half of the nineteenth century and continued into the twentieth century, aided by oyatoi gaikokujin (foreign advisers) from Western countries, hired by the Japanese government to provide development advice in industry, education, government, finance, science, technology, and medicine. Japan, seeking models for modernization, was drawn, to the German approach because of the success and progress of German science and technology, and the similarity of the German authoritarian political system under the Prussian Kaiser to its own under the emperor. Official acceptance of Western, particularly German, medicine guided the development of Japanese policy on medical administration and education and set the course for the future (Oshima, 1983).

German physicians left a legacy of authoritarianism in medical education and practice that had far-reaching effects on the majority of the Japanese medical community. This approach, combined with the Confucian self-righteousness in rendering benevolence to the patient, undermined the development of any notion of patients' rights. Research became the supreme interest at many university hospitals, and patients who presented interesting cases were treated as research material. All of these influences can be seen in the Isei (seventy-six guidelines for medical administration) drafted by Sensai Nagayo in 1874. Traditional Japanese (wahou) and Chinese medicine (kanpou) have been out of the mainstream of medical science in Japan since the adoption of Isei, although acupuncture and moxibustion (quick, light heat from an ignited powder of medicinal leaves at key points of the body, called tsubo) have remained as folk medicine with popular support among the public (Otsuka, 1976).

As capitalism became established in Japan, the serious social and economic inequities exacerbating the health problems (e.g., widespread tuberculosis, malnutrition) of factory workers, miners, farmers, and fishery workers became evident, particularly in the Taisho Era (1912-1926). Even though the socially privileged physicians' group was not eager to address these health issues through social reform, some young physicians and medical students working for the settlement movement, introduced into Japan from England at the turn of the century, provided medical care in the slum areas of big cities such as Tokyo, Osaka, and Kobe in the 1920s. In 1919, the Medical Cooperative Movement (Iryo Seikyo Undo), which sought to establish community medical centers offering equal access, found great support among many Japanese (Seikyo, 1982).

During this period, Japanese medical ethics, guided by the two powerful influences of Confucian teaching and German authoritarianism, was generally understood simply to govern a physician's personal attitude in providing medical service to patients within the traditional model of a paternalistic trust relationship. It is important to note that during this time the eminent Japanese medical historian Yu Fujikawa asserted that physicians were bound by special obligations and responsibilities, and must develop a special ethical consciousness in their daily practice. His advice was not accepted by Japanese medical experts, who were obedient to the military regime during the following war years (Fujikawa, 1941).

Medical Loyalty to State and Authority (1938-1968)

Increasing concern about the health of the Japanese population led to the establishment of Koseisho, the Ministry of Health and Welfare, in 1938. The National Health Act and additional laws protecting factory workers were promulgated during the same year. Many young radical physicians dealing with serious health problems among the population, such as tuberculosis, raised questions of justice and equitable distribution of resources, but concerns associated with the war with China (which began in 1937) now dominated. In reality, one of the government's main purposes in establishing the Koseisho was to strengthen the health of the nation to wage war. Similarly, the National Eugenic Law of 1940, promulgated ostensibly for the health of the people, reflected the government's desire for increased family size and the elimination of genetically transmitted diseases and defects. To achieve the latter goal, it authorized the use of a "eugenic operation" -voluntary or involuntary sterilization of individuals with mental illness or retardation, and those thought to be at risk of transmitting genetic diseases or physical deformities to offspring. (Although this law was abolished and replaced by the National Eugenic Protection Law in 1948, sterilization continued under the new law. Between 1955 and 1967, 418,178 women and 13,571 men were sterilized, 407,910 women and 9,608 men involuntarily. Data from the early 1990s show that, although far greater numbers of females than males continue to be sterilized, involuntary sterilization is almost nonexistent. In 1992, for example, 38 males and 5,601 females were sterilized, but only one operation on a female was repeated to be nonvoluntary [Statistics and Information Department, 1993].) With the approach of war, the traditionally authoritarian, yet basically well-intentioned, practice of medicine came under the control of militaristic state regime; this had dreadful repercussions for medicine and medical ethics in modern Japan.

Several horrible and unethical human experiments performed during World War II were uncovered after the war. The similarity of response to state authority exhibited by Japanese physicians and by Nazi physicians has been viewed with dismay. German defendants accused of committing crimes against humanity were put on trial at Nuremberg; and the medical atrocities and experiments there recounted led to the development of the Nuremberg Code in hope of preventing such practices in the future. But, Japanese medical experts serving in Unit 731 , officially called the Water Supply and Epidemiological Disease Prevention Corps, who carried out and supervised experiments on Manchurian Chinese captives using bacteriological infections, frostbite, and mustard and poison gases, were not prosecuted by the international military court (Powell, 1980; Williams and Wallace, 1989).

Official classified documents exchanged between the United States and U.S. General Headquarters in Japan, now available at the U.S. National Archives, show that the U.S. military decided not to bring this case to trial. The interrogation task force of the occupation forces in Japan granted immunity to members of Unit 731, including General Ishii, chief of this corps, on the condition that all related medical records and specimens are handed over to the United States (Kimura, 1997). The matter was regarded as highly important to national security because the United States wanted to prevent transfer of the medical knowledge gained through these experiments to the Communist governments in China and the Soviet Union (U.S. National Archives, 1949). The Soviets held their own military trial at Khabarovsk for members of Unit 731 they had captured. Based on documentation and the testimony of witnesses, the accused were found guilty (Ivanov and Bogach, 1989).

The Kyushu University Medical School vivisection case also serves as an example of unethical experimentation. Eight American bomber pilots were captured in Japan after an air raid on Tokyo in 1945; some of them were sentenced to death by the local unit of the Japanese Imperial Army, but instead were used as objects of medical experimentation. To avoid prosecution by the Yokohama District Military Tribunal, one key person involved in this experimentation committed suicide; full details may never be known (U.S. National Archives, 1949). The case served as the basis for a popular novel by Shusaku Endo, titled Umi to dokuyaku (1960), in which he dramatically depicted the quandary of a medical scientist tempted by unethical but very interesting experimentation. Endo’s novel forced consideration of the meaning and place of ethics and medicine in Japanese society --- which, he argued, lacked a standard of absolute value. These cases will be dealt also in the chapter IV – section B.

Justified by state authority, professional experts in Japan sometimes lose critical consciousness and judgment. The Japanese national character nurtured during the

Tokugawa era, and by an authoritarian government since the Meiji Restoration, demands absolute obedience to the state and to authority. As Endo points out in his novel, such pressure often creates serious problems when individuals must make independent, and individual, ethical decisions. As a member of a group --- as a family, corporation, or community --- and as a citizen, the individual Japanese tends to follow what other people do. Harmony (wa), or getting along with others, is an important element of the Japanese ethos for maintaining good relationships. To insist on individual opinions is regarded as egoistic and arrogant. Suppressing oneself in order to cope with other people is a daily practice in every aspect of life for the Japanese. This has serious ethical implications, especially in terms of weakening critical consciousness necessary in professional experts. The majority of Japanese medical experts and the lay public are not interested in drawing serious lessons from the horrible wartime human experiments because they reason that such actions are performed only in “abnormal war settings by abnormal people.”

Orders from the occupation forces led to large-scale changes in medical and nursing education, as well as in public-health policy and hospital management. An irreversible and radical shift in medical practice from the German orientation, dominant since the Meiji Restoration, to an American orientation occurred during this time. One of the first pieces of legislation implemented after the defeat of Japan was the Eugenic Protection Law of 1948. Unlike the National Eugenic Law of 1940, that was later abolished. The Japanese Criminal Code (1907), Chapter 29, Article 212-16, which still holds that abortion is illegal, but the 1948 law permitted abortion for medical, and later for social and economic, reasons. Under the Japanese Criminal Code, abortion for other reasons remains a prosecutable offense. However, due to vigorous opposition from advocates for the disabled, it did not provide legal justification for the abortion of a genetically defective fetus. The endorsement of this abortion law by the General Headquarters of Central Douglas MacArthur aroused adverse reactions from religious bodies in Japan and the United States (Kimura, 1987). MacArthur defended the policy, saying that it had arisen from and was implemented by the Japanese Diet. The law was still in effect in the 1990s.

The way survivors of the atomic bombs dropped at Hiroshima and Nagasaki were treated by the Atomic Bomb Casualty Commission (composed of U.S. medical and genetic experts) is one of the historical sources of the development of Japanese bioethics because of its significance in discussions about the relationship between human beings and science, technology, and research. Individuals suffering from the effects of radiation came seeking treatment, but instead became material for research on radiation and collection of genetic data that were stored at the U.S. Atomic Energy Commission (AEC). This situation raised the serious issue of the researcher’s responsibility to obtain fully informed consent for research. At that time, no government regulation or review boards existed to deal with the situation. The AEC is in fact the forerunner of the U.S. Energy Department, which initiated the Human Genome Project in the early 1980s on the basis of the voluminous data from the Survivors of Hiroshima and Nagasaki (Cook-Deegan).

In 1951, the Japan Medical Association (JMA) issued a statement on physicians’ ethics. This action clearly ushered in a new epoch in medical practice in Japan and signaled a return to the prewar state of medical ethics. Article I explicitly reaffirmed the fundamental and central place of the ancient principle of jin, the benevolence of Confucian teaching, in medical practice and asserted that physicians, as the elite of society, must embody the spirit of jin, always thinking about the welfare of the patient and the benefit of the treatment. Further, in cooperation with other professionals, physicians should take the initiative in social reform and, as ethically oriented people, should exercise great self-discipline (JMA, 1951).

In 1968, a series of consultations and presentations by scholars on ethical issues in medicine was held under the direction of Taro Takemi, then president of the JMA, in an attempt to update the 1951 statement. The publication of Ishi rinri ronshu (1968) was the outcome of this research, but no new ethical code was issued. During his twenty-five-year tenure, Takemi developed an interdisciplinary study project titled “Raifu saiensu no shimpo,” which has focused attention on bioethical issues such as the allocation of medical resources, applications of high-tech medicine, and ethical problems. However, its professional orientation effectively excluded the lay public. Professional autonomy and authoritative decision making that excluded patients continued to be the model.

The Japanese Constitution, which became effective in 1947, guaranteed the right to health care and social security. Article 25 provides that “all people shall have the right to maintain the minimum standards of wholesome and cultural living. In all spheres of life, the State shall use its endeavors for the promotion and extension of social welfare and security, and of public health.” The effort to implement national health insurance for all Japanese, originally begun in 1938, was finally realized in 1961. Since then, all Japanese “whoever, whenever, and wherever” they are, have had access to medical treatment for all illnesses. Treatment costs are covered by the government or by government-controlled systems, except 10 percent coinsurance for insurees and 30 percent for their family members.

Medical care for the elderly, once completely free as a result of the Health Care for the Elderly Act of 1973, now requires a payment of about 20 percent of the total fee (through a 1986 cost-containment amendment). Private medical insurance systems, once almost non-existent, have sprung up to cover the gap between the actual cost of medical treatment and the amount covered by government insurance. Such coverage is particularly needed for chronic diseases, terminal illnesses, and cancer treatments, although a high-cost medical treatment assistance system was introduced in 1973. As of 1993, the assistance system covers all expenses beyond 33,600 yen/month for low-income families and 60,000 yen/month for average-income families. In 1997, The

Long-term Care Insurance Law was passed by the Japanese Diet and it became effective since April 1st, 2000.

Even Japan felt the effects of the worldwide trend in the 1960s of questioning established authority. Revolts occurred in many universities as dissatisfied medical students stood up against the traditionally paternalistic and authoritarian medical faculty they felt was exploiting them. Special legislation eased the unrest, but this first and radical challenge of the medical establishment, a very politically powerful group, had permanent ramifications for Japanese society and moved it into a new era.

·Communal Involvement in Medical Decision Making (1969-2000s)

Towards the end of 1960s, numerous social issues competed for attention in Japan. Problems of air and water pollution, concerns about food additives, iatrogenic diseases, the revival of Kanpo (traditional Chinese medicine), and increased emphasis on health became common concerns. The growing number of older people focused attention on the need for health care for the elderly. Japan has been one of the most successful countries in decreasing the birthrate, and life expectancy in 2001 was the longest in the world, eighty-five years for women and just over seventy-eight years for men. (Ministry of

Health, Labor and Welfare, 2003).

In 1997, the long-term Health Care Insurance Law for the Elderly was enacted to create national mutual support systems for the elderly, who are traditionally cared for mainly by the family in the community. Advances in medical technology and health care have raised additional issues for the Japanese medical profession and society in general. The period from the late 1960s to the early 2000s has seen increased lay involvement in discussions about medical treatment and a strong desire to establish guidelines to protect the patient.

a. Organ transplantation.

Progress in organ-transplant technology created a demand to regulate and endorse cornea transplantation. A special law to this effect was enacted in 1958; it was combined with a law governing kidney transplantation in 1979. Kidney transplantation from live donors is quite common (approximately 73 percent of all kidney transplants; Kimura, 1991b), and there have been approximately 100 cases of segmental liver transplantation from live donors.

The most vigorous public debate on bioethical issues was generated by the first heart transplant in Japan (1968), in which a heart was taken from a drowning victim and transplanted to a patient in heart failure. The patient died after eighty-three days. A surgeon at Sapporo Medical College, Juro Wada, was accused of mishandling the surgery on both the donor and the recipient, and questions arose about the justification for the transplant and about the criteria used to determine death; but Wada was never formally prosecuted. However, the aftermath of this case gave rise to strong criticism of high-tech medical applications on ethical grounds. Concerns focused on the use of brain-based criteria of death, organ transplantation from brain-dead bodies, and the need to develop ethical guidelines to control the behavior of individual physicians who might seek fame through ill-prepared and drastic use of medical technology supposedly to benefit the patient.

This incident spawned the Patients' Rights Declaration in 1970 (Owatari, 1970). This short, spontaneous expression of feelings, stating that the Wada case was a violation of the human rights of the patient and an example of the corruption of medicine and ethics, occurred in the public meeting at which Wada was accused of violating the donor's right to life.

In 1990 an ad hoc research commission on brain death and organ transplantation was established under the Prime Minister's Office. Chaired by Michio Nagai, founder minister of education, science, and culture, the commission made final recommendations in January 1992. The final report endorses brain-based criteria for death (the irreversible cessation of the function of the entire brain) and the permissibility of organ transplantation. However, the document also respects the traditional clinical criteria (absence of heartbeat, circulation, pulse, and respiration) as the basis for declaration of death, and permits the family and individual to choose between the two criteria (Prime Minister's Ad Hoc Committee). The opposing minority opinion, which was part of the document, was signed by four out of eighteen consultants and committee members; thus the decision was not unanimous. Even though public hearings were held in Hokkaido, Kanto, Kansai, and Kyushu, the committee meetings were closed to the public and no mechanism existed to ensure incorporation of public input. Almost two years after the final report of the committee there were yet no organ transplantations from brain-dead cadavers. Draft legislation regarding these issues was presented to the Diet by the Inter-Party Committee in early 1994.

In 1997 the Law on Transplantation went into effect. This law, reflecting the legal and ethical uniqueness of the Japanese situation, makes harvesting organs difficult because of two rigid consent provisions. The first provision is the requirement for advanced consent in accepting brain death. The “brain death criteria for death” box must be checked on the donor card, expressing the intention of the organ donor when alive. The second provision is the requirement for the consent of the family for harvesting organs from brain-dead body. Article 6, section 1, allows organ donation “in the event that a deceased person had during lifetime expressed in writing his intent to donate organs to be used for organ transplants.” Section 3 of the same article also states that “when the donor during his lifetime had expressed in writing his consent to the diagnosis - made based upon the provisions – and his family informed of the removal, did not object to the diagnosis,” organ transplants can be legally permitted (Kimura, 1998)

This law is supposed to promote- by endorsement- organ transplantations. From enactment through early 2003, however, Japan has had an only a small number (twenty three) of organ transplants. Furthermore, these two elements of ethical and legal rigidness have made the enactment of more relaxed applications- such as allowing organ transplants involving infants – almost impossible to perform.

b. Criteria for Death.

Leading objections to brain-death criteria are the fear that organs will be removed prematurely and that transplants will be performed in unacceptable circumstances (Kimura, 1991b). In Japan, transplantation of vital organs from the brain dead bodies is rare because of a concern about causing the death of the donor. To a limited degree, anencephalic infants have been used as sources for donor organs because they will die anyway, and because it is believed that they do not possess the fundamental consciousness necessary to be a human being. Declaration of death in the cases reported has ostensibly been based on the total cessation of heartbeat. Nevertheless, the use of organs from anencephalics has not been officially reported since 1981, because of clinical concerns about the conditions of the organs from such donors and public concerns about the appropriateness of such practices. (Kimura, 1989a)

Resistance to hastening death and harvesting organs also comes from the traditional Japanese image of human beings as completely integrated mind-body units, rather than distinct and separate units of mind, body, and spirit. This unit continues after death, so that removing an organ from a cadaver is seen as disturbing this spiritual and corporeal unity, not merely altering the physical body. It also explains why autopsies are abhorred in Japan (Fujita, 1980). According to the Buddhist and Shinto ways of thinking, this unity extends beyond the individual to all living things. To the Japanese, death disturbs the rhythm of all living things and therefore should not be hastened. Also, Confucian teaching places strong emphasis on family relationships and filial piety. There is a strong prohibition on harming one's body, because it is derived from one's parents (Kimura, 1991b).

In addition, in accepting the reality of human mortality, some Buddhists would regard the extension of life by accepting organs from another individual's body as unnatural and unethical, since the procurement of those organs depends on the death of another person. Such an expectation of the death of someone else for the purpose of egoistic extension of life is not acceptable. Also, the totality of life should be supported by the notion of arayashiki (alaya-vijnana) (the fundamental consciousness within each individual being). This Buddhist notion holds that consciousness is not located solely in the brain; therefore the cessation of any one part or one organ (including the brain) of the individual does not extinguish consciousness, and consequently cannot be regarded as the death of the individual person (Tamaki, 1993; Fujii, 1991). Therefore, the basis for the uneasiness in accepting brain criteria for death and organ transplantation comes from both Confucian and Buddhist thought, which incorporate some ideas from Japanese traditional folk religions and Shintoism.

c. Truth-telling and Death Education.

A complicating factor in obtaining permission for organ transplantation from terminal patients is that Japanese physicians normally withhold information about diagnosis and prognosis from patients, particularly in the case of cancer, and many Japanese hospices and palliative care units make it a customary rule not to tell patients that they are dying, although there are some exceptions. Several studies examining the patient-physician-nurse relationship have been published, and several more, to examine the Japanese way of telling the truth to the patient, are proposed (JMA, 1990, 1992). Hospice care in Japan was initiated by Christian hospitals in the 1970s. Hospice units based on Buddhist beliefs were established in the 1980s, while the Japanese government began to endorse such palliative care only in 1990. There are a number of groups focusing on the study of death and dying. One of them, organized by a leading expert on death education, Alfons Deeken of Sophia University in 1982, has been expanding its network throughout Japan.

d. Euthanasia.

Media coverage has made euthanasia one of the most debated topics in Japanese bioethics. The Japanese Euthanasia Society was established in 1976 (and was later renamed the Japan Society for Dying with Dignity [JSDD]), and the first international conference on euthanasia was held at Tokyo in the same year. As of 2002, the society, now called the Japanese Society for Dying with Dignity (JSDD), has a membership more than 100,000. The Ninth International Conference of the World Federation of Right to Die Societies was organized by JSDD at Kyoto in 1992. No legally established procedure exists in Japan, but as in many other countries, the use of elevated doses of narcotics to relieve suffering and pain is acceptable even at the risk of hastening death (Murakami, 1979). According to Buddhist thought, the prolongation of life and suffering is not absolutely necessary, and ending the life of a dying, suffering patient might be regarded as a merciful act (Murakami).

A 1962 precedent-setting decision by the Nagoya High Court, which accepted the idea of euthanasia in principle, involved the case of a son who prepared poisoned milk as a result of his terminally ill father's repeated requests to die; the glass of milk was found by the man's wife, who, not knowing it was poisoned, gave it to her husband. Although the court found this case to involve unacceptable mercy killing, it established six criteria for allowable mercy killing:

(1) The patient's condition must be terminal and incurable, with no hope of recovery, and death must be imminent (as determined by modern medical knowledge and technology);

(2) the patient's pain must be so severe that no one should be expected to endure it;

(3) The sole purpose of the act must be solely to relieve the patient's suffering;

(4) A sincere request and permission are required from competent patients;

(5) In general, this act should be performed only by physicians; and

(6) An ethically acceptable method must be used.

The Nagoya High Court Ruled that, although the first four criteria had been met, the final two conditions had not. The son was sentenced to four years' imprisonment with three years' suspended sentence.

In the light of medical and technological advances, the conditions once considered fatal can now be treated effectively or even cured. Better methods of pain control have been developed, and new centers for palliative care have been developed.

The ruling of Yokohama District Court on March 28th, 1995 is significant for its clear statement of the principle of individual autonomy based on the patient's own intention to stop treatment. In this case, the physician prosecuted for murder claimed he had a clear request from the patient's son to alleviate his father's suffering. Later, the son denied, when questioned, any intention to end his father's life. The ruling does not endorse familial decision making based on the presumed wishes of the patient, however, if the patient has communicated openly enough with family members about his or her views of life, character, and values, the family will be able to make a conjectural decision to end his or her life n a natural way without aggressive over treatment. (Kimura 1998)

e. Treatment of the mentally ill.

The Japanese Mental Health Act was passed in 1950 to prevent private home confinement of the mentally ill in violation of an identified right to be cared for in institutional situations. However, in the 1980s, disclosures of violations of rights of psychiatric patients led to serious questioning of the routine admittance and institutional treatment of the mentally ill. In 1987, an important amendment to this act, which adopted more rigorous procedures for involuntary hospitalization of the mentally disabled, and established rehabilitation and treatment centers to protect the rights of patient with mental disabilities, passed after a nationwide campaign in its favor by the mass media and a strong recommendation for its passage by a special investigative mission of the International Commission of Jurists in Geneva. The commission's involvement underscores the importance and necessity of international cooperation on bioethical issues, especially those related to patients' rights.

f. Education of the public in bioethics.

Bioethical issues raised in the 1960s caught the attention of much of Japanese society, and in the 1970s concerned citizens formed bioethics study groups in Tokyo, Kyoto, and Nagoya. By the 1980s, these groups participated as bioethics volunteers in medical service organizations. The nationwide concern with health and medical services in Japan led to the new declaration of patients' rights (1984) issued by a group of patients, lawyers, physicians, and journalists (Kimura, 1987). While this document carried no official authorization, it was more systematic than its 1970 precursor and showed the impact of discussions in other countries. The General Assembly of Japanese Medical operatives, an official medical service organization of the Japanese Association of Life Cooperatives Union with 250 hospitals and clinics and a membership of l.5 million individuals, endorsed its own version of a patients' bill of rights in May 1991 --- the first such action by a medical organization (Kimura, 2000). The Patients' Rights Legislation Movement, largely initiated by medical malpractice lawyers and other members of the lay public, began in 1991 to urge passage of a statute on informed consent and respect for patient autonomy in medical decision-making.

g. Ethics committees: Reproductive interventions.

The first medical ethics committee in Japan was established at Tokushima University Medical School in 1982 in order to review in vitro fertilization (IVF) technology and its application to infertile women. In Japan, a great deal of social and familial pressure exists to have children, so there is a great demand for IVF research. Artificial insemination by donor and artificial insemination by husband have been used since the early 1950s. The Yomiuri newspaper (April 15, 1993) reported that there were

199 registered clinics (registration is not required), and that the number of children born as a result of IVF seems to be increasing steadily. At present, each of the eighty medical schools finally has its own medical ethics committee reviewing cases such as segmental liver transplantation, gene therapy, and IVF. Owing to a lack of national legislation regarding these committees, each has a different composition, although the majority of members are from the same medical faculty and are male (Kimura, 1989b).

In 1991 the Greater Tokyo Metropolitan Government established the first hospital ethics committee with membership of nonmedical practitioners and opened all their meetings to the public. This committee serves as a policymaking body for the fourteen hospitals operated by the Tokyo Metropolitan Government. It has declared “Patients’ Bill of Rights of Tokyo Metropolitan Hospitals” in 2001 for the first time for the local government level in the history of medical services in Japan (Kimura, 2003).

h. Bioethics Organizations.

Since the mid-1980s, medical professionals and government organizations have been involved in the study of bioethical issues. In 1984, the Ministry of Health and Welfare set up the Special Advisory Board on Life and Ethics; it published an official report in 1985, after a series of research conferences, then ceased activity. The JMA also set up the interdisciplinary Bioethics Council, consisting of medical experts and professionals from philosophy, anthropology, biochemistry, law, and industry. The council dealt with topics related to technological applications in clinical settings such as IVF (1986), sex selection of the fetus (1987), brain death and organ transplantation (1989), and explanation and informed consent (1990).

The Japanese Association for Bioethics, established in 1987, publishes a journal and a newsletter, and has more than eight hundred members who attend the annual national meeting and international meetings. The Japanese Association for Philosophical and Ethical Research in Medicine, the Japanese Society of Ethics, and the Japanese Society of Medical Law are also concerned with bioethical issues as they affect their respective disciplines. In addition, the members of the Japanese Diet participate in a study group called the Diet Members' Federation of Bioethics. Proceedings of the study meetings, including texts of lectures by guest speakers, and questions and answers relating to issues such as brain death, organ transplantation, anatomical gift of the body, aging, and allocation of medical resources are published and publicly available.

In the early 2000s, Bioethics committee of the Science and Technology Council (a part of the Ministry of Education, Culture, Sports, Science and Technology) has been active on bioethical issues relating to biomedical research, such as cloning. The health and Welfare Council of the Ministry of Health, Labor and Welfare is also dealing with bioethical issues, mainly relating to clinical medicine. These two ministries worked with the Ministry of Economy, Trade and Industry to prepare a document titled “Ethics Guidelines for Human Genome/Gene Analysis Research,” which was released in 2001. They jointly made an official announcement of the Guideline in 2001 for the first time as a result of cooperative work in bioethics public policy in Japan.

i. Bioethics education and publications.

In 1987, bioethics became a compulsory course in the Japanese higher education system, at the newly established School of Human Sciences at Waseda University. This course, team-taught by professionals from medicine, biology, and law, covered the beginning and end of life, the quality of life, and environmental problems. Increasing numbers of medical schools include courses in bioethics or medical ethics with their clinical curriculum, although there are very few faculty members who teach only this subject. There are now several research institutions in Japan that focus on bioethics: Kitasato University, Kanagawa; Waseda University and Sophia University, Tokyo; the Eubios Ethics Institute, Tsukuba and Hokkaido University. Waseda University's International Institute of Bioethics and BioLaw has organized joint research project with Kennedy Institute of Ethics, Georgetown University.

Beginning in the early 1980s, several books have influenced the thinking of the Japanese public and biomedical professionals on a range of ethical issues. They include Hisayuki Omodaka's I no rinri (1971), based on his teaching experiences at Osaka University's medical school as chair of the "General Introduction to Medicine" as well as full-time professor of philosophy; a book with the same title (1977) by Omodaka's successor, Yonezo Nakagawa, a leading scholar in medical humanities; and Takeshi Kawakami's book Seimei no tameno kagaku (1973), which criticized the medical establishment's cooperation with the bureaucratic health-policy planning of the local and central governments, and touched on issues of patients' rights and the ethical tasks in medical service. Clinical physician Shigeaki Hinohara, clinical pharmacologist Shigeichi Sunahara, biochemist Shunichi Yamamoto, bacteriologist and medical historian Yoshio

Kawakita, medical law expert Koichi Bai, and lawyer and Bioethicist Rihito Kimura write books and give lectures on bioethics in Japan (Kajikawa, 1989).

j. Bioethical Trends in Court Decisions, code of Ethics, and Legislation

One of the most controversial legal issues relating to bioethics in the 1990s was the revelation that HIV-contaminated blood products were used for the hemophiliac patients without heat processing, resulting in around 1,600 people being infected with HIV. After more than seven years of legal struggle, the Ministry of Health and Welfare, pharmaceutical corporations, and the plaintiffs in the case agreed to a settlement involving a compensation fee of about 400,000 U.S. dollars per person (Tokyo HIV, 2002).

In 1996 the Eugenic Protection Law was amended, and its name was changed to the Maternal Protection Law. In addition to deleting the word “Eugenic” from the name, the new law eliminated all provisions related to eugenic operations, including the lists of genetic diseases that were the subject of eugenic operations, such s Hansen’s disease (Leprosy). The discriminatory Law for the Prevention of Leprosy, in effect since 1907, was abolished in 1996 following the initiation of legal action against the government of

Japan. Later, in 2001, the Kumamoto District Court ruled against the Ministry for its responsibility and the government gave up the appeal. Diet members adapted a unanimous resolution on the issue of Hansen's disease expressing sincere remorse and apologized for committing human right violations for over 90 years.

The bioethical principle of autonomy was strongly affirmed by a 1997 decision of the Tokyo High Court relating to a Jehovah's witness who had been given a blood transfusion, a medical treatment forbidden by his or her religion. The decision was made in favor of the plaintiff, as he had not been told that he might be given a blood transfusion under certain circumstances. The notion of "informed consent" was thus taken seriously in legal terms in the context of religious beliefs and bioethical conflicts of decision making when life is at stake (Kimura, 2000).

In 2000, the Japan Medical Association adopted the "Code of Medical Ethics" in six provisions in simplified form. The emphasis on the public role of medical service and contribution to society through medical works can be seen in provision five (JMA, 2000).

The social concerns facing the increasing number of elderly population and the need of mutual support systems by the local and central government has led to the realization of “The Long Term Care Insurance Law” in 2000. This was the reflection of the shift in values from traditional ethos of family support to the mutual, societal support mainly to be managed by the community (Kimura, 2002; Ministry of Health, Labor and Welfare, 2003)

Towards Bioethics of Cultural Harmony: Concluding Remarks

The contemporary discussion of bioethics in Japan started as a movement among the lay public in the late 1970s. This fact remains symbolic and important in many respects, as evidenced by the increased degree of individual decision making about desired medical treatment, as well as all areas of daily life. Optimistic attitudes toward science and technology enabled Japan to move toward the successful achievement of modernization since the Meiji Restoration. However, the devastating aftermath of the atomic bomb and the focus on economic and technological success after World War II exacted an enormous human toll in terms of pollution, health problems, and karoshi (sudden death from overwork). Because of this history, the Japanese people have a negative memory of rapid, uncontrolled, professionally oriented science and technology and its misuse, and quite naturally express a desire to have a more cautious process of social adaptation and application of science and technology. The Japanese public's fear of unwanted and unwarranted medical practices, both before birth and after death, has led to greater control of the medical profession and a serious demand for the information necessary to make informed medical decisions about the beginning and end of life.

Japan continues to struggle to recognize bioethics as integral to all spheres of life and to discuss public policy and the environment, as well as to deal with the tension between Western values and its traditional cultural practices. In Japan, bioethics is increasingly recognized as a supra-interdisciplinary endeavor embracing all traditional academic disciplines in equal partnership, for the valuable exchange of ideas and criticism each field has to offer. In Japan there are specific cultural values and customs that are distinctive and non-Western in pattern, but there is heterogeneity, too. In any case, ethical values change, particularly among the younger generations. We need to ask: What kind of future do we want to construct? We are and will be seeing a globalization of values. In this age of global community it would be naive to overemphasize the uniqueness of a particular cultural heritage in human, family, and social relations. It is true that different cultural and ethical values should be respected, such as key concepts of the dignity of each person, the importance of the family unit and community life. But justification of any act or behavior against human dignity and the rights of the person for the sake of cultural tradition is not acceptable.

The notion of harmony is reflected in Article 1 of the Law concerning the Regulation of Cloning Technologies and Other similar Technologies Relating to Humans, which went into effect in June 2001. This article states that one purpose of the law is to “harmonize the society and peoples’ lives with the development of science and technology.”

In the international community of the twenty-first century, with a globalization of values focusing on a universally accepted notion of fundamental human rights, the reality of limited resources, and the increasing necessity of mutual cooperation, it is useful to emphasize the twin notion of “related-autonomy” and the Japanese principle of harmony (wa) in cultural bioethics.

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Chapter 2. Bioethical Aspects of Genetic Issues

A. Religious aspects of human genetic information

For many of us who are religious believers, the religious reality of our life is so natural that we usually make our important decisions on the basis of our beliefs or values derived from religious teaching or ethical criteria, unconsciously acquired through our personal religious experiences and our lives in a particular society.

The major contemporary religious teachings have a common character of transcendence which goes beyond individual cultural, national, racial and geographical boundaries, despite the variety of indigenous elements in the particular historical settings of specific religious groups and institutions.

In this article I shall analyze some of the religious aspects of human genetic information from the viewpoint of my understanding of the teachings of the major religions as expressed in relevant recent documents. It might be appropriate to approach this by focusing on the 'purpose' underlying the issues concerned.

' The purpose of knowing the human genome

What is the purpose of our life, the world, and our activities?' This is a question asked and answered by various religious teachings.

The purpose of acquiring knowledge has always been justified if the knowledge is utilized according to the message of, and within the limits of the framework of, religious teaching. This view is usually based on the universal value of loving-kindness to other people, living beings and the environment.

Research into the biological aspects of human life is leading us into the secrets of human genetic information. I do not think there have been any religious objections to continuing research on the human genome itself, so far. However, we have to ask ourselves, and the scientists, about the purpose behind such large-scale research programs, which are receiving enormous amounts of funding from government and private resources. A medical, industrial and national consensus concerning this area in certain countries also has to be achieved from the ethical, moral and religious point of view (Council of Europe 1981).

If the primary purpose of this research is the application of studies of the human genome to the cure of genetic disease in individual subjects (there will also be industrial implications for pharmaceutical concerns), human genetic research will be accepted by society. However, I foresee a possibility of danger that particular kinds of genetic information will be used for other purposes, such as making financial gain, and also for the enhancement of individual personal abilities and health, in the absence of specific disease. This is surely the mentality of eugenics, which should not be adopted, according to various religious teachings.

It seems evident to me that, in our lives, we have a 'purpose' in working for environmental improvement and for reforms of our various social systems that are relevant to our health and welfare, rather than in using our abilities to do research for eugenic programs. On this view, even in the name of the public good, if a genetic screening program were to be enforced against an individual's wishes, it would be a dangerous development.

I believe that the strictly therapeutic treatment of a patient, based on genetic information, in order to avoid severe human suffering would be permitted by most of the world religious teachings and ethical interpretations (Wertz & Fletcher, 1989). Thus, in 1973, the World Council of Churches (which consists of almost 300 member churches, including most of the Protestant and Orthodox churches of the world) organized a conference on 'Genetics and the Quality of Life' in which I participated and contributed to the final report (World Council of Churches, 1973). The issues of suffering caused by genetic disorder were described as follows:

'One purpose of reducing genetic defects is to reduce human suffering. Although suffering is an inescapable aspect of human life, it can often be avoided or diminished. Genetic disorders may cause suffering through the physical and mental limitations they impose on the patient, even to the curtailing of his life, as well as through the consequent physical, psychological and financial burdens placed on others. The family, the medical profession and society should strive to minimize such suffering whenever possible without Violating other moral values.'

This report goes on to say [that the 'Christian faith, in particular, acknowledges several aspects of human suffering. It seeks to prevent suffering and to heal the sick. It accounts solidarity with those who suffer. And in the unavoidable sufferings of life it seeks the grace that comes through suffering'.

Suffering is positive, according to an Apostolic Letter of February 1984 by John Paul II. The Pope mentions that 'Christ's revelation of the salvation meaning- of suffering is in no way identified with an attitude of passivity. Completely the reverse is true. The Gospel is the negation of passivity in the face of suffering'. In Health Care ethics, Catholic theologians Fr. Ashley and Fr. O'Rourke (1982) say that 'the right of persons to make decisions about reproducing genetic defects should be respected both by the Church and by society, and they should not be stigmatized because of their decision'. They also give their opinion that 'Catholic genetic counseling will also promote its education about genetic hazards without encouraging abortion or neglecting the freedom of decision of the parents, while actively promoting a more optimistic and life-affirming attitude toward the inevitable risks of parenthood'.

The issue of suffering and human life is dealt with in almost all religious traditions. My interpretation of Buddhist teaching is that it shows that suffering is not controlled by destiny, but some Japanese would refer to kar'na in relation to genetic disease. A Thai Buddhist philosopher, Dr. Pinit Ratanakul (I 985), stated:

'Buddhism accepts the fact that, like happiness and suffering, the painful side of experience usually outweighs happiness. However pessimistic it may seem, Buddhism tries to address the realily of suffering, without any pretense or deception, so as to focus on this sinful side of life. At the same time, it tries to probe beneath the tact of suffering in search of ills causes and a way to end its suffering.'

The fundamental notion of life according to the Judaic tradition was expressed by Rabbi Levi Meier (1986):

'Within Judaic tradition, life has intent value, even a diminished life. The value of a human life is not based upon its potential usefulness to others or upon one's own well-being. It is an absolute value, even when life is accompanied by pain, suffering and mental anguish. Humans do not possess absolute titles to life. Each is responsible for preserving his/her own life and is obliged to seek food and substance to that end. When one is sick, he/she is similarly obliged to seek medical attention.'

The purpose of using human genomic information

Apart from the utilization of human genetic information for individual therapeutic reasons, there is wider concern that the information made available by this research can be used for the purpose of preventing possible disease as a part of national or regional health policy.

In 1978 a Working Party of the Clinical Genetics Society in the U.K. (Emery, l978) made 12 recommendations, including the following:

l . Registers should be set up for the express purpose of tracing, following up and counseling individuals who are at high risk greater than I in 10] of transmitting a serious genetic disorder to their offspring. The object is to ensure that such individuals are informed of the risks and the various options available to them.

2. Registers should be organized on a regional, rather than a national basis, and should be located in a regional genetics center. When Registers already exist in Units dealing with specific genetic disorders, such as hemophilia, close liaison should be encouraged with the regional genetics center in order to provide comprehensive facilities for counseling, including risk estimations.

3. No individuals should be included the Register without their full knowledge and approval.

This approach might appeal to the need to justify human genetic intervention medically because, as we know, genetic diseases cause suffering and pain and can be socially costly, and the possibility of curing and preventing them looks very positive and also very attractive. However, I feel that the responsibility of each individual would be emphasized, such as not to marry, not to have a baby, not to embark on some particular action such as unhealthy eating, or drinking and driving, as a result of social pressure. Insurance corporations and some companies, which manufacture products hazardous to health, have great interests in human genetics information being used for the benefit of their companies and businesses. There are already some businesses, which require physical examinations, including genetic testing, from their prospective employees.

As religious believers, we have to be cautious in our approach to the fundamental, long-term perspective for the application of new scientific knowledge, particularly relating to human genomic information. Rabbi Immanuel Jakobovits (1983) has said: “genetic engineering may open a wonderful chapter in the history of healing. But without prior agreement on restraints and the strictest limitations, such mechanization of human life may also herald irretrievable disaster resulting from man's encroachment upon nature's preserves, from assessing human beings by their potential value as tool-parts, sperm-donors or living incubators, and from replacing the matchless dignity of the human personality by test-tubes, syringes and the soulless artificiality of computerized numbers.'

He concludes by saying that 'Man, as the delicately balanced fusion of body, mind, and soul, can never be the mere product of laboratory conditions and scientific ingenuity’.

A similar approach can be traced in the Islamic tradition, clearly stated in the Islamic Code of Medicine issued by the International Organization of Islamic Medicine in 1981. In chapter 10, which deals with doctors and bio-technological advances, paragraph 6 states that 'the guiding rule in unprecedented matters falling under no extant text of law, is the Islamic dictum: "Wherever welfare is found, there exists the statue of Cod".'

In relation to Scientific research, this document also says that 'there is no censorship in Islam on scientific research, be it academic to reveal the signs of God in His creation of a particular problem. Freedom of scientific research shall not entail the subjugation of Man, telling him, harming him or subjecting him to definite or probable harm, withholding his therapeutic needs, defrauding him or exploiting his material need'. I was able to recognize these trends in Islamic medical teaching when I was invited to take part in the international conference of the Islamic Medical Organization in Cairo in

1988.

It is quite understandable to find a sense of fear among various religious believers about human genetic information being used without detailed discussion and consultation. This is because the most serious issues relating to the problem of human genetic engineering involve the alteration of our lives, our characters, and our health and abilities, in a global context (Kimura, 1988).

Of course, the negative use of genetic engineering technology has enormous implications for the production of chemical weapons, expressed as 'gene wars' by Piller & Yamamoto (1988). A tragic outcome of this military strategic use of chemical substances to destroy enemy crops as well as to clear roads and communication lines, that I observed during my stay in Vietnam in 1970- 1971, was an increase in stillbirths and birth deformities, suggestively correlated with the massive use of Agent Orange (Littatuer & Uphoff, 1972).

The purpose of the religious approach to human genomic information

A significant number of religious groups and institutions as well as other organizations, are seriously concerned about health and healing issues. The word 'salvation' was derived originally from the words for healing and well-being. It is an obligation of religious believers to express their opinions on issues of public welfare such as health and science policy, in order to contribute to the making of public policy relating to bioethical problems (World Council of Churches 1982).

All individuals should be respected for their lives, dignities and rights, regardless of differences in genetic make-up, social standing, and thoughts and beliefs. A unique phenomenon in the area of health and medicine is being observed in the lay public's enthusiastic commitment, which is developing particularly in North America. Professional bioethicists are now working in hospital settings and biomedical research institutions as members of hospital ethics committees and institutional review boards. Many of them have religious educational backgrounds. In addition, at least one or two Christian and Jewish clergy or chaplains are also members of these committees.

In the USA, public concern and public participation in bioethical issues have both grown remarkably. The bioethics movement is the most important common denominator in forming bioethical public policy, which is seen to be successfully operating in the USA. It is now developing at a grass-roots level in many States and offers to the State Congress a wide range of alternative proposals on health-related topics and information on medical resources, such as organ transplantation and genetic counseling (Kimura, 1987; Jennings 1988). At the Federal government level, there are The Biomedical Ethics Board and Biomedical Ethics Advisory Committee of the United States Congress, where the human genome issue is an important item on the agenda (Congress of the United States 1988).

In Japan there has been growing concern since the early 1980s about bioethical issues among the public as well as in the Ministry of Health & Welfare and the Japanese Medical Association (Kimura 1986). This concern has led to the formation of various institutional bioethics committees and related national organizations, such as the Japan Association for Bioethics. The Japanese Science Council has expressed its concern on bioethical problems and has issued a committee report (Japanese Science Council 1989) on 'The promotion of the human genome project' which will be one of the main themes for the international conference in Tokyo to be co-organized by the JSC and CIOMS (Council for International Organizations of Medical Sciences) in 199O.

The Bioethics Panel of the National Council of Churches of Christ in the USA, of which I was a member, issued a final report (1984) which stated: “It is now possible for humanity to create, intentionally, new life forms that have never before appeared on this earth.”

It is also now possible to own a patent on the process by which certain life forms come into existence, and on certain life forms themselves.

It is now possible to alter all life forms, intentionally, with precision and speed never known before to humankind. It is also possible to alter life [so] that it not only affects the present, but also the gene pool of all future generations as well.

'Words which once were the primary language of the church are now also the words of the current biological revolution. Life, Death, Creation, New Life, New Day, New Earth are now the vocabularies of biological science, bio-technology and bio-business.

The Islamic scholar, Dr. Fazlur Rahman (1987), is also seriously concerned about the issue of genetic engineering:

'The genetic manipulation lays extraordinary grave responsibility on humans. The most fundamental questions to be asked in this connection are these: What does genetic improvements of the quality of human life mean? Who is authorized to decide? What are the criteria of judgment? The Qur'an says about Saul, 'We granted him amplitude of knowledge and physique' (2,247). This shows that a combination of mental (where mental includes both intellectual and moral qualities) and physical qualities is to be aimed at. But who is to decide upon the nature of these qualities, particularly the moral ones? While there could be in principle no objection to genetic engineering-indeed, it is a welcome opportunity we know that this unique opportunity also carries with it grave and unprecedented risks.'

The future of the human genome project holds out great hope, promise, and fear. The development of genetic information technology may be very fast, beyond our present assumptions. There are many reasons for this. It will be the most interesting, important, large-scale, cooperative, global scientific project in the coming century (National research Council 1988).

We know that science projects, and particularly genetics technology, are not value-free entities. This is why we have to be very cautious about proceeding too fast. We need to re-examine our values towards the future so that we may have more wisdom in understanding our human nature and may fully achieve the welfare of the sick, weak and disabled by making more efforts in changing our surroundings, our society, as well as our own selves, through education, in a democratic way.

I believe that our religious heritage give us valuable insights that will enable us to be responsible for our neighbors, nature, and truth.

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B. Jurisprudence in Genetics

It is quite clear that legislation is an instrument of social control that leads societies to change the function and system of their traditional ideas and behavior (Schubert, 1975). Law is not identical to moral regulation and control, but legislation requires moral support if it is to be adjusted to the political, cultural, and economic framework of particular societies, which actually produce new legislation (Miller 1979).

Due to the rapid development of biomedical science and biotechnology, as well as strong interest in their application to the public's interests in health, several achievements in the form of new legislation have been made by health experts and bureaucrats concerning public health issues (Brahms, 1990).

In Japan, immediately after World War II, some of this legislation came into being followed rapid changes in society. In this paper I shall adopt the framework of past and present Japanese legislation, and consider prospective legislation in the form of case studies to clarify the basic jurisprudential issues that arise due to advances in modern genetics.

These topics are:

1. Eugenic protection legislation and mental disabilities;
2. Maternal-child health legislation and genetic screening; and
3. Health information legislation and human genome analysis.

Eugenic Protection Legislation and Mental Disabilities

The Eugenic Protection Law (Yusei Hogo Ho) was promulgated on July 13, 1948, and it was amended as the Maternal Protection Law in 1996 by eliminating the fundamental eugenic principles. However, it is important to analyze the Eugenic Protection Law as a historical stigma of Japanese legislation related to health policy. This is one of the reasons to look into the historical background of this law in this doctoral thesis.

It took as its model the National Eugenic Law (Kokumin Yusei Ho) enacted in 1940. The enforcement of this National Eugenic Law rested on a clear policy of increasing Japan's population, in its quality and quantity, to serve as a base of state power under the influence of a wartime, military-oriented government bureau at that time.

This legislation was influenced by the powerful ideology of the worldwide Eugenic

Movement (Suzuki, 1983). The aim of the legislation was to develop and promote a future Japanese population by employing eugenic screening processes to *prevent* an increase in the number of genetically inferior descendants, including physically and mentally impaired descendants. The health of mothers was not much taken into account in this National Eugenic Law, although the words "Umeyo Fuyaseyo" (Be fruitful and multiply) became a national slogan for a state policy supported by the military regime in power during the war years, 1941-45 (Kimura 1984a, 1987).

After the war, due to a fundamental change in state policy - in transition from a military regime to a democratic political system based on a new constitution (Nov. 3, 1946) - and in the midst of social and economic confusion as well as an enormous population increase, the old National Eugenic Law (1940) was abolished and the new Eugenic Protection Law (1948) was enacted. Even though drastic political changes occurred in Japanese society, which led to the formation of a law relating to the health of the people, the term "eugenic" remained. Yet this new legislation had a completely opposing objective: to decrease the Japanese population by permitting abortion without prosecution only in cases of particular medical and social indications provided in article

14 of the Eugenic Protection Law. Indeed, even now, abortion remains illegal in Japan (Chapter 29, art. 212-216, Japanese Criminal Code, 1907).

Controlling the size of the Japanese population was also the policy of the Occupation Forces under the command of U.S. General Douglas MacArthur and his staff. The Eugenic Protection Law was proposed by a Japanese congressman, Dr. Ohta, who had been an advocate of family planning practices since the 1930s; however, there had been a good deal of pressure from the National Resource Section of the General Headquarters to enact this new legislation, and various comments concerning this proposed law appeared in official documents of the government (Kimura 1984a).

Thus the new Eugenic Protection Law was simply regarded as an abortion law rather than a eugenic law by medical professionals and the lay public. One of the important articles in this law requires that there be no legal justification for abortion due to a genetically defective fetus. There has been a proposal to amend this article, but it has not yet been adopted.

The purpose of the Eugenic Protection Law is stated in Article 1:

"The purposes of this law are to prevent the birth of inferior descendants from the eugenic point of view, and to protect the life and health of the mother as well."

The Eugenic Protection Law actually serves as a law for eugenic and maternal protection by applying the methods of "eugenic operation" (Article 2) and "artificial interruption of pregnancy" (Article 2-II). In this law the term "eugenic operation" refers to any surgical operation that makes a person unable to reproduce without removing the reproduction glands, as prescribed by Order. "Artificial interruption of pregnancy" refers to the artificial discharge of a fetus and its appendages from the body of the mother during the period when a fetus is unable to remain alive outside the body of the mother. (This particular time period ends around the 22nd or 23rd week of gestation.)

It is quite important to note that the original text of the Eugenic Protection Law included no provisions permitting economic and social reasons as justifications for an artificial interruption of pregnancy. In 1949 the law was amended to remove the rigid provisions concerning maternal protection, with the qualifying statement that: "if the mother's condition is seriously endangered by economic reasons..." In 1952, another amendment was introduced to abolish any investigation by the District Eugenic Protection Commission and to give physicians the final authority to decide when to artificially interrupt a pregnancy, as well as to provide women a program for practical guidance in birth control and family planning.

The Eugenic Protection Law has three major elements:

1. Articles relating to the process of eugenic operations;
2. Articles relating to the conditions for having artificial interruptions of pregnancy;
3. Articles relating to practical guidance for birth control methods and family planning.

According to the Eugenic Protection Law there are two forms of "eugenic operation." One is called the discretionary eugenic operation (Article 3), which the physician may perform at his discretion after he obtains the consent of the woman and the spouse. There are five clear indications for this operation:

1. The person in question, or the spouse, has hereditary psychopathia, hereditary physical disease, or hereditary malformation, or the spouse suffers from mental disease or mental disability;

2. A blood relative, within the fourth degree of kinship of the person in question or

the spouse thereof, has hereditary mental disease, hereditary debility, hereditary psychopathia, hereditary physical disease, or hereditary deformity;

3. The person in question or the spouse thereof is suffering from leprosy, which is considered to be contagious for the descendants;

4. A mother whose life is endangered by conception or by delivery;

5. A mother who actually has several children whose health condition is feared to be seriously affected by any future delivery.

The second method is called the non-voluntary eugenic operation. If, as the result of an examination, the physician discovers one of the diseases enumerated in Table 1 and recognizes that a eugenic operation is necessary for the sake of the public interest to prevent the inheritance of the disease, he is required to report this finding to the Prefectural Eugenic Protection Committee (PEPC).

In cases of eugenic operations and sterilization, there are fundamental and crucial elements, which are closely related to the protection of the rights of the individual (Brakel and Rock 1971; Wexler 1980). This is why the Japanese Eugenic Protection Law includes several articles that provide for appeals to challenge the first decision taken by the PEPC, and the second decision taken by the Public Health Council (PHC), and finally open the way for the initiation of a lawsuit in civil court, as provided in article 9 (see Fig. 1).

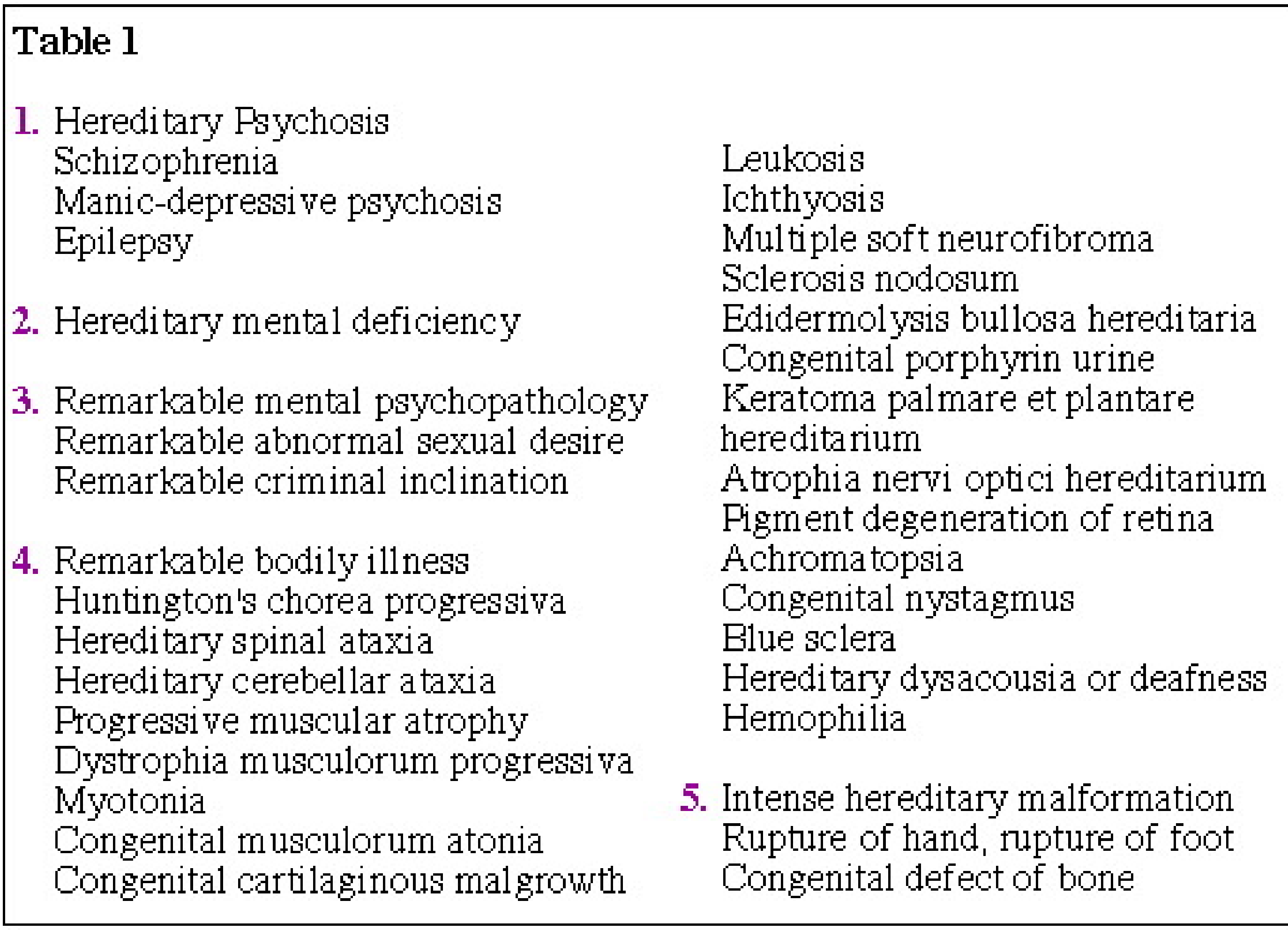

Table 1

1. Hereditary Psychosis
   Schizophrenia
   Manic-depressive psychosis
   Epilepsy

2. Hereditary mental deficiency

3. Remarkable mental psychopathology
   Remarkable abnormal sexual desire
   Remarkable criminal inclination

4. Remarkable bodily illness
   Huntington's chorea progressiva
   Hereditary spinal ataxia
   Hereditary cerebellar ataxia
   Progressive muscular atrophy
   Dystrophia musculorum progressiva
   Myotonia
   Congenital musculorum atonia
   Congenital cartilaginous malgrowth
   Leukosis
   Ichthyosis
   Multiple soft neurofibroma
   Sclerosis nodosum
   Edidermolysis bullosa hereditaria
   Congenital porphyrin urine
   Keratoma palmare et plantare hereditarium
   Atrophia nervi optici hereditarium
   Pigment degeneration of retina
   Achromatopsia
   Congenital nystagmus
   Blue sclera
   Hereditary dysacousia or deafness
   Hemophilia

5. Intense hereditary malformation
   Rupture of hand, rupture of foot
   Congenital defect of bone

Very few of these non-voluntary operations are being performed (see Table 2), and these are mainly requested by parents, guardians, or spouses. Such requests are made, as a matter of fact, due to eugenic considerations on behalf of a particular person. Non-voluntary operations are usually not performed if the person concerned brings the issue to civil court, because the majority of Japanese tend to think that courtroom resolution of these conflicts might not be socially appropriate (Kawashima 1963; Kimura 1988a).

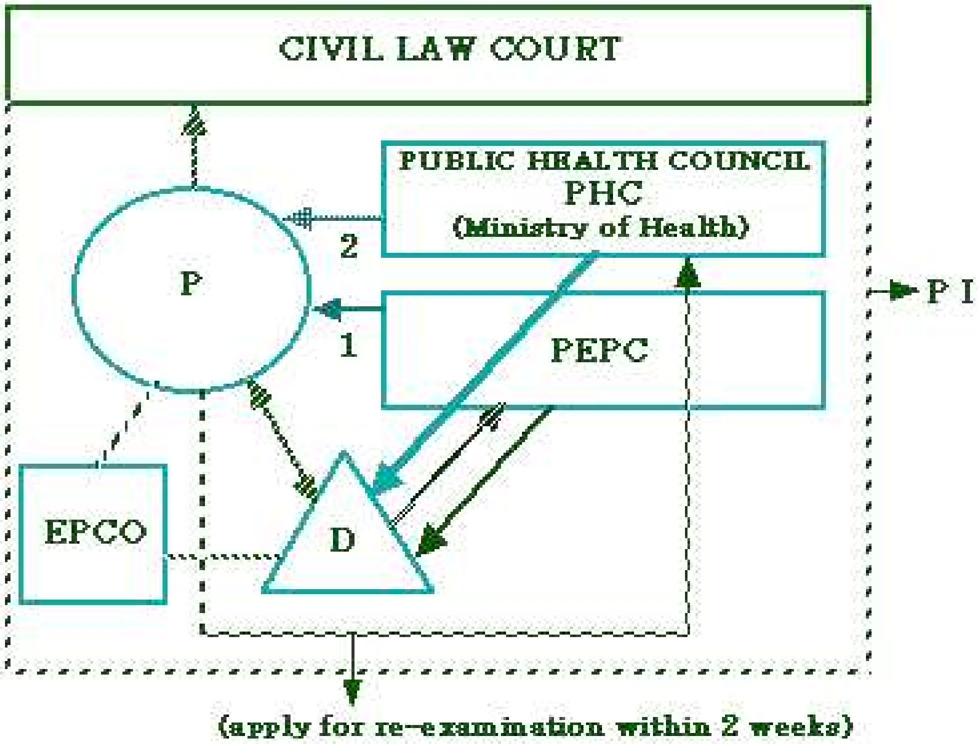

Fig. 1. Compulsory eugenic operation procedure and system in Japan according to the Eugenic Protection Law of 1948. **P**, person (spouse, guardian, parents, etc.); **D**, medical doctor; **P.I.**, public interest; **PHC**, Prefectural Eugenic Protection Committee (10 members); **EPCO**, Eugenic Protection Consultation Office.

One can raise a serious question concerning the fundamental ideological premises of the Japanese Eugenic Protection Law. One of the most problematic articles in this law concerns providing eugenic operation to patients who are in different categories than are indicated in the attached list (Table 1) of the Eugenic Protection Law, e.g., mental illness. Article 12 states:

In regard to a person who is psychotic or mentally deficient (other than by hereditary causes mentioned in item 1 or item 2 of the Annexed List), a physician may obtain consent from the person who is responsible for protecting the patient under the provision of article 20 (in cases where the guardian, spouse, person exercising parental authority, or the person under obligation to sustain becomes person obligated to protect patient) of the Mental Hygiene Law (Law No. 123 of 1950) or article 21 (in the case where the mayor of the city or the chief of the town or village becomes the person obliged to protect the patient) apply for investigation concerning the reasonableness of performing eugenic operations to PEPC.

Article 13 provides that if an application to the PEPC is made, PEPC shall investigate whether or not this patient suffers from a psychosis or mental deficiency based on Article 12, and whether or not the performance of a eugenic operation is necessary to protect the patient. Thus the PEPC decides the reasonableness of performing the eugenic operation and informs the applicant and those who give consent (provided in Article 12).

Table 2. Number of sterilizations reported from 1955 to 1967, by sex, and stated reason[a]

Year	Sex	Total	Voluntary sterilizations				"Non-voluntary" sterilizations	
			Hereditary diseases of: the person concerned	Hereditary diseases of: the relative	Hereditary diseases of: Leprosy	Protection of maternal health	Hereditary diseases	Non-hereditary mental diseases
1955	M F	1,528 41,727	54 271	52 184	14 115	871 40,402	504 726	29 79
1956	M F	1,774 42,711	36 243	70 105	17 86	1,158 41,504	482 728	11 45
1957	M F	955 20,727	9 98	11 47	3 13	698 20,187	222 360	12 22
1958	M F	1,641 40,344	27 155	22 120	9 63	1,174 39,324	394 655	15 39
1959	M F	1,215 38,887	29 161	8 81	8 47	823 37,988	336 563	10 47
1960	M F	1,150 37,992	37 208	20 74	7 58	868 36,997	208 567	10 55
1961	M F	1,049 34,434	21 182	12 57	13 33	724 33,561	270 544	9 57
1962	M F	964 31,470	18 125	10 49	1 5	717 30,763	197 450	21 69
1963	M F	832 31,884	10 121	7 82	0 72	629 31,102	166 460	20 47
1964	M F	708 20,780	5 97	10 56	1 10	547 20,207	133 346	12 64
1965	M F	697 25,525	11 125	5 25	0 9	533 25,001	127 309	21 56
1966	M F	535 22,456	10 93	0 40	2 15	427 21,971	86 272	10 65
1967	M F	553 20,911	5 93	10 32	2 21	456 20,463	70 251	10 51
Total	M F M+F %	13,571 418,178 431,749 99.99	246 1,975 2,223 0.51	237 832 1,069 0.25	77 549 626 0.14	9,608 407,910 417,518 96.70	3,219 6,216 9,435 2.19	184 695 879 0.20

[a] Data are based on statistics from the Japanese **Ministry of Health and Welfare**

Even though there are legal mechanisms to protect the rights of mentally ill patients, there have been quite a few cases concerning violations of these rights in various institutions for the mentally ill. Observations and documented reports, as well as recommendations by an International Commission of Jurists in Geneva together with a nationwide campaign for the reformation of this situation in Japanese mental hospitals, led to an open debate on these issues (International Commission of Jurists 1985). As a result, an amendment to the Mental Hygiene Law was passed in 1987. This shows the grave importance of international cooperation concerning changes in the traditional system, not only regarding mental diseases but also in the area of policy. Today, the people still need much more information and better education concerning mental and genetic diseases (Hirano, 1987; Grostin, 1987).

・Maternal-Child Health Legislation and Genetic Screening

In Japan, there are several genetic screening programs for newborns. The Maternal-Child Health Law (Boshi Hoken Ho) of 1966 was enacted for the maintenance and promotion of the health of mothers, neonates, infants, and children.

One of the unique practices based on this law (Article 16) is the issuance of a Maternal-Child Health Notebook to all of those who register at local offices or health centers governed by local authorities. Any woman who becomes pregnant informs the local office (Article 15) to receive various medical and health services, which she must then record in her Maternal-Child Health Notebook each time she receives these services (Kimura, 1986).

There is no precise provision regarding a genetic screening program under the Ministry of Health and Welfare or local government. However, a practical ordinance from the MHW gives administrative and legal justification for a genetic screening program, which was initiated, by health experts and bureaucrats at the level of central and local government (Ohkura and Kimura, 1989).

In 1977, the mass-screening tests for inborn errors of metabolism were performed on only 29.2% of all newborns; in 1984 this percentage grew to 99.6% (Health and Welfare Statistics Association, 1986). These screening programs for inborn errors of metabolism include PKU, maple syrup urine disease, homocystinuria, histidinemia, and galactosemia. The screening program for cretinism began in 1979, and for neuroblastoma in 1985.

These practical medical and health services are justifiable given the present legal framework. However, the detailed information provided for these screening practices, and the final endorsement by the lay public, should be considered seriously in the health education process in the community, in local health centers, and in local schools. The initiative taken by the central and local governments on these issues of mass screening has delicate implications, relevant to an individual's health and the importance of protecting the privacy of genetic information. In this sense, even though there is a very positive side to the promotion of maternal-child health based on legislation, the practical requirements that all pregnant women file a report with the local authorities might cause some uneasiness for those who are seriously concerned about the real meaning of *privacy rights* (Kimura, 1984).

The positive reaction of Japanese pregnant women to this government ordinance reveals that the benefits of receiving genetic screening could also be recognized as a right of pregnant women to receive services from the government (Ohkura, 1984).

Health Information Legislation and Human Genome Analysis

There is growing concern regarding future research on, and the application of, human genome analysis. The information acquired from human genome analysis could radically change the traditional notions of medical and health services, since some illness situations will be predictable beforehand. Genetic information about ourselves could change our lifestyles, behaviors, habits, etc. (Kimura, 1990).

Health information legislation designed to protect personal privacy has not yet been proposed in Japan. However, such legislation should be passed before scientific and technical "fixes" become available; otherwise, violations of privacy could occur too often. Schools, employers, insurance businesses, and future spouses might claim that it is necessary for them to obtain genetic information to protect the persons concerned. What criteria should be established to give or not give genetic information to these people and organizations?

The control and maintenance of genetic information in Japan has already begun, e.g., the registration of all pregnant women. There is no guarantee that personal privacy will be protected, even though there are some articles in the law that provide penalties for disclosure of particular information acquired by health professionals in the process of conducting their services (Kimura, 1990).

Additional integrated legislation concerning the private nature of health information (particularly as it relates to the human genome) is clearly required.

International guidelines are needed prior to initiating new legislation in various nations. The centralization of genetic information would give those in control enormous power over a population, and this could lead to rather serious consequences.

"The right to be different" in pluralistic, multi-cultural nations in the contemporary world should be a fundamental principle in jurisprudence that must be maintained as a basis for future legislation.

Genetic manipulation for the enhancement of the body or abilities in a direct way should not be recommended and might be prohibited by legislation. However, genetic manipulation for the cure of disease and suffering would be justified bioethically and legally. Public debate on these issues of genetic manipulation would be extremely helpful, including contributions from various disciplines such as jurisprudence, bioethics, religion and genetics. Open communication between experts and the lay public should be a basic factor in making public policy and regulation relating to genetic health issues (National Institutes of Health 1990; Kimura 1988a).

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C. Genetic Diagnosis and Gene Therapy in the Cultural Context: Social and Bioethical Implications in Japan

･genetics and public policy

Issues and problems related to human genetics, and in particular to genetic disease, are attracting much attention in Japan today. The rapid development of genetic science has increased the potential of genetic diagnosis and gene therapy as a means for the treatment of currently incurable diseases such as cancer and AIDS. However, even though there might be no direct threats of ideological manipulation by genetic science at present, we should not forget the numerous and tragic mistakes that have been committed in the name of human welfare and progress throughout the world in conjunction with supposedly "genetic" or "eugenic" legislation (Kimura, 1991a). Moreover, we must remember the intentional harm to human genes caused by the Atomic Bombs in Hiroshima and Nagasaki in 1945 and the use of the defoliant "Agent Orange" in Vietnam. I had direct contact with victims of the latter during my stay in Saigon in the beginning of 1970s (Spinsanti, 1995).

Clearly, science and technology need to be guided by a bioethical public policy. For, as history teaches us, if there is no opportunity for public scrutiny, science and technology are more likely to be used for military and dehumanizing purposes.

This is one of the reasons why ecumenical organizations such as The World Council of Churches have had a series of consultations on science, technology and religion in the face of rapid social change. I had the opportunity of participating in one of the pioneering conferences held in Zurich in 1973 on the issue of "Genetics and the Quality of Life." The participants were theologians, lawyers, policy makers, and medical experts, including Dr. Robert Edwards, the first person to carry out a successful birth of an in vitro fertilized baby, Louise Brown in 1978 (Abrecht, 1973). I still remember the dialogue with eminent physiologists, theologians and ethicists on the necessity for the open and public participation of lay-people in order to lay down bioethical public policies and guidelines for the sound future development of medical and scientific technologies.

In Japan, due to the lack of timely input from traditional religious organizations etc., there is a risk that society will repeat past mistakes in the face of new innovative types of medico-technological applications and scientific developments, in particular with respect to genetic science, including human genome analysis (Kimura, 1991b).

Genetic diagnosis of familial cancer in Japan and the proposed Ethical Guidelines of 1998

For many years, the Japanese word *"Iden Byo"* (genetic disease) has had a rather negative connotation. Some people believe that the appearance of genetic disease in a family member indicates some sort of wrongdoing in the previous generation. This belief is based on a traditional Japanese idea, which may originate from the Buddhist notions of Karma or destiny (Ohkura and Kimura, 1989).

Genetic disease was regarded as shameful to the family and something to be hidden and kept secret, in particular because genetic diagnosis and disease might result in social discrimination against a particular "family clan" when it comes to marriage, employment, schooling, etc. One important aspect of genetic disease in Japan is that it is not only a matter for the individual and the immediate family members, but also for the whole generational family.

a. Ethics of familial cancer research in Japan

Serious bioethical issues are raised by familial cancer diagnosis. Openness among family members is often not the norm in the case of serious disease. Misdirected efforts to cure the patient are made, and false hopes for recovery are proclaimed. In the case of terminal illness, such as cancer, the patient would not be told the truth that he or she is dying. However, if the situation is not terminal, but involving genetic defects or diseases like breast cancer or familial polyposis coli, the individual patient would be told the facts, but he or she would usually not tell the truth to other family members who might be affected by similar genetic defects in the future. This illogical contrast in not telling the truth to the patient in the terminal stage of cancer (not telling the truth to a dying patient) while presenting the genetic diagnosis of familial cancer (but not telling the truth to other family members at risk) might be interpreted as a psychological protection mechanism in Japanese culture. This mechanism aims at preserving a gentle feeling of loving-kindness without telling the "truth" in order to avoid the harmful reality.

However, the traditional ethos of the Japanese people has been changing during the last twenty years, at least slowly.

b. Patients and the formation of the "Family Support Group"

One example of slow change is the formation of the patient and family self-help group called "Harmony Line (Fellowship Association for the Patients of Polyposis Coli)."

This organization had around 40 members at its establishment in 1998. Two thirds of its members are patients themselves; the rest are relatives. The purpose of this organization is to share and exchange various kinds of information regarding their disease, living conditions, medication, surgery, alternative treatment, etc. (Gondo, 1998)

In this social and cultural context, the Ethics Committee of The Japanese Society for Familial Tumor (JSFT) in 1998 presented its draft guidelines for familial cancer research and clinical trial (JSFT, 1998). JSFT was originally formed to be a key research station for Familial Cancer and Prevention Project of Unio Internationalis Contra Cancrum (UICC) in the Asia-Oceania region (Utsunomiya, 1998).

c. The outline of Genetic Diagnosis Research Guidelines

JSFT's Ethics Committee had been working on these draft cancer research guidelines since 1996. Below follows a brief summary (A revised version, May 30th, 1998), which I have paraphrased to denote the main elements of each clause in the original Japanese text (Ethics Committee, JSFT, 1998).

In the Introductory Notes, the guidelines explain the purpose of familial cancer research and other relevant issues, such as the meaning of susceptibility, the protection of privacy, the guarantee of human rights and dignity of patients and family, and the necessity of ethical consideration in order to carry out scientific work.

In addition, the following nineteen recommendations are put forward.

I. Fundamental Principle of the Guidelines.

1. The priority of genetic diagnosis and research in familial cancer should be the protection of the human rights of the concerned participants and family members as it relates to the whole lineage of the family.

II. Purpose and Conditions of Research.

2. The research should only be performed for the advancement of diagnostic, therapeutic and prophylactic procedures, as well as the understanding of the etiology and pathogenesis of disease. Medically non-relevant research should not be performed.

3. Prior to carrying out a genetic test, it is necessary for the participants and society in general to make a comparative medical, psychological and social study of the balance between expected advantages and disadvantages. The test will be carried out when its advantage is confirmed and the informed consent has been obtained from the subjects.

4. The selection of participants should only be based on those individuals who have

a probable genetic susceptibility due to various familial and clinical data. Moreover, in the case of carrying out genetic tests on minors, the tests should be beneficial directly to them.

5. Genetic diagnosis should be performed by a physician who has an understanding of the meaning and limitations of genetic testing.

6. The research should be in accordance with ethical principles expressed in the Helsinki Declaration of the World Medical Association. Justification of the research should be stated clearly and in detail in the protocol.

7. The protocol for research and application of genetic diagnosis in medical services should be reviewed by a proper institutional ethics board.

III. Informed Consent.

8. Prior to genetic diagnosis research and the taking of samples, the participant should be made aware of the following, orally or in writing: the aim, the procedure, the expected benefits, the potential disadvantage (the possibility of having mental stress), the limitations of genetic testing (i.e. the occurrence of false positives or negatives) and the protection of privacy. Moreover, it is necessary for the physician to obtain the consent of

the subject based on his or her free will. The consent should be secured in writing.

9. In genetic diagnosis and research, detailed discussions concerning the research should be carried out in order to obtain an informed consent from the participant. The premise is that he or she should be informed about the name and condition of the disease.

10. The participant has a right to refuse genetic sample testing and there should not be any medical disadvantage due to this refusal. Moreover, he or she may also change the decision in due course without receiving any negative outcome.

11. In receiving genetic diagnosis and testing, the participant should be informed clearly that while there might be potential advantages in terms of better treatment and prevention, there are also potential social disadvantages with respect to marriage and conflicts among the lineage family members.

12. The participants should be clearly informed whether particular genetic tests and diagnoses are still on the experimental stage or are established procedures of medical practice. It should be explained that at this stage the majority of genetic diagnoses have been carried out for research purposes.

13. Third parties such as parents, guardians or proxies could be given the right to

consent on behalf of non-competent participants if this is in the patient's best interests.

14. The result of the genetic test and diagnosis should be disclosed to the participant, if he or she wants to know, and should be withheld if he or she prefers not to know. The possible benefits and disadvantages of declining information should be explained to the participant.

IV. Maintenance and Protection of the Genetic Information of the Individual.

15. The right to have access to genetic information belongs to the participant. Right to have access to the information could also be possible for medical staff members and researchers.

16. The maintenance and confidentiality of genetic information of the individual should be strictly controlled in order to protect the privacy of the participants.

17. The maintenance of the individual and the registration of the genetic information of the family lineage of the participants is necessary for the advancement of the study of familial cancer and for securing its scientific quality.

V. Support Systems for the Participants.

18. It is necessary to provide genetic counseling in keeping with the need of individuals and family members and in response to their psychological changes.

19. The arrangement of a medical, psychological and social support system in receiving the opinion of the subjects and the support group is recommended.

d. A break-through for medical research in Japan

As I mentioned above, these guidelines are the result of the continuous efforts by JSFT (Tsunematsu, Kakee, 1998). We see in them a full recognition of the principle of respect for the autonomy of the participants in research and of the fundamental idea of informed consent in genetic diagnosis, testing and research. After detailed discussions on drafts and amendments, the Ethics Committee finally presented them at a general assembly of JSFT in 1998 (JSFT, 1998).

In our cultural context, the ethical aspects of research on the genetic problems of individuals always raise the complicated question of family relationship and conflict. However, I think that these JSFT guidelines reflect a very well refined sensitivity to the family issues as well as the participant-centered, anti-paternalistic research on genetic diagnosis and testing. This is for many Japanese medical researchers a radical departure.

And this is one of the reasons why, after three years of repeated revision, presentation and amendment, these guidelines still remain a "proposal" (a draft) without receiving the official endorsement of the general assembly of JSFT.

･Ethical aspects of gene therapy and informed consent in Japan

In this section, I shall focus on the recently emerging gene therapy and some bioethical problems of the research protocol including informed consent documents.

･Guidelines for gene therapy in Japan

In February 1994, the "Guidelines for Gene Therapy Clinical Research" (GGTCR) were issued as an official "Notice No. 23" of the Ministry of Health and Welfare (MHW) followed by similar guidelines by the Ministry of Education (MHW, 1994). By this Notice, a review board, the so-called Central Evaluation Committee for Gene Therapy, was established. Some of its members have assigned memberships in committees of both the Ministry of Health and Welfare and the Ministry of Education.

According to these guidelines, genetic manipulation for the enhancement of the body or particular abilities by using germ cells should be discouraged and even prohibited, as is the case in many countries in the world. This is also in line with statements issued by international organizations such as WHO, CIOMS, UNESCO and the Council of Europe.

A 1991 survey carried out by the Prime Minister's Office has shown that more than 50% of the public supports gene therapy (Prime Minister's Office, 1991). Moreover, professionals argue that the medico-technological intervention on particular genes for the purpose of gene therapy would be justified bioethically and legally if the patient's situation is regarded as incurable, and if the patient agrees to become involved with full informed consent.

I think that in the public debate on gene therapy, contributions from various disciplines such as bioethics, religion, philosophy, genetics and medicine are extremely important and even necessary. Furthermore, open communication between the general public and the experts should be a basic factor in all public policy-making and regulation (National Institute of Health, 1990, pp. 6-7).

The first gene therapy protocol in Japan was carried out at Hokkaido University Hospital in 1995. The subject was a patient with ADA deficiency. According to a report published in 1997, after 11 rounds of treatment, the patient's condition had improved. This case received quite a lot of attention in the Japanese media as an innovative new medical technology to be applied to very rare types of disease.

e. Review of scientific and ethical quality

In the spring of 1997, the National Commission on Health and Welfare Policy18 was officially established at the Ministry of Health and Welfare. Its Subcommittee for the Evaluation of Advanced Technology of Medicine has been functioning as a national review board for gene therapy research since 1997 when it replaced the former Central Evaluation Committee for Gene Therapy.

As a member of this National Commission and its Subcommittee for the Evaluation of Advanced Technology of Medicine (Sentan Iryo Gijyutsu Hyoka Bukai), I have been involved in the public review of scientific and ethical aspects of several gene therapy protocol applications.

In 1998, the Subcommittee reviewed applications of gene therapy protocol for kidney cancer at the Hospital of Tokyo University's Medical Research Institute, for lung cancer at the Hospital of Okayama University Medical School, for esophageal cancer at

Chiba University Hospital, and for breast cancer at the Cancer Research Society's Hospital in Tokyo.

Common to many of the applications were insensitive and immature phrases used without serious attention to the patient's and family's feelings, and this in spite of the emphasis of the Guidelines on the "protection of patient's rights and respect for human dignity" (NCHW, 1998. Chapter 2, section 3). For example, one research protocol justified its purpose by mentioning that "this experimental gene therapy treatment is not quite verified yet because of lack of data about the cure of disease and because the risk factors are not known in detail. But, this would not be of any obvious harm to a patient who is in the terminal stage of life." This can be interpreted as: "The researcher still does not know the degree of risk or safety of this gene therapy. However, the patient is going to die soon anyway. So this could be justifiable (Tokyo University, 1998)." The patient, the family, and the general public would certainly be much offended by these so-called "scientifically and medically accurate and objective phrases."

According to GGTCR, the subject must be confronted with lethal and fatal sickness such as severe hereditary disease, cancer, AIDS and other life-threatening diseases.

Moreover, in Chapter 1, section 2 and 3 it is stated that the expected benefits of this clinical research should be superior to those of presently existing alternative methods, and that the benefit to the patient should outweigh the foreseeable disadvantages.

In accordance with the GGTCR, the insensitive ways of writing research protocols, disregarding the rights and dignity of the patients, should be avoided. This is particular important in the Japanese cultural context.

A scientifically oriented mind sometimes leads researchers into hasty expectations of positive results in an "If it works, it's O.K." mentality without serious consideration of the fact that the patient places his or her last hope in gene therapy. However, this mentality could also be regarded as a result of a cultural tradition of medical paternalism in Japan (Kimura, 1995).

It is very important to mention here that the GGTCR state their objectives to be both to ensure scientific and ethical validity and to promote the proper conduct of gene therapy clinical research.

f. The difference between "claim" and "revoke"

In the research protocol documents of various institutions, it is stated that the patient is "able to claim" to stop the experimental procedure anytime he or she wants. This expression might seem quite acceptable to a medical expert. However, as a lawyer-bioethicist, I have pointed out in the committee that there is a problem with the phrase "able to claim" to stop and insisted that this vague statement should be revised. I proposed an amendment, which changes this phrase to "the experimental treatment of gene therapy should be definitely halted due to the claim of the patient". Otherwise, I stressed, there would be cases of patients being "able to claim" to stop the experimental treatment but not being able to actually stop it. And, once it has begun, patients and family are usually not "claiming" since there is no guarantee of "halting" the treatment (MHW, 1998).

The GGTCR state more accurately that any subject who has consented to gene therapy can "revoke" his or her agreement anytime (1994. Chapter 3-5). The difference between "able to claim" and "revoke" is obvious from the patients' point of view.

In addition to the lack of sensitivity expressed in research protocols, Subcommittee members have also recognized the limited number of references to the variety of existing and possible alternative treatments. Moreover, the protocols sometimes lack detailed description of the nature of the disease to which the experimental treatment of gene "therapy" would be applied. Even among medical experts the application of the word "therapy" for this gene transfer is questioned due to the present limited success rate for the cure of disease by this procedure. Particularly in the case of a "clinical research trial of gene therapy", a balanced description of the benefit to patients is vital.

After evaluating several gene therapy protocols, a majority of the Subcommittee members, including myself, concluded that many of them were not written well enough to be understood by lay-people such as patients and their families. The majority also concluded that sometimes they were written in a manner that was insensitive to the patient's and family's states of mind which are usually characterized by a hope for complete cure.

As mentioned above, there is in Japan a cultural difficulty of having straight communication between patients and physicians with respect to disease. However, in accordance with international trends of research ethics and protocol review process, the Japanese Gene Therapy Guidelines of 1994 state the full assurance of "informed consent." The rapid development of high-technology medicine and its application to the cure of diseases has various implications in our particular cultural, social context. However, we also have to recognize the positive challenge to change traditional values in this particular cultural context, especially in the ethics of medical research (Kimura, 1995).

·Towards patient-centered research

Finally, I will try to explain these attitudes of Japanese scientists doing research on genetic diagnosis and gene therapy. First, there are remains of a paternalistic medical tradition. It has been difficult for many Japanese to ask questions to superiors and authoritative persons such as physicians, teachers and government bureaucrats.

Second, in Japan there is an *"Amae"* (sense of dependency) mentality to the superiors and the professionals including parents. This sense of *"Amae"* is uniquely characterized as one of the components of the Japanese personality, which is naturally reflected in the mind of the Japanese patient. According to this interpretation, patients are traditionally expected to be dependent on the physicians, nurses and other medical staff members without asking any questions. They are usually making their decisions in a communal, familial and contextual manner. The decision is usually not based on purely individualistic and autonomous considerations (Doi, 1973). As a matter of fact, the person with a very independent and individualistic behavior would be regarded as an egocentric person, and might be blamed for lacking the sense of dependency, which is the basis for communal living in the Japanese cultural context.

Third, quite a number of Japanese have a feeling of resentment against the arrogant, authoritative professional dominance of medical experts. This could be symbolized in the unhappy memories of the first heart transplants in Japan in 1978, which were a failure and led to accusations of murder against the paternalistic surgeon (although he was not prosecuted) (Kimura, 1991c).

The lack of openness among professionals, particularly in the field of advanced medical science, is a very serious issue, since the public sometimes does not properly understand the application of new medical technology such as organ transplants, genetic engineering, and gene therapy. Therefore, it is good that GGTCR have proposed a more open public review system by gathering experts from different fields such as molecular biology, genetics, clinical pharmacology, pathology, law, and bioethics, and also inviting clinical experts on the particular disease regarding which the gene therapy is to be performed.

To be sure, the attitudes to informed consent are changing (Kimura, 1993). Decision-making becomes more individual and autonomous. However, some traditional family values remain, for instance the practice of not telling the truth to other family members when sharing a common fate such as unexpected disease or terminal disease. But, even though family values and bonding have some positive aspects, I believe that the Japanese should not be encouraged to justify a violation of human dignity and human rights in the name of culture or tradition.

In the process of application of new medical technology, we need to establish an open, public, and internationally acceptable Bioethics Public Policy. In doing so, traditional attitudes, typical for an Asian cultural context, and in particular for Japan, could be seriously challenged.

Within the framework of a bioethical reconceptualization, the study of the Japanese situation regarding genetic diagnosis and gene therapy shows a possibility for changes of the Japanese public policy with respect to the cure of patients suffering from genetic disease (Kimura, 1990).

Regarding these trends of value change in the Japanese culture, it is very important to note that the background document on clinical gene therapy research issued by the Health Science Council in April 1993 is a positive sign of public understanding. It states: "Thus, researchers and related individuals should make efforts to gain the understanding of the general public by always being aware of social and ethical problems, conducting research with these issues in mind, by explaining clearly what gene therapy is, by informing subjects very well in each case of clinical research, by actively making information open to the public, and actively disclosing it to the public (Kimura, 1993)."

This is one of the accomplishments of the bioethical input to public policy-making in Japan. Moreover, the Japanese public has also got an opportunity to be present in protocol review sessions, from time to time, which has never been the case before. And all the minutes of the Council meetings, committees and sub-committees are in the public domain and available through the internet homepage of the Ministry of Health and Welfare.

I conclude by stressing once again that a well-informed public and advanced hi-tech medical experts should work together towards achieving the hope of full care and cure of patients with fatal and hopeless diseases.

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Chapter 3. Death, Dying, and Organ Transplants

A. Japan's Dilemma with the Definition of Death

The Japanese people generally take great pride in the technological innovations that are so omnipresent in Japan. But an important instance of public resistance to new technology is the failure to accept the use of brain criteria to determine death, and to harvest organs for transplantation. In this, Japan is unusual, perhaps even unique, among industrialized nations today.

Transplant surgery is performed in Japan, but it relies heavily on organs from live donors; donation of kidneys are common as well as segmental liver transplantations from live donors, and increasingly parents donate liver segments to children in need. Some kidneys and corneas also have been imported, but without public acceptance of the use of brain criteria to determine death of the supply of organs is severely limited even after the enactment of an organ transplantation law of 1997. Some Japanese go abroad for transplants; parents have taken infants with con-genital biliary atresia to other countries for liver transplants, for example, and other Japanese have also obtained transplants elsewhere (Research Committee, 1990). Meanwhile, a larger portion of end-stage renal disease patients in Japan receive kidney dialysis than in any other patients in industrialized countries. Both pragmatic and cultural reasons underlie the public doubts about use of brain death criteria and the harvesting of organs even though the situation is changing gradually. In this section I will provide an overview of the controversy and consider the trends in public opinion in the 1980s and the 1990s.

Memory and Distrust

A significant factor in attitudes about brain criteria and organ transplants is widespread public distrust of the medical profession. This distrust has its origins in the case of Dr. Juro Wada in 1968. Dr. Wada received extensive publicity in the media as the first Japanese surgeon to successfully perform a human heart transplant; it was the fourth transplant performed in the world. The heart was taken from a drowning victim and transplanted to a patient in heart failure (Wada et al., I968).

Initially, the news of the transplant was welcomed. However, the patient died after eighty-three days, and Dr. Wada's disclosure of the patient's history, diagnosis, and previous treatment were so incomplete and obscure as to raise questions about whether the transplant was justified. Questions also arose about the donor. Dr. Wada claims he used professionally developed brain criteria to declare death, but witnesses dispute this, and there is no written record (Morino 1988).

Accusations of wrongdoing led to criminal investigation of Dr. Wada. Although he was never convicted of a crime, the publicity seriously dam-aged public trusts in the medical profession. People were fearful that mistaken diagnosis and treatment might occur behind closed doors. I think that it was an important symbolic event affecting public attitudes toward brain death and organ transplantation.

The memory of Dr. Wada's case remains. Today, thirty-six years later in 2004, people still point to the unanswered questions in that case as a basis for their fear that organs will be removed prematurely and transplants per-formed in unacceptable circumstances if brain criteria are sanctioned. Part of the reason for its lasting impression is that medical professional groups did not condemn Dr. Wada, and Dr. Wada never apologized. In Japanese society, great importance is placed on individuals assuming moral responsibility for possible wrongdoing, even if they are not found guilty by the legal system (Sengoku, 1975).

・Brain Criteria and Religious and Cultural Values

The debate about brain criteria also involves sensitive issues concerning traditional values. Western technology and medicine have been introduced into Japan gradually over the past few centuries, beginning in the sixteenth century with the influence of the Dutch who lived on the small Japanese island of Dejima. The goal of modernization has been to acquire science and technology without losing the Japanese spirit. Over the past 100 years the Japanese even have adopted a phrase, a sort of motto, to convey this proper mix of the Japanese spirit and Western technology: Wakon-Yosai.

Death is an integral part of the Japanese cultural tradition. Most Japanese people resist the modern, technological death in which machines can supplant important rituals surrounding death and dying. Many Japanese, for example, believe that a gradual decrease in body warmth should be felt in the process of dying, and that hastening this and removing organs from a still-warm body suggests an unnatural end to human life (Namihira 1990).

Resistance to hastening death and harvesting organs also comes from the traditional Japanese images of human beings as completely integrated mind-body units, rather than distinct and separate units of mind, body, and spirit. This unity continues after death so that removing an organ from a cadaver is seen as disturbing this spiritual and corporeal unity, not nearly altering the physical body. This also explains why autopsies are abhorred in Japan (Fujita 1980).

The unity extends beyond the individual. The eminent Japanese ethicist, Dr. Tetsuro Watsuji, said about the life of the ancient Japanese, "There is in their love an elegant harmony between body and mind and in their appreciation of nature a tranquil embrace of nature" (Watsuji 1978). As many Japanese see it, the essential destiny of human life involves a rhythm in which all living things-plants and animals-live together at the same "level." This Shinto and Buddhist teaching differs from the Judeo-Christian ethic, which regards humans as uniquely in the image of God, and therefore in a different relationship to other living beings (Yuasa, 1987). The Japanese, death disturbs the rhythm of all living things and therefore it should not be hastened. In contrast to the concern in the United States not to prolong the dying process unnecessarily, Japanese people are far more concerned with maintaining dying rituals and not ending life prematurely.

Other Japanese values also affect attitudes toward the dead and dying. The Confucian concept of Jin or Loving-kindness is a humanitarian idea that is the basis of medical practice. Confucian teaching also embodies the notion of ancestor worship with its implications for family relationships based on filial piety (Kaji, 1990). These concepts provide strong prohibitions against harming one's body since it is derived from one's parents (Kaibara 1714).

Despite a long religious tradition, many Japanese people today are not deeply religious. However, religious values all traditions remain deeply embedded, and for significant life events such as birth, marriage, death, and funerals, Japanese people usually turn to religious institutions for proper ceremonial rituals. Death rituals, in particular, are closely tied to family and kin relationships and often involve large social gatherings and ex-change of money and goods. Each stage of the ritual, including the wake, placing the body in the coffin, picking up the cremated bones and burial, are very meaningful moments in the Japanese culture. The Japanese attach great importance to these rituals and religious traditions, and many of them are confused by brain criteria and harvesting of organs, fearing that they violate the traditional confirmation process of death.

A Cultural Compromise

The medical profession is more amenable than the public to the use of brain criteria. Some medical schools and medical associations have developed brain criteria for diagnosing death, and clearly some doctors are using it although they may be telling families simply that the patient is dead without specifying the way that death was determined. The Bioethics Committee of the Japanese Medical Association (JMA) issued its final report on brain death and organ transplantation on January 11, 1988 (Bioethics Committee, 1988, see also Kato, 1988). The Committee is an advisory board appointed by the JMA president. Its members include two physicians, two lawyers, and one expert in each of the following fields: molecular biology, philosophy, cultural anthropology, literature and industry. The key recommendations of the report include the following points.

1. Brain death (i.e. irreversible dysfunction of the entire brain) should be recognized as the death of an individual, in addition to the traditional cardiopulmonary criteria.

2. The minimum standard for brain death should be based on a standard adopted by the Special Task Force on Brain Death within the Ministry of Health and Welfare (chaired

by Kazuo Takeuchi).

3. The determination of death by brain criteria should be provided by physicians who respect the patient's and/or family members' wishes as evidenced by informed consent.

4. Determination of death by applying whole brain death criteria is justified socially and legally if (i) it is grounded in the consent of the patient, (ii) it is determined by an appropriate method, and (iii) it is carried out by a physician in accordance with the guidelines of the Japanese Medical Association.

5. The time of death should be recorded no later than six hours after the initial determination of brain death.

6. Organ transplantation should be performed according to the guidelines of the Japanese Transplantation Society, which require informed consent by the donor or the donor's family, and the recipient or the recipient's family.

It is significant that these recommendations require informed consent; the patient or family can refuse to accept the life of brain criteria in the determination of death. This is a compromise aimed at introducing its use in a way that will not offend those Japanese who continue to oppose it. Some physicians and lawyers strongly object to this approach, arguing that it will cause confusion and difficulties. These recommendations have no legal force; they are intended primarily to build a consensus.

Then, the prime minister's office convened the Provisional Commission for the Study of Brain Death and Organ Transplantation, chaired by Dr. Michio Nagai, to review the various aspects of brain criteria in Japan and overseas, and to make recommendations about how the issue should be addressed. It is the first government commission created to seek some kind of conscious, and possibly legislation, relating to life and death issues.

I expect the Japanese public to gradually accept use of brain criteria and organ transplantation, although with serious reservation. Public opinion polls have documented increased public support. A survey by the prime minister's office in 1989 found only 24 percent of the public accepted use of brain criteria (Prime Minister's Office, 1989). In three subsequent polls by NHK, the public broadcasting system in Japan, support increased. The NHK polls asked Japanese citizens, "What do you think of the transplant of organs from a brain dead person?" Support was at 38 percent in October 1988, then grew to 41 Percent in March 1990 and by October 1990 reached 47 percent (NHK 1990).

Support among professional groups is greater. A 1990 poll of intellectuals by the Provisional Commission found that 65 percent of those surveyed, professionals in medicine, law, philosophy, ethics, religion, economics, and journalism - favored use of the criteria. The survey also found that 61 percent of the approximately 750 respondents were willing to donate organs (Provisional Commission, 1990).

Campaigns by professional medical associations, and increased media publicity, have probably contributed to changing attitudes. The change also reflects a shift in public attention from the dead or dying person to the person who needs a transplant. There is increasing public pressure from the tens of thousands of people who are on dialysis, and from others whose life could improve dramatically with a transplant. Pressure is also coming from other countries that have a limited supply of organs; questions have been raised about Japanese coming to their countries and the fact that Japan is importing organs rather than building a system of its own. The newspaper has accused Japan of exploitation, in its purchasing organs from less developed nations (Shimizu, 1989).

History teaches that a change in public attitudes in Japan is possible. At one time, the Japanese had strong objections to blood donation. That has been overcome, and the

Japanese now have one of the highest rates of blood donation in the world.

The brain death controversy highlights the need for open, public discussion between the public and professionals (Kimura, 1991). If the medical profession supports such open debate, there is an extremely good chance that it can regain the credibility and trust that it lost with the Wada case. Harmony between professionals and a public concerned about the implications of new medical technology is essential.

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B. Death and Dying in Japan

A majority of Japanese, at present, feel that the modern biomedical and technological innovations pertaining to human life and death have been forcing a change in our common understanding of what, historically, was simply the natural event and process of death and dying. The meaning of death and the dying process in our lives is changing, as have the traditional criteria for determining death, namely, cessation of heartbeat and respiration.

An individual's death should be a personal and private matter as well as a familial, communal, and social matter. It has been regarded as such for many thousands of years in our Japanese society and culture. It is well understood that our traditional socio-cultural understanding of human life positively admits the natural process of death as the final event of life. The ideas expressed in Zen-Buddhist phrases such as "accept death as it is" and "life-death as one phenomenon" have been key motifs totally integrated into our traditional understanding of life (Tomomatsu, 1939).

However, the traditional perception of death as an acceptable process has been vanishing as the Japanese have applied modern biomedical technologies more frequently in well-equipped hospital settings. Although the involvement of family members in the process of dying and particularly in the death event continues in a variety of ways, the care of dying patients in Japan is becoming much more similar to that delivered in advanced hospital settings in many countries of the world, than it is different. Now, in Japan, a majority of people end their lives in the hospital, surrounded by high-technology machine. Yet, in a survey by the Yomiuri Shimbun of 15 June 1991, half of the respondents said they would prefer to die at home.

In addition, there has been a tradition of not explaining to terminally ill people the true nature of their condition, on the ground that this is most appropriate way to proceed (Kashiwagi, 994). However, views on this matter are changing. There is a gradual move toward telling patients the truth, and the notion of informed consent has been widely publicized in the clinical setting (Leflar, 1996). In the 1991 nationwide opinion poll by the Yomiuri Shimbun, 65 percent of the participants said that they would like to be given full diagnostic information about themselves even if they were terminally ill. Nevertheless, only 22 percent of the people questioned said they themselves would definitely be prepared to disclose such information to a family member.

The same survey indicated that 78 percent of people considered palliative care desirable, even though it might shorten life, while 16 percent thought life should be sustained as long as possible, irrespective of the pain that patients might be suffering.

·Challenges of Care for the Dying

A special task force on terminal care, set up by the Ministry of Health and Welfare, issued a report in 1989 that encouraged the disclosure of diagnostic information to patients, provided that consideration was given to patients' life histories, personalities, relationships with family members, and other factors. The report favored the use of drugs for pain control; it also dealt with matters such as spiritual requirements and the care of the family members.

Traditionally, the physician-patient relationship in Japan is based on a complete and unquestioning trust of the physician by the patient, such that the physician acts to make health care decision on behalf of the patient (Kimura, 1991). However, increasingly it is believed that people should not have to accept without question the authority of doctors in the treatment of disease. Responsibility for the care of the dying should be shared between family members and all health professionals, not only physicians. Changes are needed in the mentalities of health care providers, patients, and family members, and it must be recognized that the medical system and institutions are not immutable (Annas and Miller, 1994).

To complicate matters even further, although a patient's family is informed of the incurable nature of the disease affecting their family member, the patient, as noted above, usually is not told of the terminal diagnosis. Therefore, patients often do not have the information necessary to make their health care wishes known in advance should they desire to do so.

Some people express their uneasiness with the idea of a documented expression of their wishes at the end of life. They think that this serious event at the end of life should be dealt with in a more harmonious way by "tacit agreement" or "Ishin-denshin" (heart-to-heart communication without word) among the patient, family members, and the attending physician.

· A Legal Case for Euthanasia in Japan

One of the most important Japanese legal precedents relating to issues of death and dying has never been applied since its establishment in 1962. The case, which is usually cited as the "Nagoya High Court Decision of 1962", involved a son who prepared poisoned milk to kill his terminally ill father in order to fulfill his father's request to spare him continued pain and suffering. The son urged his mother, who did not know that the milk was poisoned, to give it to her husband. In reaching its judgment, the court identified six conditions that must be fulfilled before one is legally permitted to end a suffering patient's life.

(1) The patient's situation should be regarded as incurable with no hope of recovery, and death should be imminent;

(2) The patient must be suffering from unbearable and severe pain that cannot be relieved;

(3) The act of killing should be undertaken with the intention of alleviating the patient's pain;

(4) The act should be done only if the patient himself or herself makes an explicit request;

(5) The euthanasia should be carried out by a physician, although if that is not possible, special situations will be admitted for receiving some other person's assistance;

and

(6) The euthanasia must be carried out using ethically acceptable methods

(22 December 1962, Nagoya High Court, Collected Criminal Cases at High Court).

In this case, the Nagoya High Court ruled that the first four criteria had been met, but that the final two conditions had not. The son was sentenced to four years imprisonment with a three years suspension. The Japanese Criminal Code provides for severe punishment, capital punishment or life imprisonment, for ascendant homicide; however, in this case, the Court felt that the son's desire to honor his filial duty to follow his father's spoken "directives" was evident and so applied for a lesser sentence.

In the light of medical and technological advances, the ramifications of the Nagoya High Court decision have changed in many ways. Conditions once considered fatal, can now be treated effectively or cured. Better methods of pain control have been developed, and about 25 hospitals with palliative care units, including hospices, have been officially recognized since 1990.

In 1991, however, a physician actively ended the life of a patient at Tokai University Hospital. The case has captured great media attention because the physician acted on the surrogate request of a family member. According to the physician, the patient's son asked the physician to alleviate his father's suffering. However, when questioned later, the son stated that he had not meant the physician to end his father's life. At the time of the alleged request, the patient was hospitalized with an incurable and terminal condition, and the patient was already comatose when the physician administered potassium chloride by injection. Due to the family's denial that they asked for help in ending the patient's life, the physician was accused of murder and dismissed from the hospital. On 28 March 1995, the physician was sentenced to two years in prison with a two years suspension. Even though the case does not involve a patient's advance directive, public opinion is rather supportive of the defendant physician and of a family member's oral "directive" to ease the life of a dying patient. The involvement of family members in making surrogate decisions on behalf of patients is generally accepted behavior, and the relationship among patient, family, and physician is very important in the Japanese social context (Kimura, 1995).

There is a widening gap between the positions of medical professionals and the lay public on issues in terminal care. The general public is more supportive of the actions of the accused physician at Tokai University and of a more recent case of active euthanasia at Kyoto Keihoku Town Hospital in April 1996. In contrast, the medical profession has a very negative view of such actions even in the case of terminally ill patients. Indeed, at present, there is no legal recognition of any type of advance directive.

However, if advance directives are legally recognized in Japan in the future, these advance directive documents preferably should be based on a more familial model of decision making. Family members might reach a decision different from that desired by the patient. Thus, individuals should share their wishes with other family members so that they can be respected. A "Family Unit Advance Directive", directed toward the family, would permit families to prepare for future decisions concerning life and death issues so they may accurately convey the patient's wishes to the physicians.

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C. Death, Dying, and Advance Directives in Japan: Socio-Cultural and Legal Point of View

I. The Traditional and Cultural Acceptance of Death

Human death and dying are socio-cultural events and processes of human persons embedded in particular historical contexts and environments. The end of human life should be understood by society not only in terms of medical criteria, but also as a cultural phenomenon. At present, a majority of Japanese feels that modern biomedical and medico technological innovations affecting human life and death have effected a change in our common understanding of the process of death and dying. Historically, death was a natural event, and the criteria for death, cessation of heart beat and respiration, was unquestioned. This is no longer the case.

An individual's death should be a personal and private matter as well as a familial, communal, and social one. It has been so regarded for many thousands of years in Japanese society and culture. It is well understood that our traditional socio-cultural understanding of human life admits the natural process of death as a positive event marking of the end of life. The ideas expressed in Zen-Buddhist phrases such as "accept death as it is" and "life-death as one phenomenon" have been a key motif totally integrated in our traditional understanding of life (Fujii, 1991).

Indeed, even the intentional ending of one's life has been regarded as positive, if it was intended for some noble cause within a particular historical context that justified the action. For example, Jyunshi (self-immolation) and Seppuku (disembowelment -- same as Hara-kiri) are methods of sacrificing one's life for the greater benefit of one's Feudal Lord or Emperor, and in some cases for family and friends. This emphasis on readiness for self-sacrifice, of course, also has its negative side. The expression "education for death" still causes negative sentiment and resentment among some Japanese as a result of strong encouragement in Japan during World War II to wage a "sacred just war". By this it was meant that all Japanese persons needed to be ready to sacrifice their own lives with glory for the honor and victory of the God-Nation of the Japanese Empire. This ideology was initiated by the Japanese military government and its ultra-nationalistic leaders of the time. For the Japanese citizenry, life and death were totally in the hands of a militaristic national authority (Pinguet, 1993).

In both war and peace, however, it is certain that we Japanese value communal goals as more important than mere biological life and have a tendency to sacrifice our individual lives for larger ideals. In our cultural tradition, death is given special concern and recognition as an event. Many heroic and unique Japanese figures have appeared in historical documents, usually expressing their last word in the form of Jisei. Jisei is a kind of poem composed on the occasion of one's death consisting of 31 syllables (Hoffmann, 1986). Though death itself is abhorred, it is understood and accepted as a natural part of the life-process. In this sense, Jisei could be interpreted as a traditional cultural expression of a dying person, almost a "living will", according to Japanese folk study expert Prof. Tetsuo Yamaori (Yamaori, 1994). However, in my understanding, Jisei is by no means a legal document or an "advance directive" expressing one's wishes when end of life decisions need to be made.

II. RECENT TRENDS IN THE SITUATION OF DYING IN JAPAN

These traditional socio-cultural elements of perceiving death as an acceptable process have been vanishing as the Japanese have applied modern biomedical technologies more frequently in well-equipped hospital settings. However, the involvement of family members in the process of dying and particularly in the event of death itself continues in a variety of ways. The Japanese situation in terms of dying patients is becoming much more similar to that found in advanced hospital settings in many countries of the world than it is different. Now, in Japan, a majority of people end their lives in the hospital, surrounded by high-technology machines, apparatuses and equipment. However, in a recent survey published by the Yomiuri Shimbun on June 15th, 1991, half the respondents said they would prefer to die at home.

There has been a tradition of not explaining to terminally ill people the true nature of their condition, on the grounds that this is the kindest way to proceed (Kimura, 1991a). However, views about this matter are changing. In the same nationwide opinion poll published by Yomiuri Shimbun, 65 percent of the participants said that if they were terminally ill they would like to be given full diagnostic information about their condition. However, only 22 percent of the people questioned said they themselves would definitely be prepared to disclose such information to a member of their family. The same survey indicated that 78 percent of the respondents considered palliative care desirable, even though it might shorten life; 16 percent thought life should be sustained as long as possible, regardless of the pain that patients might be suffering.

The National Matsudo hospital is one of the few hospitals in Japan with a palliative care unit. The use of morphine has significantly reduced pain levels for a high proportion of the patients in this establishment (NHWJ, 1995).

However, until very recently, methods of pain control were not well developed in the Japanese medical service system. For example, my father was hospitalized with lung cancer 20 years ago. Although he suffered very severe pain, he was never told the result of the diagnosis. Even the easing of his pain through the administration of morphine was restricted to a particular time sequence, and often his pleas for an injection were rejected on the grounds that the proper time had not arrived yet. This was the reason he sincerely expressed his final wish to die peacefully at that very moment; tragically, however, he suffered tremendously with this unbearable pain until his death (Kimura, 1987).

One of very few surveys exploring cancer pain, conducted by Dr. Mizuguchi of Chiba University in 1987, revealed that 68.9 percent of end-stage cancer patients experience pain and 8.7 percent of them die without having that pain relieved (Mizuguchi, 1987). Mizuguchi has also gathered some interesting comments indicating less understanding of and interest in the use of pain control among physicians than is desirable. These physicians seem to fear that their use of such measures may create a narcotic addict or possibly shorten a patient's life.

Japan has a very rigid Narcotics Control Law (Law 14, March 17th, 1953) that functions effectively, but according to this survey the medical use of narcotics is extremely limited. Such a rigid and complicated system of justifying the use of narcotics has forced many cancer patients with treatable pain to suffer, compared with other advanced countries. The situation is changing only slowly (Takeda, 1994).

A special task force on terminal care, set up by the Ministry of Health and Welfare, issued a report in 1989 that encouraged the disclosure of diagnostic information to patients, provided that consideration was given to patients' life histories, personalities, relationships with family members, and other factors. The use of drugs for pain control was favored. The report also dealt with various additional matters such as spiritual requirements and the care of family members. The idea that people should not have to accept without question the authority of doctors is gaining ground in Japan.

Unfortunately there are still too few trained people to cope with the many problems associated with dying. Therefore, responsibility for the care of the dying should be shared among health professionals as well as those in other careers. Changes in the mentalities of both health care providers and patients, including recognition that medical systems and institutions are not immutable, are sorely needed.

Efforts have been made by some volunteers and hospitals in Tokyo, Osaka and elsewhere to improve the care of the dying. There are signs of public approval for such work; since April, 1990, the government has increasingly approved the provision of financial support for palliative care through the national health insurance system (Kimura, 1991a).

III. Advance Directives as a Non-Legal Document in Japan

In the context of terminal care in Japan, the notion of "advance directives" has never been regarded as a legally endorsed expression of the patient's intention, whatever the form of particular documents. For example, various kinds of documented advance directives issued by several voluntary organizations have no legally binding force on the medical provider.

It is true that the number of members of the Japanese Euthanasia Society, established in 1976 and recently renamed the Japan Society of Dying with Dignity

(JSDD), is increasing. It is also notable that the JSDD makes available a very general form called the "Dying with Dignity Declaration (Living Will)", which seeks to prevent the provision of futile medical treatment. However, the number of living will card holders is very small and the JSDD's "Dying with Dignity Declaration" has never been legally recognized during the 19 years of its existence (JSDD 1990).

3.1. Socio-Cultural Aspects

Several factors particular to Japanese culture and society may serve to explain this situation. Traditionally, the physician-patient relationship in Japan is based on the patient's complete and unquestioning trust of the physician such that the physician acts to make health care decisions on behalf of the patient.

To further complicate matters, while patients' families are informed of the incurable nature of the disease affecting their family member, patients themselves usually are not told of terminal diagnoses. Therefore, the patients often do not have the information necessary to articulate health care preferences in advance, should they wish to do so. A mixture of Shinto, Confucian, and Buddhist beliefs wherein death should not be hastened to avoid disturbing the harmony of the universe also muddle the issue, as does a commonly-held view that life and one's body are to be regarded as gifts from one's parents to be treated with traditional filial piety.

The traditional Japanese mentality of "Amae", which is a sense of inter-dependence; turns the focus away from the individual and toward the family or socially related group (Doi, 1971). This almost certainly plays a role in limiting the appeal of the notion of advance directives.

The authority given to the family in making decisions on organ donation is illustrative of the major role the family plays in medical decision-making. Some people express their uneasiness about having documents relating to the end of life. They think that this serious event of ending-life should be dealt with in a more harmonious way, such as a "tacit agreement" or "Ishin-denshin" (heart to heart communication without words) among the patient, family members, and attending physician (Lebra, 1976).

Dr. Gen Ohi, in his book Terminal Care, discussed the difficulties he encountered in conducting a survey on death and dying issues in rural Japan. He commented that the majority of the participants were uneasy about the concept of a documented expression (Ohi, 1988).

There is a particularly strong concern among medical providers and their patients that a complicated legal intervention such as an advance directive would be inconsonant with life and death issues. This mentality is one of the most important socio-cultural factors that mitigate against advance directives, even though some people acknowledge that these documents will become increasingly necessary in the future.

Do-Not-Resuscitate (DNR) orders provide an example of another kind of advance directive in Japan. According to recent data compiled in 1994, 96.7 percent of those surveyed answered that, depending on the situation, a DNR order was necessary. The idea of "dying with dignity" was cited as the main reason for having a DNR order. The unique finding of this survey is that 84.9 percent agreed that the patient's will is not indispensable. In other words, a patient's physician and family members would be granted the authority to make a decision. More specifically, 68.4 percent agreed to have a decision made by the attending physician, perhaps after consultation with other relevant physicians. This finding clearly shows the strong medical and professional orientation that impacts the decision to make a DNR order in Japan (Arai et al, 1994).

3.2. Legal Aspects

Unlike the codes of Germany and several states in the United States, the Criminal Code of Japan (Law No. 45, April 24, 1907) has provisions related to assisted suicide (Jisatsu Hojyo), murder by request (Shokutaku Satsujin) and murder with consent (Doi Satsujin). They are classified as criminal offenses as follows.

Article 202 (Participation in suicide): A person who instigates or assists another to commit suicide or kills another at the request or with the consent of the latter shall be punished with penal servitude or imprisonment for not less than six months nor more than seven years. This article has provided an enormously powerful justification for physicians to prolong life as long as possible. Physicians are considered to be experts in the care of patients, and therefore are usually permitted to ignore the patient's desire to be treated in a way that allows the natural ending of life. Instead of respecting such wishes, many physicians favor the provision of aggressive medical intervention to prolong life. For example, when my mother-in-law's 85-year-old mother was dying of colon cancer and suffering severe pain, my mother-in-law suggested to the attending physician that aggressive intervention be forgone. However, this suggestion was simply rejected by the physician, who stated that "my professional ethics can not accept such a proposal."

However, if the physician him or herself determines on the basis of medical judgment that additional treatment would be futile, the physician is able to end the treatment. This is considered a justifiable act, according to Article 35 of The Criminal Code of Japan, which provides that, "No person shall be punished for an act done under law or ordinance or in the course of legitimate business." When considered in this context of Japanese Criminal Law, the reason for and aim of efforts to legalize advance directives may be properly understood as very important steps.

There are several legal opinions regarding a patient's wish and/or autonomy to end his or her life peacefully and to reject treatment in the process of terminal care. The situation surrounding terminal care in Japan is gradually changing. However, I think that, particularly in our country with its article 202 (described above), the legal difference between the phrases "agree and act based on patient's rejection of treatment" and "assisting committing suicide" should be recognized. If we strictly apply article 202 to both situations, the person who acted will be prosecuted. However, in the particular clinical context of end-stage illness, the former case should be understood as a justifiable "non-doing" (Fusakui, which is a similar legal term to Unterlassung in German) because of the counter-benefits of relieving severe pain and honoring the patient's own intention to reject treatment.

IV. SOME UNIQUE ELEMENTS IN JAPANESE ADVANCE DIRECTIVES

As I mentioned before, in Japan advanced directives are not legally binding documents. Rather, an advance directive is merely a private document expressing a person's wishes for future medical treatment and care at the end of life (JMA, 1992). However, there have been some efforts among concerned individuals and organizations to make an "Advanced Directive Document" similar to the type that has been developed in some countries in Europe and the United States.

I will discuss three different types of advance directives: 1) Songenshi no Sengen Sho (Declaration Document of Death with Dignity-Living Will), which is provided by the Japan Society for Dying with Dignity, 2) Shumatsuki Sengensho (Declaration for the End of Life Stage), which is provided by the Citizen's Group in Thinking of End of Life Stage, and 3) "Living Will-Proposal by Kyoto Women's University".

Since 1976, the Japan Society for Dying with Dignity has made available a very general form that enables individuals to declare their desire to avoid futile medical treatment. The "Dying with Dignity Declaration" requests that medical technology not be used to artificially prolong life in irreversible or incurable situations, asks that effective pain reduction methods be used even though they may hasten death, and permits the withdrawing of life-sustaining technologies in the case of a persistent vegetative state of several months duration.

As of November 1995, no legal mechanism exists to honor this declaration or any other "advance directive" in Japanese society. However, public awareness of the death with dignity movement is rapidly increasing, and as of August 1995 the number of memberships in the Japan Society for Dying with Dignity stands at 72,567.

Another organization, called the "Citizen's Group in Thinking of Terminal Care" has become very active during the past five years. They issued another type of "advance directive", which attempted to simplify matters by providing a place for a check mark in front of each statement. There are some unique elements in this document that address "Truth Telling", "Vegetative State", and "Brain Death Situations". For example, sentence No. 1 says, "please tell to my family members as it is but don't tell me the truth clearly", while No. 2 states, "I do not want to be connected to a life sustaining machine continuously when I became the Persistent Vegetative State (PVS)", and No. 4 offers a choice of "Brain dead situation as death or not". An opportunity to express one's wishes in terms of organ donation was also provided in the following sentences. Finally, this document has a place expressly designed for the designation of a surrogate decision maker, to be signed by the person who made the statement. This means that the statement has combined the characteristics of a "Living Will" and a "Durable Power of Attorney" in one document. Of course, similar to the JSDD's Living Will declaration, such a document is not legally binding in any way and need not be respected by the physician in charge. Naturally, however, these expressions of patient preference might have some influence, depending on the individual opinion of the physician.

The Student Bioethics Study Group at Kyoto Women's University proposed a unique model document of advance directives, written from the perspective of a pregnant woman. Statement II, B. (a) says that, if a guardian for the unborn baby had previously been designated, the document specifying this should be retracted and the best medical treatment for continuation of pregnancy and delivery should be performed. This proposal also has statements that request the forgoing of life-sustaining technologies in the event of the onset of PVS, and also attempts to address the situation in which a mental disability would make a decision impossible. The statement says that in the case of an incurable disease in which death is imminent, hydration, nutrition, and cleaning of the body should be provided, however the mere prolongation of the dying process through the use of life-sustaining machines should be avoided.

This proposed "Living Will" has suggested having the names of two physicians listed as witnesses to this document, as well as choices of physicians for making a diagnosis of "PVS".

V. CASE DISCUSSION

In addition to the efforts of the JSDD and other recent interest groups focusing on issues in death and dying, and the validity of the explicit expression of individual intention in advance directive documents, there are three important cases that serve to reflect the Japanese situation concerning advance directives and the experience of an extremely painful terminal stage of life due to chronic disease.

5.1. Rejection of the Suit Claiming Legal Validity of Living Will

There is only one legal case relating to the legal validity of the living will that should be mentioned here.

In 1980, Mr. Tobita, who was then the chairman of the Edogawa Machine Metal Industrial Cooperatives and a board member of the JSDD, filed an action in the Tokyo District Court. He asked for a confirmation of the validity (Feststellungsklage) of an individual person's intention of "Dying with Dignity". He, as the plaintiff, quoted article 13 and 25 of the Japanese Constitution, which endorse the "pursuit of happiness" and the "right to live". Mr. Tobita insisted that the opportunity to experience pleasure, displeasure, pain, and non-pain has been guaranteed to all Japanese citizens by this fundamental constitutional law, and thus, a person has a right to choose a way of death according to his or her individual intention.

For this reason he claimed that the state should confirm "the person's intention to express his or her wishes precisely as written in a document such as a living will, when the person is competent, not to suffer in death unnecessarily, and to reject futile treatment". The Tokyo District Court decided February 17th, 1982, that this case could not be accepted for ruling in the Court as it was not concrete, and could not be included in the category of "all kinds of legal conflicts" delineated by the Court Law, Article 3 section 1. Also, the court claimed that this case lacked the legally necessary conditions to be dealt with as a suit in the Court. The Court concluded that this case must be turned down (Zuruckweisung), by applying Article 202 of the Civil Procedure Code (Tokyo District Court, 1982).

This example of Case No. 1 shows that such a suit that seeks the confirmation of validity of personal choice in dying cannot be accepted by the court. This idea of dying with dignity according to an individual's value of life might be possible only through the legislation of laws supporting living wills in Japan.

Questions about advance directives were raised in a concrete legal case in which a patient was dying painfully due to an incurable disease. The following two cases, Nos. 2 and 3, involve "oral directives", one made by the patient and the other by a close family member who seek the termination of treatment and an end to suffering through active euthanasia, performed by the patient's son in the first case and by the physician in charge in the latter case.

5.2. Legal Criteria for Active Euthanasia in Japan

One of the most important Japanese legal precedents relating to the issue of death and dying has never been applied since it was set in 1962. The case is usually cited as the "Nagoya High Court Decision of 1962". In this case, a son killed his terminally ill father, was charged with "ascendant homicide", and was subsequently prosecuted for his act. In the Japanese legal system, ascendant homicide, or the killing of one's lineal ascendant or a lineal ascendant of one's spouse, is a more serious crime than ordinary homicide. The punishment for ascendant homicide carries a sentence of death or penal servitude for life, while the sentence for murder can be as little as three years. The standard sentence for cases of assisted suicide is six months to seven years. The particulars of the Nagoya case are as follows: the father, a farmer and head of a household, became completely paralyzed. Because of his very severe pain and suffering, exacerbated by frequent occurrences of hiccups, the father repeatedly expressed his wish to die, saying, "Please let me die, please let me go. I want to go to the other world."

The physician informed the family that the farmer's situation was worsening and that his death would probably occur within ten days. The man's son, a kind person, thought that his last filial duty required him to save his father from his severe pain and suffering by killing him, based on his father's verbally articulated "directive". The son prepared milk mixed with an agricultural pesticide to which he had ready access at his home. The glass was given to the man by his wife who did not know its poisonous content, and the man died.

In reaching its judgment, the court identified the following six conditions that must be fulfilled before one is legally permitted to end a suffering patient's life.

First, the patient's situation should be regarded as incurable with no hope of recovery, and death should be imminent;

Second, the patient must be suffering from unbearable and severe pain that cannot be relieved;

Third, the act of killing should be undertaken with the intention of alleviating the patient's pain;

Fourth, the act should be done only if the patient him or herself makes an explicit request;

Fifth, the euthanasia should be carried out by a physician, although if that is not possible, special situations shall be admitted for receiving some other person's assistance, and Sixth, the euthanasia must carried out using ethically acceptable methods (Nagoya High Court, 1962).

In this case, the Nagoya High Court ruled that, although the first four criteria had been met, the final two conditions had not. The son was sentenced to four years imprisonment with three years suspended. As mentioned earlier, the Japanese Criminal Code (JCC) provides for severe punishment, such as capital punishment or life imprisonment, for ascendant homicide; however, in this case, the Court believed that the son's desire to honor his filial duty and to follow his father's spoken "directives" was evident and warranted a lesser sentence.

In the light of medical and technological advances, the ramifications of the Nagoya High Court decision have changed in many ways. Conditions once considered fatal can now be treated effectively or even cured. Better methods of pain control have been developed and new centers for palliative care have been developed (Kimura, 1991a).

The interpretation of the Nagoya criteria has been very strict. In the 33 years since the Nagoya Court decision, there have been only four cases brought before the court wherein a family member acted to end the life of a patient suffering grave pain.

All of these cases were prosecuted as criminal cases and none were found to be in accordance with the six requirements laid out by the Nagoya High Court, but the defendants all received lesser sentence: 1. Homicide case of a wife suffering from a chronic disease of the autonomic nervous system, severe hip gout, and tuberculosis (Kagoshima District Court Decision, 1975); defendant was sentenced to one year imprisonment suspended for two years on the criminal charge of "murder with consent"; 2. Homicide case of a mother suffering from a cerebral hemorrhage (Kobe District Court, 1975); defendant was sentenced to three years imprisonment suspended for four years on the criminal charge of "homicide"; 3. Homicide case of a wife with painful stomach cancer (Osaka District Court Decision, 1977); defendant was sentenced to one year imprisonment suspended for two years on the criminal charge of "murder with consent"; 4. Homicide case of a wife having severe pain due to sarcoma (Kochi District Court Decision, 1990); defendant was sentenced to three years imprisonment suspended for one year on the criminal charge of "murder with consent".

Though the Nagoya High Court ruling established the legal criteria for active euthanasia and specifically confirmed the importance of the individual wish of the patient to have his or her life terminated, all three district courts seem reluctant to apply these conditions fully. An explanation for this phenomenon may be the court's unwillingness to accept the concept of active euthanasia.

On April 4, 1973, in another case of ascendant homicide relevant to Case No. 1 as presented above, there was a drastic change in this attitude of reluctance. In this case, the Supreme Court ruled that article 200 of the Japanese Criminal Code, which entails a heavy criminal charge in cases of ascendant homicide, is an illegal and unfair clause contrary to the equal treatment clause of the Japanese Constitution. "If the sentence is extremely heavy and if there is no justifiable ground for it, this discriminatory provision is very much unreasonable to be applied. Therefore, it is against Article 14, section 1 of the Japanese Constitution and it is invalid". This ruling indicates a positive change in the established legal value of the Criminal Code, based on a cultural ethos that is significantly influenced by a Confucian ideology of filial piety. In the enforcement of new and more contemporary official phrasing and modification of the Criminal Code of Japan, Article 200 was completely eliminated on June 1, 1995.

5.3. A Physician's Active Ending of a Patient's Life by Family Request

The recent case in which a physician actively ended the life of a patient happened in 1991 at Tokai University Hospital. The case attracted great media attention because it involved a physician who ended the life of a patient based on the request of a family member. According to the physician, the patient's son asked the physician to alleviate his father's suffering. However, when questioned later, the son stated that he had not meant the ending of his father's life. At the time of the alleged request, the patient was hospitalized with an incurable and terminal condition, and was already comatose when the physician administered an injection of potassium chloride. Due to the family's denial that they asked for help to end the patient's life, the physician was accused of murder and dismissed from the hospital. On March 28th, 1995, the Yokohama District Court sentenced the physician to two years imprisonment with a stay of execution of two additional years. This ruling is significant for its clear statement of the principle of individual autonomy based on the patient's own intention and its establishment of a limit on a physician's immunity for failing to treat those patients whose treatment is deemed medically futile. According to this ruling, when making a decision to withhold a treatment, it is clearly necessary to have a confirmed statement of the patient's intention to stop treatment. The decision goes on to note that, although there is at present a general lack of existence of these kinds of clear patient statements, in the future there will be widespread acceptance of living wills among the public. The presence of a patient's advance expression of will could serve as a verification that the physician indeed made a judgment by taking into account the patient's own wishes when decisions to withhold treatment are made.

Moreover, if the patient has communicated openly enough with family members about his or her view of life, character, and values, the family will be able to make a conjectural decision to end his or her life in a natural way (without aggressive over treatment). By endorsing the family's ability to presume a patient's wishes, this ruling has set a sort of standard for allowing indirect euthanasia provided that the physician considers it to be an appropriate medical procedure for terminal care in the clinical context. In such cases, the withdrawal of treatment could be justified. However, in the case of positive or direct euthanasia, the ruling does not endorse familial decision-making based on the presumed will of the patient. The following four points should be taken into account in making the decision: 1) the patient is suffering with intolerable, severe physical pain caused by disease, 2) the patient's death is imminent, 3) there is no possible medical treatment that can ease the pain, and 4) the patient has clearly agreed to the shortening of his or her life (Yokohama District Court, 1995).

Although this is not a case only focusing on patient's advance directive, public opinion is rather supportive of the defendant physician in recognizing the family member's oral "directive" to ease the life of the dying patient. As the involvement of family members in making decisions on behalf of the patient is generally accepted behavior, the inter-relationship with patient, family, and physician is very important in our Japanese social context and human relations (Kimura, 1991c).

However, one must be very careful in making any sort of surrogate decision for a family member, even though the process of dying is regarded not as an individual event but as a family event in the Japanese culture.

VI. Family Role in Medical Decision-Making

It is not clear whether the situation would be different in the Tokai Hospital Case if the family declared that they had asked the physician to assist in the euthanasia of their father. If this were the case, the first through third, fifth, and sixth conditions of the Nagoya Court criteria for permissible euthanasia would have been fulfilled, although it is not clear if the patient or only his family made the request for death.

The traditional importance and authority of the family in medical decision-making is illuminated by the fact that they, and not the patient, are informed of a terminal diagnosis. The family's role has been confirmed in the currently ongoing debate about brain death criteria and organ transplantation. The draft of legislation and additional guidelines issued by the Inter-party Council on Brain Death and Transplantation in December 1993 cited a number of situations wherein the family may sontaku, or "make a guess as to some other person's internal mind to allow the pronouncement of brain death and permit organ donation even in the absence of any clear expression of wishes in that regard by the deceased person." The scope of family authority in medical decision making is highlighted again by the fact that consent from the family is required concurrently to consent from a potential donor when the individual's desire to donate kidneys is registered at one of the regional kidney banks.

Cases of comatose and terminally ill patients are rarely brought to the court, as these problems are usually regarded as medical and clinical cases to be confined to the authority of the medical profession. A very strong sense of the rights associated with professional discretion is confirmed in many legal cases. In Japan, those in the field of medicine want to practice medicine and conduct research without intervention from any other profession, such as law, religion, or economics.

Traditionally, the paternalistic behavior of physicians has been accepted without question. The recommendations regarding medical treatment made by physicians on behalf of comatose or terminally ill patients are accepted unquestionably by the family members of these patients. The traditional practice of not explaining to terminally ill people the nature of their illness, on the grounds that this is the kindest course of action, often results in surrogate decision making by the family on behalf of the patient, as mentioned before. Some movement toward truth-telling to the patient is gradually occurring, and the notion of informed consent has been widely publicized in clinical settings (Morikawa, 1994).

VII. Review of the Litereture

There have been several important and influential books and documents published in recent years. I will discuss a book by Professor Koichi Bai, an official report of the Japanese Medical Association's Bioethics Council, and the final report of the special committee on Death and Medical Services, Japan Science Council.

7.1. Professor Koichi Bai's Book

One of the most important Japanese books in this area of study was written by Professor Koichi Bai. Published in 1990, this book was entitled Seimei Iji Chiryo no Hori to Rinri (Legal Reasoning and the Ethics of Life Sustaining Therapy). Even though the book focuses mainly on the analysis of cases and the situation in the United States concerning treatment at the end of life, Section 4, entitled "Terminal Care and Law", does comment on relevant issues in Japan. Professor Bai points out several elements in the process of making the decision to forgo a patient's treatment: first, a confirmation of the patient's real desire; second, the importance of informed consent; third, an assessment of the patient's competency; fourth, continued treatment for the prolongation of life if the patient's desire is not clear; fifth, a respect for a patient's wish to change hospitals due to a difference in values between the physician and patient; and sixth, the necessity of care and the continuation of minimum treatment even if life-sustaining technology is terminated. Professor Bai's book is unique in its legal analysis and overview of the implications for advance directives in Japan (Bai, 1990). Other resource books are mentioned in the Japanese section of the annotated bibliography at the end of this volume.

7.2. An Official Report of the Japanese Medical Association's Bioethics Council

The title of the report issued by the Japanese Medical Association's Bioethics Council on March 18, 1992 is, "How a physician should handle the treatment of terminal patients in the final stage" (JMA, 1992). An official statement in 1978 by the JMA stated, "When a doctor is held responsible for disconnecting a life-prolonging device, the existence of a Living Will is significant as a mitigating factor only, and nothing more." After 14 years, the JMA changed its position, saying, "Even without the force of law, the attending physician will not be held responsible for a patient's death as a result of withdrawal of life-prolonging treatment." This did not state that the physician should follow any advance directive document prepared by a patient or presented by a family member on behalf of the patient. But this sentence implies an acceptance of the patient's wish not to have life-prolonging treatment, and an assertion that the physician will not be blamed for carrying out whatever action is in accordance with those wishes. It goes even further in affirming the patient's wishes, stating that, "Still, even if the patient does not have a signed document, a clear and unequivocal verbal statement expressing his/her wishes should be respected", and "In cases where the patient is unable to express his/her wishes, the question arises as to the extent to which family or friends may act on the patient's behalf. In principle, however, it is the patient's wishes [not those of others] that should be adhered to. In cases where there is reliable testimony from friends or family with respect to the patient's wishes, such testimony may be taken as an accurate reflection of the patient's wishes [and treatment undertaken accordingly]."

However, the following statement is problematic: "On the basis of connections with the Civil Code, for anyone over the age of 15, some declaration written by that person is, in essence, required. Further, in cases where the person is deemed to possess the capacity to make a decision, there may be no objection to the decisions of a person under the age of 15." The relevant Civil Code Article 961 states that, "Persons who have attained the age of 15 are entitled to write a will."

These statement may appear acceptable and practical in a clinical setting. However, I think the underlying message is one of avoidance of a clearly documented legal framework to which physicians must adhere. The intention seems to have been to retain, in the tradition of paternalism, medical professional hegemony in order to exclude legal control and legislation of living will laws, which are seen as a source of complications.

7.3. The Japan Science Council's Final Report on Death With Dignity

The Japan Science Council's final report on Death with Dignity was most recently issued on May 26th, 1994. This report caused a heated debate among professionals already in the midst of the ongoing Tokai University Hospital case mentioned before. The JSC is a sort of house of representatives sponsored by the Japanese government that consists of various eminent scholars elected by national academic societies in the fields of humanities, social sciences, natural sciences, medical sciences, etc. In this report, the words "death with dignity" mean a withdrawal of life-prolonging treatment. The report confirms that in the terminal stage, the patient's wishes should be respected based on the patient's autonomous choice. The importance of the patient's intention is particularly stressed. The treatment plan, according to this report, should be based on "Advance Directives such as Living Wills", thus respecting the patient's own choice for deciding when to withdrawal life-prolonging treatment, including hydration and nutrition (JSC, 1994).

However, the report concludes by stating, "We have to consider seriously whether we need to have legislation endorsing Living Wills or not". This report points out the possible risk of abuse and the difficulties in applying such a law. In conclusion, this report articulates that the withdrawal of life-prolonging treatment could be justifiable under specified conditions, and states that appropriate and cautious application of this law to actual cases should be performed.

Once again we are faced with a repeated unwillingness to legalize advance directives, and an avoidance of legal support in this kind of discussion. In addition, public policy debates regarding how life and death decisions should be handled in medical and clinical settings have been neglected (Kimura, 1994).

There is a widening gap between the position of medical professionals and the lay public on issues in terminal care. The general public is relatively positive in their support of the actions of the accused physician at Tokai University; however, the society of medical professionals has a very negative view of such actions in the case of terminally ill patients. It is almost impossible to legalize living wills in Japan. If any advance directives are to be developed in Japan in the future, they will need to be based on a familial type of directive. It might be possible for individual family members to make different decisions. However, the individual family member's idea should be shared with another family member; otherwise, the individual wish cannot be respected and followed. It might be called a Family Unit Advance Directive. This type of advance directive might have a more practical effect for future family preparation for life and death issues.

For many years, issues relating to death have not been openly discussed in Japan, as it is considered a "taboo" topic (Kimura, 1991). However, in considering the reality of advanced medical technology and its impact on medical decision making, an opinion poll conducted by the Ministry of Health and Welfare in 1993 revealed that around 80 percent of all Japanese citizens are concerned about the issues relating to death with dignity, euthanasia, and terminal care. Conferences, research efforts, and educational programs focusing on death and dying are now very popular. Dr. Alfons Deeken's pioneering educational program at Sophia University on preparing for death had its 13-year anniversary of activities in 1995. International dialogue and joint research programs on death and dying issues are taking place between various institutions around the world, such as the Bioethics Project of Advanced Research Center for Human Sciences at Waseda University, and The Kennedy Institute of Ethics at Georgetown University (Waseda Univ., 1992). In working on this Volkswagen Project and comparing advance directives in Germany, the United States, and Japan, we have learned a great deal about cultural differences and similarities.

Finally, I will briefly discuss a survey I conducted at Waseda University with 473 students in a Bioethics class. Approximately 70 percent of students responded "no" to the statement "I want to live as long as possible if I am permanently unconscious" and 77 percent wanted their own values to govern treatment decisions. Approximately 87 percent responded "yes" to the statement "I want to be without pain", while around 87 percent of students expressed a desire to have a comfortable dying process.

One might speculate that some of these data might elicit similar responses from students of other countries. We now share common values relating to issues such as the ability to understand the limits of life and death, the capability to alleviate pain and to foster a comfortable dying process, and the right to govern treatment decisions based on our own values. This commonality of values illustrates the enormous importance that advance directives have among the young generation of Japan.

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D. Anencephalic Organ Donation: A Japanese Case

Of the several cases of organ donations from anencephalics reported in Japan since the 1960's (Nakayama), one in 1981 (Oshima, 1984a, 1984b) calls for special comment. The transplant surgery was reported in both Japanese- and English-language academic medical journals. The reports were the same in content, emphasizing common issues about the merits of organ transplantation from anencephalics. The Japanese version, however, lacked any equivalent to the English version's sentence, "Despite respiratory assistance the neonate died". This difference reflects willingness on the part of the Japanese simply as sources for potentially viable organs.

In the following, I should like to discuss the bioethical standpoint implied in this view and its relation to Japan's traditional ethos.

Anencephalic Organ Transplantation in Nagoya

The recipient of a renal transplant from an anencephalic baby was an 8-year-old girl. In early 1981, she had been screened by the school health program, which periodically performed a urine test for protein. Due to the high level of urea nitrogen in her blood as well as her severe anemia, she was admitted to Shakai Hoken Chukyo

Hospital in Nagoya, where she was diagnosed as suffering from rapidly progressive glomerulonephritis. In early October 1981, she became uremic, and by October 21st she was given renal hemodialysis. As there were no live kidney donors available, she was placed on the waiting list for a cadaver renal transplant since her parents were ABO incompatible. On December 11th an anencephalic baby weighing 2000 grams was born at Nagoya University Hospital after 36-weeks gestation. The medical team obtained consent for kidney donation from the anencephalic baby's family (i.e., the father of the baby, who received a full explanation describing the baby's clinical situation and prognosis).

The renal transplantation was performed by the physicians in the Department of Obstetrics and Gynecology of Nagoya University Hospital. That evening, according to one reporter (Miwa, 1988), the attending physicians maintained that they had confirmed the death of the anencephalic baby by applying the criterion of total cessation of heartbeat. In his clinical report, one attending physician mentioned that he judged renal transplantation as the optimal treatment for the 8-year-old patient's terminal kidney deficiency (Tsuzuki, 1984a). Since there are very few cadaver donors available in Japan compared with European and North American countries, Japanese physicians have decided to utilize anencephalic neonates as organ donors even for patients who are not infants.

· Physicians' Attitude towards Anencephalic Neonates

At the time the medical report was written, medical experts were very optimistic about the usefulness of anencephalic neonates as possible sources of organ donation. Dr. Oshima, in a recent interview with Nikkei Medical Magazine, said that anencephalic infants should be permitted to serve as organ donors, since Japanese physicians are obliged to treat critically ill infants whenever they appear in the clinic (Miwa, 1988). However, his opinion had changed slightly due to the compromised quality of anencephalic donors' organs, and he expressed a less than optimistic attitude regarding anencephalic organ donation. Originally, Dr. Oshima thought that organ donation from cadavers would remain very rare in Japan due to the absence of brain-death criteria for declaring anencephalic infants dear. (The incidence is 1-per/1000 live births.)

There had been no official public and/or medical guidelines until January 1987, when the Japanese Society of Obstetrics and Gynecology addressed the use of organs from dead fetuses and dead newborns:

The Ethics Committee on Research and Clinical Practice has deliberated at length on the ethicality of and limits to the use of organs from aborted and stillborn fetuses and dead neonates in research. In light of the social and moral implications of the issue, Society members are advised to observe the following guidelines.

1. Regardless of the stage of gestation, the provisions of the Autopsy Law (Shitai Kaibo Hozon Ho) must be observed in the handling of dead fetuses and neonates.

2. The use in research of organs from dead fetuses and neonates should be limited cases where no other research method exists and the benefits from such research are expected to be extremely great.

3. In principle, research using organs from dead fetuses and neonates must be performed by a physician; all those who undertake such research, including collaborators, must be fully aware of its unique nature and social implications.

4. Those who wish to use organs from dead fetuses and neonates in research must fully explain the purpose of the research to the mother and the father (or legal guardian) beforehand and obtain their consent. Furthermore, the privacy of the fetus or neonate and their parents must be fully respected.

The clinical treatment of living fetuses and neonates for research purposes, however, may be conducted only in cases where such treatment is considered certain to improve the prognosis, and the consent of the mother and the father (or legal guardian) has been obtained.

Dr. Shinagawa, who in chairing the Society's Ethics Committee on Clinical Research was active in formulating these guidelines, mentions that the Committee discussed anencephalic neonates as sources for organ provision. He concludes that the issue is too complex and difficult to be encompassed by the present guidelines (Miwa, 1988).

·Issues concerning to Brain Death in in Japan in the 1980s

In the anencephalic organ donor case discussed above (Nagoya, 1981), lack of cadaver organs was due to the Japanese public's rejection of brain death criteria for declaring patients dead. On January 12, 1988, the Bioethics Council of the Japan Medical Association (which includes two physicians, two lawyers, and one expert in each of molecular biology, philosophy, cultural anthropology, literature, and industry) issued its final report on brain death and organ transplantation. The main points made were the following:

1. Brain Death (i.e., irreversible dysfunction of the entire brain) would be recognized as the death of an individual in addition to the traditional absence of heartbeat (circulation, pulsation, and respiration).

2. Minimum standard of brain death would be based on the standard adopted by the Special Task Force on Brain Death within the Ministry of Health and Welfare (whose chairperson is presently Dr. Kazuo Takeuchi).

3. The determination of Brain Death by brain-death criteria would be provided by physicians who respect the patient's and/or family member's wishes evidenced by a truly informed consent.

4. Determination of death by applying whole-brain-death criteria would be justified socially and legally if it (1) is grounded in the consent of the patient, (2) is determined by appropriate methods, and (3) is carried out by a physician in accordance with the guidelines of the Japanese Medical Association.

5. The time of death would be recorded no later than 6 hours after the initial determination of brain death.

6. Organ transplantation would be performed according to the guidelines of the Japanese Transplantation Society, which requires providing a full explanation for a free, uncoerced, and informed consent by the donor, the recipient, and the recipient's family members.

This final report clearly encourages organ donation by those who wish to donate organs for transplantation based on the individual's and/or his family's decisions. But the document also respects the traditional clinical criteria (e.g., heartbeat, circulation, pulsation, and respiration) for declaring a patient dead, and permits individuals and families to choose between the two criteria. Understandably, it has caused great debate among the public and the experts, as the brain death issue had already been discussed for several years. The report sought to achieve some sort of consensus within Japanese society concerning issues of life and death provoked by emerging biomedical technology. However, it did not accomplish its aim. A negative opinion on the conclusion of the report was issued by the Japanese Federation of Bar Association on July 15, 1988. And according to public opinion polls issued by the Prime Minister's Office in October 1987, only 23.7 percent of those surveyed accepted brain death criteria, and 17.8 percent agreed to donate organs.

As the Japanese psychoanalyst T. Doi explained in The Anatomy of Dependence (1973), in Japanese society people are encouraged to be dependent on each other and are expected to suppress egoism. In other words, Japanese society is not 'rights' oriented, as Western societies tend to be. Moreover, Japanese bioethical principles require a more subtle sense of the ways in which all living things are related to one another, based on the Buddhist notion of En (relatedness). A sharing-of-life principle, for example, would be more appropriate in a Japanese social context, than a right-to-life principle, because it affirms the values of dependent life and togetherness. The idea of sharing life with others, including all living beings who suffer, are sick or dysfunctionally aged, is viewed as a positive, creative living principle that is critical to human empathy.

This sense of relatedness of all life, along with various Buddhist strictures about the integrity of the human body, helps to explain why Japan is one of the few medically advanced nations that has not a definitive clinical standard of brain death. As a result, most kidney transplants in Japan come from living donors, and there has been only one heart transplant operation. This was done in 1968, but caused serious questions to be raised about the use of brain-death criteria to declare the donor dead. The case also raised questions about medical experts making decisions and practicing without public scrutiny.

Cases like the anencephalic neonate and the 8-year-old girl in Nagoya clearly need greater public exposure so clinical decisions in Japan's broad social context as well as among medical experts can receive the ethical, religious, and social scrutiny they deserve. Toward this end, the Bioethics Council of the Japanese Medical Association has made a meaningful contribution or at least it played a role in placing bioethical issues before the public.

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E. Organ Transplantation and Brain-Death in Japan: Cultural, Legal and Bioethical Background

In this chapter I would like to concentrate on three important and very recent developments in the area of organ transplantation in Japan. First, I would like to discuss the now infamous heart transplantation conducted by Dr. Wada in 1968 and analyze the reaction of the Japanese public exactly thirty years ago (Wada, 1968). Second, I would like to address the unique Japanese practice of using live donors almost exclusively for organ transplantation, particularly in the cases of kidney and segmental liver transplantation. Third, I would like to analyze the background process for making the new Organ Transplantation Law, which has been effective since October 16th, 1997.

· Aftermath of the First Heart Transplantation in Japan

I still remember the big headline of the newspapers praising and admiring Dr. Wada's performance of the first heart transplant on 8th of August, 1968 (Kimura, 1991). Many Japanese did not understand the full significance of this case and the need for investigation of possible criminal liability by the public prosecutor. In the end, the case was dismissed by the Sapporo Prosecutor's Office due to the lack, distortion, and concealment of major related medical records, as well as on the basis of medical experts' opinions and evidence of witness. As a result of this non-indictment decision, it is quite ironic that in 1970, two years before the American Hospital Association's Patients Bill of Rights was declared, a Japanese activist group endorsed a declaration of Patients' Rights, at a meeting in Tokyo condemning Dr. Wada's performance of heart transplantation (The Group for Condemning Dr. Wada's Heart Transplantation, 1970).

The key issue in the Wada case was the clear disregard and neglect of the human rights and human lives of the two patients involved. The fact that the donor became a candidate for organ harvesting much earlier than Dr. Wada originally mentioned promoted serious questions about the extent of the medical treatment given to this victim of drowning in the effort to save his life. In addition, according to testimony from the members of the transplant team, the recipient's condition was not as critical and his heart was not as diseased as would make replacement with a donor heart necessary at that time (Fujimoto, 1970). The Japanese general public learned later of the extent of mismanagement in this case through mass media, which were divided on the issue. For many people, the most troubling element was the lack of any guidelines pertaining to heart transplantation and the application of brain death criteria.

The concept of brain-based criteria for death was quite new and in 1968, as at present, no public consensus existed regarding a new definition of death in Japan. The Japanese were simply afraid of an unwarranted and premature diagnosis of death by physicians acting on brain criteria, and that the desire for donor organs would cut short their medical care. The fears raised by the Dr. Wada case still remain, in part because no official statement of regrets or admittance of premature performance of this transplantation procedure has been issued by Dr. Wada or by any professional medical organization such as the Japan Transplantation Society (JTS).

However, since the mid 1980s, at its own initiative, JTS has organized several series of public debates on issues raised by organ transplantation throughout Japan (Akiyama, 1991). The JTS Special Commission on Social Problems in Organ Transplantation has been active in providing an open forum, together with various professionals such as physicians, nurses, lawyers, ethicists and journalists. It has also published documents based on these activities (Japan Transplantation Society, 1990).

According to the national survey in May 1997, the numbers and percentages of individuals expressing a positive opinion on transplantation is gradually increasing in spite of the strong reluctance towards establishing legislation for organ transplantation among the Japanese public (The Yomiuri Shimbun, National Opinion Poll, May 9, 1997).

"The emergency liaison committee opposing the hasty legislation for organ transplantation" was formed in Tokyo in May 1994, and it has been organizing several open public forums on related issues in brain-based criteria of defining death and organ transplantation. The situation might have been changed following the new legislation on organ transplantation. But the point still remains of fears of the possible tendency too easily to apply the brain-based criteria of death now justified in law. The majority opinion of this group expresses the Japanese familial empathy for continuing the process of care for the dying, and fears that this would be lost due to the sudden and forced identification of a brain-dead patient.

They also state that the notion of harvesting organs from brain dead but apparently still living bodies would not be culturally acceptable, and would cause tremendous psychological difficulties and trauma among the family members.

· Organ Donation and Family Members' Decisions

Transplantation of organs from brain dead bodies is not completely banned in Japan, and in several cases organs have been donated based on offers by family members of the deceased. In the majority of these cases, however, physicians who performed these transplantations were later accused of violating existing provision of the Criminal Code of Japan against homicide, because of public failure to achieve consensus about the use of brain death criteria to declare death (Machino, 1993).

However, the Public Prosecutor's office and the courts are not very willing to deal with these cases efficiently enough to develop public policy on the issue. Generally speaking, the Japanese public has a tendency to avoid court resolution of disputes even in the case of medical malpractice suits, which number only about 400 annually, with about average 1500 cases pending annually in the last twenty years.

In reality, the number of cases involving family consent for organ donation is very limited and even the traditional criteria for death, cessation of cardiac or respiratory functions and the lack of pupil responsiveness, are not widely applied for organ transplants except in the case of cornea and kidney donation. Integrated legislation for cornea and kidney transplantation was enacted on Dec. 18th, 1979. This former law for transplantation, which is now integrated into the new law, has regulated a procedure whereby both organs can be procured from a cadaver. Despite this legislation, however, interesting differences exist in the sources of donor kidneys between Japan and other industrial nations; while 70% of kidney donors in Japan are live donors, the opposite is true in Western countries where 70% of kidney donors are brain dead. For example, in 1990 in Japan, 741 cases of kidney transplantation occurred but only 209 were from cadavers, while in the United States in the same year, 9491 cases of kidney transplantation occurred with 7498 of the donor kidneys coming from cadavers (Yasumura, 1992). About 80% of 141 cases of segmental liver transplantation from live donors in Japan since 1989 (as of July 1994) had four years' survival (Kawasaki, 1995).

Due to the extreme scarcity of donor organs in Japan, some Japanese seek treatment and donor organs in foreign countries. There is increased criticism of this trend, because no country has a surplus of donor organs, and no reciprocal access has been granted in the Japanese health care system to foreigners.

In Japan, common features of decisions to donate organs were analyzed as follows: 1) decisions are usually made by a group or family and not by individuals' decisions; 2) the majority of decisions are not obtained through a confrontational exchange of opinions but rather through a consensus of the people concerned; and 3) strong conflicts in opinions arise primarily among members of the group which does not favor organ donation (Coordinating Council for Kidney Transplantation, 1992).

The majority of opinions against organ donation are based on opposition to the mutilation of the dead body. On the other hand, consent is given mainly because of an expressed wish for some sort of continuation of life for the deceased even through someone else's body. Even individuals who have expressed a willingness to donate organs may request the added consent of their families.

For this reason, in some facilities such as the Japan Kidney Bank, consent from family members is requested in documents even at the time of initial registration. This procedure is legally endorsed, and consent is necessary from a family member in most cases of organ donation.

This approach shows the importance of family group members in health care decision making, particularly in the case of organ donation.

A 1990 survey indicated that the sustained campaign to promote organ donation between 1979 and 1985 was unsuccessful. The survey reported that of 6284 adult respondents, including 1500 health care workers, only 0.8 percent had registered as kidney donors and only 10.7% were aware of the procedures for registration (CCKT, 1992). At the same time, other studies showed an increasing need for kidney donors in Japan (CCKT, 1992). It is clear that Japan needs a more effective method to disseminate information and to educate the general public about organ transplantation. It is hoped that increased knowledge will contribute to an increase in the number of organ donors in Japan in the future. The establishment of the Japanese Association of Transplantation Coordinators in 1992 is one of the indications that a greater number of organ transplants may become a reality.

Proponents of organ transplantation are becoming more vocal in attempting to point out the potential to save lives through organ donation and transplantation. A wide range of educational programs has been launched at all levels of Japanese society to ensure that the discussion does not focus solely on the rights of the organ donor to the exclusion of those who could benefit from an organ transplant (Aoko, 1993).

For example, the Association for the Protection of Infants with Congenital Biliary

Atresia was established in 1973 to seek treatment for these children through micro-surgery and also to provide coordination for efforts to focus the attention of the media and medical community on the need for liver transplants for various end-stage patients. This Association has led several successful campaigns and saved the lives of numbers of these infants by encouraging the donation of organs (Fujiwara, 1987).

In March 1995, just before the opening of the session of the Health and Welfare Committee of the Diet to discuss the proposed pending bill on organ transplantation, a public educational symposium was held in Tokyo on the theme of "Thinking Heart Transplantation in Japan" to support the legislation. Around three hundred and forty people were present. This forum was organized by the citizens' group called the National Association for the Protection of Children with Heart Disease. Fifteen heart disease patients out of twenty, who had transplantation abroad, including their family members, were in the forum. They told of their experiences and appealed for support of the necessary legislation to endorse organ transplantation in Japan.

･Towards the New Law of Organ Transplantation in 1997

It is quite clear that high-technology medicine has increased the number of lives that can be saved, and that it has many benefits provided that it is practiced in accordance with bioethically appropriate standards. These standards must be regulated by national and international legislation or guidelines. The professionally oriented, exclusive and paternalistic approach of the past can only lead to repetition of past situations in which the rights of patients were ignored. I hope that discussion and education can prevent any such repetition of cases involving organ and tissue transplantation. The establishment of several governmental, professional and political organizations since 1985 has been encouraging in this regard. Some of these groups are the Commission of Life and Ethics, the Ministry of Health and Welfare, the Bioethics Council of the Japan Medical Association and the Investigation Committee of the Liberal Democratic Party, which works to evaluate issues regarding brain-death criteria and organ and tissue transplantation.

The most important one, the Ad-Hoc Research Commission on Brain Death and Organ Transplantation, established in 1990 by special legislation of the Diet, intended to conduct an intensive investigation on related issues in order that there will be some form of outcome such as national consensus possibly leading to new legislation. The majority of the Commission members supported the idea of integrated legislation dealing with brain-death and organ transplantation. However, some members, including two consultative members, strongly opposed the notion of brain-death criteria by pointing out the unacceptability of a definition of death based on brain function. The final recommendation of the Commission was a very unusual document by the Japanese standards, because it published the dissenting opinion in full, as a separate part of the final report; usually, such reports publish only a unanimous or compromise opinion (Ad-Hoc Research Commission on Brain Death and Organ Transplantation, 1992). While there was disagreement on the use of brain-death criteria, the opponents agreed to respect the wish of a donor who has expressly given consent in a prior document. The final minority opinion of the Commission also agreed to proceed with organ transplantation but not to harvest organs from individuals who have not yet been declared brain dead, but are considered still living (Ad-Hoc Research Commission, 1992).

This Commission's final report was issued on January 22, 1992, and finally the new organ transplantation law has passed Diet and been effective since October 16th 1997. Since proposal of this law to the Diet in April 1994, the Diet carried it over to the following session every year until 1997 without having further investigation in the Health and Welfare Committee of the House of Representatives.

This new law confirms the importance of family members in medical decisions by granting them power of consent to organ donation on behalf of newly deceased family members. Therefore, even if the deceased was registered as a possible donor, the surviving family may refuse organ donation. The new organ transplantation law identifies the circumstances in which the family can and cannot decide for organ transplantation on behalf of a brain dead individual who left no specific written evidence of his or her wishes. In light of the draft legislation from the Inter-Party Council in which the family is granted authority to make decisions on behalf of the patient, often based on rather vague evidence, it is interesting to note that the earlier report of the original Ad-Hoc Commission did not extend the principle that the decision regarding organ transplantation should be based on respect for the wishes of the individual patient insofar as possible. This was a rather closer conclusion to "The Final Report on Brain Death and Organ Transplantation" of the Bioethics Council of the Japan Medical Association, which was issued in January 1988.

The new law of 1997 provided the basic approach of respecting the intention to donate organs on the part of the patient and a notion of the voluntary nature of organ donation; however, it also state that a person's expressed desire to donate organs will be honored only if family members do not object and if the intention of the person is clear in stating the acceptance of criteria for death based on brain assessment (The Law concerning Organ Transplantation, July 16th, 1997. The Law No. 104 of 1997) Article 6., Sections 1. 2. 3.) .

In Japan, generally speaking, the process of making laws has been in the hands of professionals, government appointed academics, and bureaucrats noted to have vast knowledge and experience in the particular field in question. Professional credentials are of great importance to the Japanese in an official decision-making process. This process traditionally has not sought input from the public.

However, since the mid-1960's, there has been an enormous interest in the general public about issues in bioethics. Members of the public have become vocal and involved participants in areas of concern traditionally regarded as restricted to professionals in the historically paternalistic field of medicine.

The rapid progress and development of medical and scientific technologies have demanded participation and cooperation between local grass-roots lay people and medical professionals to ensure better decision-making and respect for the autonomy of patients (Kimura, 1989).

Unfortunately, most professional Bioethical Commissions in Japan exclude from their membership a variety of professionals, any representation of the lay public, and any female members. The discriminatory membership of these committees has undermined the general public's confidence in and support for these bodies. In addition, the deliberations of these Commissions traditionally have been closed to the public except in rare instances when concurrent but separate public hearings were held on particular issues. Reasons for continuing to hold closed meetings range from a concern that frank debate will become impossible to concerns about the secrecy of potentially patentable procedures. Whatever the reason, the more universal bioethical principle of reflecting public opinion in the process of making public policy on issues of life and death is very underdeveloped in Japan, which results in frustration and loss of confidence in the ability of these commissions on the part of the public.

A radical shift in the mentality of both Japanese medical professionals and legislators must occur to embrace the new and rapidly developing medical technologies and developments in science, and to meet the needs of suffering patients. In order to break through in the legalization on organ transplantation and brain-death criteria, the lay public's influential contribution was developed positively (Kimura, 1987).

In the absence of a real "Bioethical" approach to public policy, which demands public participation and open debate, fundamental human rights of suffering patients, potential organ donors and organ recipients will not be seriously reflected in the Japanese legal system and public policy process.

The issues raised here in the Japanese social and cultural context are really matters of human life and human rights which should be respected in the whole process of bioethical decision-making at the individual private and national public levels, and in an international context of bioethical guidelines.

Debate on brain-based death criteria and organ transplantation during the last thirty or so years in Japanese society shows the clash between modern scientific culture, represented mainly by medicine, and the traditional Japanese cultural ethos concerning life and death. It also shows the enormous impact of challenges arising from the development of the bioethics discipline. Even the universal hope through science and technology to benefit human life, such as by organ transplantation, could not be applied easily without an internal struggle of the cultural mind of the people of Japan.

However, our starting point should be a recognition of the existence of injustices, and our continuous involvement in the struggle against injustices, particularly to achieve a better system of welfare and to advance the health of the people according to the well accepted principles of the Universal Declaration of Human Rights developed by the United Nations in 1948, which marks its fiftieth anniversary in December 1998.

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Zoki no Ishoku nikansuru Horitsu (The Law concerning Organ Transplantation, July 16th, 1997. The Law No. 104 of 1997) Article 6., Sections 1. 2. 3. (Removal of Organs)

"The Simultaneous Transplantation of Pancreas and Kidney of the Brain Dead Woman to the Diabetes Patient at Tsukuba University on September 26, 1984." In: Machino, Saku. ed. Shinzansha, 1993. pp. 30-41. In this well publicized case, the organ recipient died after one year.

Chapter 4. Ethics Committees and Experimentation on Humans

A. Ethics Committees for “HIGH TECH” Innovations in Japan

In Japan, principally because of its traditional Confucian ethos, medical paternalism has been unquestioned until quite recently. Medical practice was regarded as the "Art of Jin" (the loving-kindness of Confucian teaching) for more than one thousand years (Kimura, 1986). It reflects the benevolent action of physicians on which all patients tend to depend.

The authoritative and fiduciary relationship between medical professionals (physicians, nurses, and allied health personnel) and patients and their families has been so common that even today patients are not expected to raise questions concerning their own bodies and health care when they are ill. Of course. This situation is gradually changing due to the effect of various socio-cultural values of the younger generation, which views traditional medical values (particularly medicine's paternalistic practices) rather negatively. However, for many Japanese, even though "persons' rights to health" are provided for in Japan's Constitution - and all Japanese nationals are covered by the Health and Social Security Insurance instituted in 1961 - the "rights"-oriented approach in medical settings is not so common. In comparison with other social developments, the "patients' rights" and "consumers' rights" movements are quite small in Japan. For example, medical malpractice suits are relatively very few in number due to out-of-court resolution mechanisms called "Jordan", "Choteau", and 'Wake" (Kawashima, 1963; Kimura, 1988b).

In addition to the social ethos which permits "medical paternalism" to go unquestioned in Japan, there is a very strong research-oriented mentality among many Japanese medical experts who often treat patients as interesting medical cases rather than as persons deserving of respect (Sunahara, 1988). But clearly persons ought to be fully respected, for it is they who make moral choices in this age of secular pluralism. Further, the dignity and rights of persons should not be disregarded simply because of cultural differences. Thus. in turning our attention to bioethics committees in Japan. We should evaluate the extent to which such committees protect patients' rights, the cultural heritage of many nations in the world. As expressed in "The Universal Declaration of Human Rights," well as in various bioethical statements and guidelines such as the Helsinki Declaration of the World Health Organization (Kimura. 1988a).

The Ethics Committee in Japan and Positive Public Image

There are no regulatory bodies established to control any of the bioethics committees in Japan. In December 1982, the first Japanese ethics committee was established at the Medical School of Tokushima University, because its faculty members expressed serious concern about the ethics of in vitro fertilization (IVF). Dr. Takao Saito was one of the key persons who formed this Committtee; he had previously participated in the "Ethics Committee for the Protection of Human Subjects" at the University of California at San Francisco's Medical School (Saito, 1985). This first ethics committee was composed of eight members. Six of them were faculty members in the medical school: the dean (a pediatrician), the hospital director (a dermatologist), an enzyme chemist, a physiologist, an anesthesiologist, and a medical radiologist; and two were non-medical persons - a philosopher from the Faculty of Arts and Sciences, and a lawyer from another institution. The research protocol was presented to the Committee on IVF Issues on December 1982. After eight meetings the committee had heard testimony from various experts concerning the socio-cultural and ethico-religious matters that bear on IVF procedures. Those who testified included a Buddhist scholar a legal expert on malpractice cases, experts on animal IVF experiments, journalists, an expert on hereditary malformations, an expert on women's issues. A child psychologist, a Catholic physician, and the present author as a bioethicist. After two additional meetings the Committee announced the result of its deliberations: it approved IVF research and practice, but with several restricting conditions. This committee process caught the attention of the mass media, which noted the symbolic change in Japanese medical paternalism and the new openness to a wide variety of opinions concerning the research work, which was ongoing at the Medical School.

The first IV-F baby was born not at Tokushima University Hospital but at Tohoku University Hospital where there had not been any previous effort to carry out bioethical analysis of these techniques by careful committee review. The chief of the Tohoku medical team, Dr. Suzuki, stated that his colleagues were seriously concerned about the ethical issues that related to IVF. Nevertheless the announcement of the IVF guidelines at Tohoku University was made on the same date that its team publicly confirmed the successful implantation of a human fertilized egg (Suzuki, 1983).

The contrast in the two universities' approaches to research involving IVF has led to a more positive public image of Tokushima University's medical school and its ethics committee. Since then, there have been further efforts to establish similar types of ethics committees. Like the one at Tokushima University, in order to provide for the ethical review of other "high-tech" biomedical advances. Even though there are not at present codified regulations governing ethics committees in Japan, as of July 1987 there were 41 ethics committees at the 42 government-supported medical universities. And three ethics committees at the eight local government-supported medical universities. Twenty ethics committees have been established among the 29 private medical universities. Thus, among the 79 medical universities in Japan, 64 (81%) now have ethics committees (Ministry of Education, 1987).

Because of growing public concern over the complexities of new biomedical technologies and their social, ethical, and legal implications, the idea that ethics committees will discuss, evaluate, and approve or disapprove a proposed medical protocol has generated a very positive public image of biomedical scientists, physicians, and ethics committees in Japan (Sunahara, 1988). Due to the absence of a common standard, however the image of ethics committees that review clinical protocols remains varied.

The Role of 'HIGH TECH" Biomedical Ethics Committees in Japan

Some may view the role of ethics committees merely as a public relations mechanism for the medical "insider' to show the "outsider' that ethical problems are being considered seriously. The committees' role becomes even more important for the Japanese medical researcher as he or she prepares to submit papers to international medical journals, which usually require prior clearance by an ethics committee where the faculty members are conducting "high tech' research work (Yokoyama, 1985). In short, some citizens continue to distrust medical experts whom they believe not to be serious when claiming to protect patients' rights and dignity.

It should be mentioned that in 1968, when Dr. Wada and his medical team at Sapporo Medical University performed the first heart transplant surgery in Japan, the recipient lived for 83 days following the transplant operation. Since there had been no confirmed record of the brain death of the donor, and no ethical review had been conducted prior to performing the heart transplant public support for the transplant has not been forthcoming. In fact, the district attorney's office considered prosecuting Dr.

Wada, but decided not to bring this case before the court due to the difficulty of verifying the issues 'on camera" (Ishigaki, 1970). At the Tokyo meeting where the public accusation against Dr. Wada was made, a statement on patients' rights and the dignity of human life was read (Ishigaki, 1970). The Japanese are still experiencing the after-effects of the Wada Case; this is one of the reasons why Japan has not yet established any official brain-death criteria. This situation might change rapidly if Japanese medical experts shifted from their long-standing paternalistic stance to a more open. , Egalitarian, and cooperative approach to other professions and patients.

The growing number of ethics committees may one day be viewed as a positive sign of the changing Japanese medical context. However it has been suggested that Japanese-style ethics committees are only camouflage to distract the public's gaze (Sunahara, 1988). In order to determine how ethics committees in Japan actually function. The Japan Federation of Bar Associations (JFBA) recently undertook a comprehensive survey

· A Summary Report on Ethics Committees by JFBA

In May of 1986, the TFBA conducted a survey on ethics committees in Japan.

Some results of this survey are as follows (Japan Federation of Bar Associations. 1986, pp. 56-78):

1. The committee's responsibilities include guideline development and the review of each protocol (70%).
2. The average number of committee members is ten, the most frequent number is Eight.
2. The Dean of the Medical School and/or Hospital Director is a member of the Committee (88%).
4. The average number of non-university affiliated members is 1 .7 members.
5. The committee is comprised of male members only (78%).
6. The committee is comprised of medical faculty members only (20%) or of medical faculty members plus other faculty in the same university (5O%).
7. Unanimous agreement by the attending members of the committee is required (71%).
8. There is no appeal from committee decision (71%).
9. Committees impose no penalties on investigators if investigators disregard the

final decisions of the committees (78%).

10. Committees take no responsibility for research-related injuries to subjects (54%).
11. Committee meetings are open to the public (O%); open with stipulations (29%); or closed (59%).
12. There is disclosure of the deliberation process and results in the case of decisions with conditions attached (71 %).
13. No guidelines have been developed for organ transplantation (80%).
14. The duration of the review process is from one to seven months.
15. The number of meetings required for making a final decision on a protocol ranges from one to eleven.

These key elements of the findings show the individuality of various Japanese ethics committees. Note that no committee has lay community members on it. This survey also reveal that ethics committees in Japan tend to be male dominated, professionally dominated, and closed mechanisms that defend medical experts' supremacy in conducting their research work in a paternalistic setting.

The democratization of Japan's Constitution was initiated by the U.S. Supreme Commander in Chief during the occupation of Japan following World War II. However the democratization of Japan's traditional values is still in process because of the nation's cultural ethos. reflected in the Japanese mind, this process will take more time to be realized. Japan's cultural heritage stresses the importance of mutual interdependence, respect for the aged, and professional and bureaucratic authority given over to the sacred Emperor (now a mere symbol for the unity of Japan). For a thousand years, the word "Ko" (public) was interpreted in Japan as "on the side of the Emperor', which, of course, has nothing at all to do with the people's power (demokratos) (Yasunaga, 1976).

In conclusion, the Japanese need to emphasize their concern about bioethical questions through coherent and just policies formulated in a democratic social context (Kimura, 1987). In Japan, bioethics should not be merely the analysis of various ethical and religious theories and principles irrelevant to the human situation. Indeed. the notion of bioethics as civic action remains a challenge to all Japanese citizens.

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B. Experimentation on Human Subjects in Japan: Bioethical Perspectives in a Cultural Context

I. Cultural Background

The phrase jintai jikken (human experimentation) is taboo in the Japanese socio-cultural context. Experimentation on other human beings, sometimes even on animals, is regarded as cruel, degrading and not acceptable in both Confucian and Buddhist thought, nurtured in the Japanese traditional religion of Shintoism.

Almost all Japanese medical schools hold special ceremonies at least once a year in memory of all animals experimented upon and killed for research purposes. Many researchers are expected to attend this ireisai (memorial service) according to Shinto or Buddhist tradition. The Japanese had to accept scientific experimentation in medicine and biology for the sake of research and development. This was in contrast to the Japanese sense of attachment to animal beings.

Humans are regarded as part of all living beings and acts of loving-kindness to all fellow living-beings are a very important virtue in the Japanese cultural tradition. This is therefore part of the character of medical practice. The preface of the first Japanese medical encyclopedia-, entitled Ishinpo, edited by Yasuyori Tamba in 30 volumes and published in 982 A.D., states that such "medical service is the expression of the great mercy of Buddha and the loving-kindness of Confucian teaching".

Traditionally accepted standards of medication, practice and treatment, which originated in China, have been well developed and dominant in Japan. Western medicine, particularly the German medical model, came to Japan only at the end of the last century, when Japan engaged in its modernization process.

Although in Japanese traditional medicine generally there is reluctance to perform human experimentation, there have been some exceptions. An example is the case of breast-cancer surgery in 1805, in which general anesthesia was used for the first time in medical history. Dr Seishu Hanaoka (1760-1835) used his new combination of traditional herbal medicine on his mother and his wife for the validity and efficiency test, and finally for the successful operation of breast cancer.

Traditional Confucian teaching stated "Do no harm to one's body, which was given by one's parents, since this is the source of filial piety". However, in the Japanese cultural context, when the situation was very critical and it was important to help and serve others, as in the case of Dr. Hanaoka with his research trial, his wife and even his mother were willing to submit themselves to a justified experimental procedure as an expression of their affection for their husband and son. Internal family relationships and psychological elements in the socio-cultural background of Japanese society at the beginning of the 18th century were beautifully analyzed in the novel, The Wife of Seishu Hanaoka, written in 1966 by one of Japan's most eminent female novelists. Particularly in rural communities, the family unit and family bonds are expected to be very strong and easily recognizable.

Live organ donations among family members, even in the experimental stages, are common because of these familial ties. It is a unique aspect of Japanese organ transplantation that 70% of kidney donations are from living donors, and in all cases of segmental liver transplantation the donation is from one of the recipient's parents. This is because brain-death criteria have not been established for cadaver organ donation in Japan.

Japanese sentiment nurtured in traditional culture still survives in every sphere of life, even in westernized medical settings. For the general public, it is simply impossible to accept a dualistic approach to mind and body, to the notion of brain-based human personality, and to the technical replacement of human body parts in experimentation on human beings.

Behind this reluctant attitude of the Japanese public to experimental-mental medical technology have been various symbolic medical tragedies that have come to public attention recently. Recovery of trust in medicine and in the medical profession is the key to demystifying the phrase jintai jikken, mentioned at the beginning of this paper.

II. Patients as research material - "the Dr. Wada incident"

It is essential in medical experimentation on human subjects that there should be strict conditions to protect the rights of the patients. Without having final applications of all kinds of technological inventions and medications in the treatment and cure of disease, new developments in medical science would not be realized.

In Japan, as I mentioned briefly before, the general public has not been seriously aware of the importance and meaning of jintai jikken, and has simply rejected the idea of human experimentation. Medical professionals and researchers were seriously mistrusted and thought to be insincere. This is a reasonable and acceptable reaction from the lay public's point of view, as there have been several reports of cases clearly categorized as jintai jikken (human experimentation).

Such a typical case was "the Dr. Wada incident". This happened in 1968, when Dr. Wada became the first Japanese surgeon to perform human heart transplantation. This was only the fourth transplantation of brain-based human *personality~~ and in the world. The heart was taken from a drowning victim and transplanted to a patient with heart failure from mitral stenosis and insufficiency. The recipient died after 83 days and Dr. Wada's disclosures about both the donor's and the recipient's clinical data aroused serious suspicions. These doubts involved his brain-death criteria decision, his lack of an alternative treatment suggestion without having obtained full informed consent from the families of both the patient and the "donor", and a rather hasty transplantation without having done sufficient basic research beforehand on such problems as graft rejection or postoperative infectious disease.

Dr. Wada was accused of wrongdoing and this led to criminal investigation by the Sapporo District Attorney's Office, although he was not indicted. In 1970 a public gathering was held in Tokyo on the issues raised by the Dr. Wada incident. "The

Declaration of Patients' Rights" was officially announced at the end of the meeting. Its contents were very simple in proclaiming the protection of the rights of patients, with special reference to the Dr. Wada incident. Now, 24 years later, many people still remember this, and Dr. Wada still insists that he did nothing wrong.

It is quite true that until very recently the physician's unquestioned paternalistic authority was an accepted reality of Japanese medical culture. It is accepted practice to perform therapeutic research or to do research on patients in the name of clinical trial, in closed confidential clinical settings, y without full informed and written consent, and with no peer review before or after treatment. There has been no; scrutiny and there is little tendency to malpractice litigation (the average number of new malpractice cases is around 400 a year) as the Japanese public traditionally have a very strong sense of respect, trust and obedience with regard to physicians, without knowing the details of what is happening to their bodies.

The Dr. Wada incident opened up the core issue of the physician-patient relationship. The incident was totally unbelievable because it broke the traditional "trust" relationship. The societal trauma of jintai jikken became a nightmare for many people by revealing the symbolic research-oriented mentality of advanced medical experts such as Dr. Wada and others who dared to do jintai jikken on patients as mere research material.

III. The source of professional failure in bioethics and ethics committees in Japan

Almost all "ethics committees" for biomedical research and innovative treatment in Japanese medical schools or hospitals have some guiding principles and bylaws, including some statements of policies, to guide ethical decision-making. These principles and policies always reflect the relevant accepted codes of standards and professional consensus on ethical principles in medical practice and research issued by international medical and health organizations, including the Council for International Organizations of Medical Sciences, the World Medical Association and the World Health Organization.

Public concern about the protection of the patient in therapeutic research and of research subjects was considerable at the time of the Dr. Wada incident. However, an increasing number of jintai jikken have been reported by the mass media since the middle 1950s, but very few criminal charges have been brought against the medical researchers. Neither have there been any serious efforts to set up ethics committees in accordance with bioethical guidelines. In November 1984 for the first time in a Japanese medical school, the Tokushima University, officially established "The Ethics Committee", to review the research protocol of in vitro fertilization.

Japan has no national regulations requiring any sort of review committee such as the institutional review board in the USA. All 8O medical schools and some other hospitals voluntarily have their own local ethics committees. They usually claim to have guidelines for clinical research trials or therapeutic research in accordance with the Declaration of Helsinki and, in some cases, mention the CIOMS Proposed International Guidelines (1982).

CIOMS documents on ethics committees were particularly influential and became basic reference material for the ethics committee established in 1981 at the Tokyo University Institute of Medical Sciences.

Although Japanese medical researchers are becoming aware of international trends in protecting the rights of human subjects involved in clinical research, there seems to have been no serious internal or professional initiative reflecting disclosure in the actual jintai jikken mentioned above, when setting up ethics committees.

During World War II, war crimes committed by Japanese military medical professionals in Northern China at Unit 731 were not taken seriously as the outcome of a systematically structured problem of the Japanese medical community. Rather it was noted as an exceptional case, due to the extraordinary wartime situation. Several cases of actual jintai jikken were performed with human "material", mainly on Chinese captives, to verify the results of research for the production of biochemical weapons, freezing experiments, bacterial infection experimentation, exposure to poison gas, etc.

Unlike the Nuremberg Trial defendants, all of the Japanese medical criminals were granted immunity from punishment for their inhuman crime of experimentation on captives, in exchange for giving all "extraordinarily valuable" data to U.S. Army researchers. Forty years after these secret deals, by using the Freedom of Information Act of the U.S. Federal Government, I investigated some of the "top secret" documents of the U.S. Occupation Forces and the Pentagon, kept at the National Records Center in Suitland, Maryland. It was considered "a matter of national security" not to give any resource material or information to Communist countries by opening up the issues of the Tokyo War Tribunal. This superseded the matter of justice and prosecution of medical professionals. I feel that we missed the timely chance of total disclosure, immediately after the war, of this very serious crime of human experimentation by Japanese medical experts in China. If the Japanese medical community had had in place a similar code of medical ethics as that which followed the Nuremberg trials, the Japanese public would have trusted the medical community.

Other experiments on humans, which resulted in the death of human subjects, were performed in China and even in Japan on captives of the allied forces. These were done in the name of vivisection practice and for the collection of some anatomical data. The vivisection case, which happened at the Kyushu University Medical School, was brought to the Yokohama War Crimes Tribunal. The record clearly shows the violation of international law, as well as the wartime mentality of the medical professionals in seizing all possible chances to perform medical research.

IV. New trends regarding rinsho chiken (clinical trial)

The pace of development of bioethical ideas is slow. However, the medical professional community cannot now function without social support, including the support of the lay public.

In 1986 the Japan Medical Association set up its Bioethics Council, composed of 10 members from other professions, including the legal, the social-anthropological, the business, the philosophical, and the biochemical fields, as well as the medical profession. Bioethical topics chosen by this Council were "Brain death and organ transplantation", "Pre-sex selection of the fetus", "Care of the terminally ill patient" and "Explanation and consent". In the final report, issued in January 1992, the Japan Medical Association, one of the most authoritative Japanese medical organizations, for the first time endorsed the notion of the "Japanese way" of informed consent being applied in the clinical and research setting. The setsumei (explanation) by the physician to the patient and doi (consent) are strongly recommended-mended. This is a considerable advance over the situation in the early 1980s when I began to challenge the Japanese medical profession to emphasize the bioethical aspects of medical services and patients' rights issues.

Now bioethical problems are so well reported in the Japanese daily newspapers that even the phrase "informed consent" has become common parlance not only among medical professionals but also among the lay public.

There have been no permanent bioethics commissions at the national level, but special bioethics boards, affiliated with the Ministry of Health and Welfare (Koseisho), have existed since 1983-85. During the two year-year periods 1990-92, there was an Ad Hoc Commission on Brain Death and Organ Transplantation, which had been established under the Prime Minister's Office (Sorifu).

Because of the complication of the Dr. Wada incident, many Japanese are reluctant to accept organ donations from cadavers diagnosed as brain-dead. The Japanese Federation of Diet Members on Bioethical Issues is preparing special legislation relating to organ transplantation in order to integrate existing legislation with that governing transplantation of kidneys and corneas.

In the case of the drug-testing protocol for prospective pharmaceutical- products, the system of Good Clinical Practice (GCP) was initiated in 1990 by the Ministry of Health and Welfare. This is in accordance with international trends in procedural justification of research protocols, informed consent of subjects, and the constitution of ethical review committees.

In the face of extraordinarily rapid biomedical, biotechnological and pharmaceutical development, people in Japan feel that it is important to protect the weak and the sick, particularly children, women and the aged. Some of the Japanese lay public has taken the initiative in developing aspects of bioethics that focus on patients' rights. There is a movement to propose new legislation for the protection of patients' rights, for the family as well as for responsible health-care institutions, communities and government organizations.

In this age of the global community it would be naive to overemphasize the uniqueness of a particular cultural heritage in human, family and social relations. It is true that different cultural and ethical values should be respected, such as key concepts of the dignity of each human person, the importance of the family unit, and community life, but justification of any act or behavior against human dignity and the rights of the person for the sake of cultural tradition is not acceptable.

In this sense we need international dialogue and understanding for the establishment of internationally acceptable guidelines for conducting research, especially biomedical research. In Japan we have learned much from the I 982 Proposed International Guidelines for Biomedical Research Involving Human Subjects (CIOMS) and it has been a challenge to our cultural tradition. Because of its impact, as well as public input from national and international sources, the situation of clinical and research setting is clearly changing.

The Japan Association for Bioethics was formed in 1988. There are now more than 20 bioethics-related projects in process and several research centers have been established. Since 1987 compulsory bioethics courses have been required at the School of Human Sciences of Waseda University for all 6OO senior students. Human experimentation issues have been one of the main topics of these courses, which are jointly taught by three faculty members - a biologist, a medical scientist and a lawyer bioethicist (R.K.). Increasing the number of courses and curricula in bioethics studies at various levels of educational institutions would greatly increase awareness in Japanese society of medical-service and health-care Issues.

The very recent amendment, in June 1992, to the Medical Service Act (1948) accepted the new provision that not only physicians but also nurses, pharmacists and other health-care workers are providers of medical services. Also, in the new supplementary provision, the notion of informed consent has been mentioned as a basis of trust between physician and patient. It states also that full implementation of this concept is a continuous task of the welfare and health administration for the preparation of a total amendment of the Act, possibly soon.

The issue of jintai jikken (human experimentation) will not be taboo any more in view of these new developments and expressions of concern about bioethical problems. As Japanese we are encouraged to be members of the global community by fully participating in the international process of developing ethical guidelines for biomedical research involving human subjects.

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C. Bioethical "Norms" after Nuremberg Military Tribunal and Medical Crime of the Unit 731, Japanese Imperial Army

One of the most important ethical norms which has been re-confirmed by the Nuremberg Military Court was, of course, the principle of autonomy and the right of informed consent that belongs to the patient or research subject in a biomedical setting.

It is surprising that the Nuremberg court decision and its ethical norms have not been implemented by the medical profession in Japan until very recently even though it was known by many clinical and experimental medical experts.

My premise is that the ethical "norms” of the Nuremberg trials had a great impact in ethics discourse, however they did not significantly change the stagnant situation of the physician-patient or researcher-subject relationship, which remains embedded in the traditional paternalistic hierarchy of biomedical professionalism in Japan.

The ethical " Norm" in biomedicine has not been radically changed by affirming the very important event of the Nuremberg decision.

But change has come through the process of international social upheaval of the 1960’s and 1970’s challenging professionalism, authority and establishment before unquestioned. Various decisions recognizing the right of informed consent, together with various social movements in support of patients' rights, womens' rights, and grassroots commitments to health services for the poor and minorities, were mutually reinforcing phenomena that brought gradual changes in laws, medical practices and ethical norms.

And without these active social movements claiming justice in civil rights, equal treatment and opportunity between both sexes and various races, and actual social action in order to establish an institutionalized system for protection of human rights in various social infrastructures including academic, research and clinical settings, the ethical "Norms" in biomedicine could not have been changed so radically during these twenty years (Kimura, 1986).

But we carefully 1have to recognize the difference between practical application of ethical "Norms” in ordinary and routine clinical practice, and academic and theoretical efforts to analyze ethical " Norms" in a more abstract way.

I. The "Ab"normal out of Normal?

There are many books on medical ethics in Japan. And almost all of them quote or mention the Nuremberg Code in some pages or chapter. However, they explain these principles in an abstract way; the actual reality of the normal clinical situation has been that physicians have unquestionable authority to which patients were usually obedient (Kimura, 1991).

To make the situation worse, there are very few books of medical ethics in Japan referring to the War Crimes of the Japanese medical profession. During W.W.II. Japanese physicians engaged in human experimentation on POWs, making biochemical and bacteriological weapons used for battles, performing vivisection practices on living persons, etc.

Now, historical documentation together with several living witnesses in Japan has shown some horrifying human experimentation cases in China using human subjects captured from Chinese, Russian and some other peoples during World War II. (Williams amd Wallace, 1996)

The approach to the human subject was basically similar to Nazi experimentation in concentration camp. The Japanese military biomedical expert utilized the captured prisoners as experimentation material, and performed anatomical vivisection material for demonstration for autopsy training in causing death finally (Yuasa, 1994)

There is a great difference between the policy of dealing with German and Japanese medical experts who were engaged in these kinds of human experimentation. The occupation forces in Europe and in Asia-Pacific took different approaches to prosecution of war crimes in these two nations.

There were different standards of military codes of ethics to be applied to the occupied personnel accused of War Crimes before a military tribunal.

Even though there were similar cases of crimes against humanity, the case of Japanese medical experimentation on human subjects should not be brought to the court, according to U. S. policy decision makers. In order to get all of the information relating to the results of experimentation, interrogation was extensively made of the former staff members of the Unit 731 (the official name is Water supply and Sanitary Corp.) who were immunized by the U.S. authorities (Hubbert, 1947).

This was confidentially justified by the U.S. Military as a " National Security" matter, which should be classified to the public as top secret. Now, more than 40 years, due to the " Freedom of Information Act in the U. S.", I was able to verify the related documents at the U. S. National Archives in Suitland, Maryland (USN, 1947)

Very few Japanese people knew of this whole process of investigation of Japanese medical professionals, including the actual happening of this incident during the war, while the Nuremberg medical court was known widely among the international public.

The Japanese Military biomedical experimentation became known in 1970's by many people because of the publication of the book written by a leading contemporary writer, Seiichi Morimura. The title of the book is " Akuma no Hoshoku (The Devil's Gluttony)" and it was a result of an intensive search for documents and a series of interviews.(Morimura, 1981)

When this was published, the majority of the medical profession as well as the general public expressed feelings of shock and uneasiness to hear of such inhuman experimentations on human beings. And the incident was regarded as an "ab" normal event, which occurred in the abnormal situation of War and was done by rather abnormal people.

Here, I would like to point out the most relevant comments also relating to Nazi medical experimentation and policies. These problems relate to the most fundamental issues of "Norms" for normal person that should apply to a person in a particular specified situation. I know that some people would say that it is "unfair" to criticize the particular person's action and behavior out of context of a particular social and ethical "norm" of a particular age.

However, I must say, on behalf the dead and those experimented upon to say that what is "abnormality" in that era does not solve the issues nor immunize those involved from responsibility.

We are able to recognize common elements which penetrate the cases between Nazi-Germany and Imperial-Japan in relationship to human experimentation. That is to say even the "normal" people professionally trained with high motivation would do their service in the name of superior cause, such as in the name of Hitler (see the testimony of Mengele) or Emperor. In particular situation, it is easy to recognize the lacking of a sense of "Norms" to fellow human being.

One example can be seen in the notorious case of Tuskegee for the study of Syphilis among the black population in the U.S. The medical historian Dr. James Jones mentioned that " There was a similarity between the Nazi experiments and the Tuskegee Study, one which went beyond their racist and medical natures. Like the chain of command within the military hierarchy of Nazi Germany, the Tuskegee Study's firm entrenchment in the PHP bureaucracy reduced the sense of personal responsibility and ethical concern (Jones, 1993).

For the most part doctors and civil servants simply did their jobs. Some merely " followed orders"; others worked “for the glory of science". This is exactly the sort of expressions by some of the Japanese biomedical experts charged and sentenced at Soviet Russian Military Tribunal at Khabarovsk in l949 based on the Order of the Supreme Soviet of the USSR, 19th April 1943 (Moscow Publishing, 1950).

The human being could not be normal without ethical "Norms" against killing and prohibiting experimentation on humans without consent, and these are the elements of the reaffirmation of the traditional human "Norm" clearly mentioned in the decision of the Nuremberg Military court focusing on human dignity and autonomous decision making (Kimura, 1991).

II. Ethics of Time-lag

Those researchers who know well what's happening in Germany have got a detailed information about Nuremberg Court Decision. However, I think, the general public has been less familiar with these kinds of new developments of principles in biomedical ethics. In relating to this gap between public and professional understanding, one of the recent examples of investigation in the U.S. could be mentioned here.

The Report issued in 1995 by the Advisory Committee of Human Radiation Experiments in the U.S.A. states that " the actual impact of the Nuremberg Code on the biomedical community in the United States, both inside and outside of Government, is a matter of some disagreement". For some medical professionals in the U.S., the principle of "consent" has a rather extreme connotation as bioethical standard for clinical trials (ACHRE, 1995)

An eminent medical researcher, Dr. Henry Beecher, formerly at Harvard Medical School, expressed some sense of dissatisfaction of the medical profession with the idea of the Nuremberg Code. He mentioned that it is easy enough to say, that the subject should have sufficient knowledge and comprehension of the subject matter involved as to enable him to make an understanding and enlightened decision. Practically, this is often quite impossible". Dr. Beecher says also that “It is not my view that many rules can be laid down to govern experimentation in man. In most cases, these are more likely to do harm than good".

One of his colleagues, Dr. Joseph W. Gardella observed in 1961 that " The Nuremberg Code was conceived in reference to Nazi atrocities and was written for the specific purpose of preventing brutal excesses from being committed or excused in the name of science. The code, however admirable in its intent, and however suitable for the purpose for which it was conceived, is in our opinion not necessarily pertinent to or adequate for the conduct of medical research in the United States".

Faced with various revelations about human experimentation reported in the mass media in the late 1960's and 70's in the U.S. and elsewhere in the world, there were very drastic changes of ethical "Norms" in clinical settings including hospitals and biomedical research institutions. The Japanese Declaration of the rights of sick persons in 1970, accusations of a hasty and failed transplantation failure by a surgeon Dr. Wada, AHA's patients' Bill of Rights in 1972, the National Research Act of 1974 mandating" Institutional Review Boards" are obvious results of growing acceptance of patients' involvement in medical decision making and commitment to the "Informed Consent" process.

The confirmed legal precedents particularly in the U.S. were also causing great effects in international medical research community giving enormous influence in supporting these institutional change of ethical "Norms" in clinical settings even though there were some "time lag" after the important event of the Nuremberg.

III. Ethics of Transcendence

The documents with full medical data and some of the photos are accessible to be investigated by the general public at the Holocaust Museum in Washington D.C. The subjects of experimentation-- many of whom are unidentified --are dead, but the results of experimentation in signs, data, graph and statistics remain as living examples of the tragic violation of ethical "Norms".

With deep empathy and vivid imagination to be identified with the experimented in these photos, I feel my strong sense of moral responsibility to advocate the necessity for ethical "Norms" in the field of biomedical and clinical settings.

"Nuremberg" is still our starting point to recognize the lack of "Norms" in the past, and our continuous effort to ensure autonomy and informed consent in the present and future. Systematic and institutional efforts are a necessity for protecting human dignity and fundamental rights of the person in sickness.

The admission of wrongdoing by an entire professional group is, I think at least, a positive start in order to not repeat similar mistakes in the future.

We have heard that with many agonies and great regrets, the German medical community has gone through this hard process in organizing a special exhibition in 1989 in Berlin on the theme of The Value of Human Being: medicine in Germany 1918-45. This exhibition was also held at Kanagawa University in Japan. By doing this, some elements of public accountability in the medical profession were regained; the common understanding between lay public and medical profession which is now totally different identity then existed under the Nazi regime. On the other hand, in Japan, the issues continue to be obscured and hidden. There have been no serious and official statements made by any biomedical professional body or group. Only very recently, the Japanese citizen's group investigating this matter of biomedical human experimentation focusing on Unit 731 has been organizing the special exhibition around the nation that caught the attention of the mass media.

In the process of investigating and tracing the work of Unit 731, we have recognized the continuation of blood research and its application technology were utilized in one of the pharmaceutical corporation in Japan, Midori-Jyuji. Its late president was a former staff member of Unit 731. The company was producing blood supply by using imported material for the hemophiliacs without testing for HIV which caused around 2000 HIV infected patients which some of them died of AIDS. All the necessary information was bared to the public and now the corporations and the Ministry of Health and Welfare officially admitted the total failure of blood supply policy in the beginning of the1980s. All of these mistakes were just recently opened to the public and this has shown the typical example of attitudes of medical experts and bureaucrats who were not admitting any wrongdoing until last moment. It is the responsibility of the Japanese public to level up the professional ethical standard from the people’s point of view using more political pressure.

The Japanese medical crime of the human vivisection cases in China and Japan are less talked about, and do not receive enough public attention. In writing fiction based on this fact, one eminent contemporary author, Shusaku Endo, in his novel titled as " Sea and Poison" dealing with the medical atrocity of vivisection cases on captured American

POWs at Kyushu University Medical School during W.W.II, asks the question of " Absolute ethical principle" transcendent from "Time" and place. The answer given by one of the members of the medical team who was going to be involved in this horrifying inhuman vivisection, was saying that there are no transcendent values and all questions are relevant to the context.

The meaning of Mr. Endo's story is very clear. There should be a " Norm" that creates a boundary, which any human being could not step out from in the realm of mutual respect for dignity and rights of persons. Mr. Endo challenged the still existent mentality of Japanese medical experts who are so eager to accomplish research oriented studies in order to write a paper and publish without confronting complicated ethical issues.

Nuremberg Tribunal (Ex Parte Quirin, 317 U.S. I, 63 S.Ct.2 [1942]) clearly stated that " Individuals have international duties which transcend the national obligations of obedience imposed by the individual state. He who violates the law of war cannot obtain immunity while acting in pursuance of the authority of the State if the State in authorizing action moves outside its competence under international law."

The narrow egocentric, and nationalistic orientation of the medical experts could be seen in some cases to be at the expenses of scientific progress to save a life of patient.

International acceptance of bioethical principles is getting more and more important beyond cultural, historical and national differences among countries of the world today.

We have to avoid fostering any kind of milieu, such as war, or motivation to pursue innovative treatments leading into experimental "temptation" as biomedical and clinical scientists, and we have to not only deliver ourselves from that kind of opportunity but also create our sacred norms to engage and envisage new human hope in the true understanding of human dignity and human rights in our daily practice of medical services.

We should remember these medical tragedies of human experimentation in Japan, Germany, U.S. and elsewhere by taking vows of our constant efforts to live by bioethical norms of "autonomy", "informed consent" and "institutionalized system of open and public scrutiny" to be guaranteed in the development of biomedicine in clinical and research settings.

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Chapter 5. Aging and Bioethics Public Policy Making Process

A. Bioethics and Socio-Legal Aspects of the Elderly in Japan: With Special Reference to Life-Sustaining Technologies in the 1980s

In this section I shall analyze bioethical and socio-legal aspects of the elderly in Japan by focusing on the issues which life-sustaining technologies have created with respect to the growing number of elderly in Japan in the 1980s. As the Japanese situation is quite unique, a general overview is needed in order to appreciate the specific technical issues, which relate to the penultimate stage of life. Finally, I shall deal with the trends in the care of the elderly focusing on 1980s. The Japanese health care system and Japanese health care policy is now at a critical turning point where radical changes has happened in the 1980s and 1990s which relate to the dynamics and change of Bioethics public policy.

One of the most important issues relating to the long-term care will be dealt in the next section.

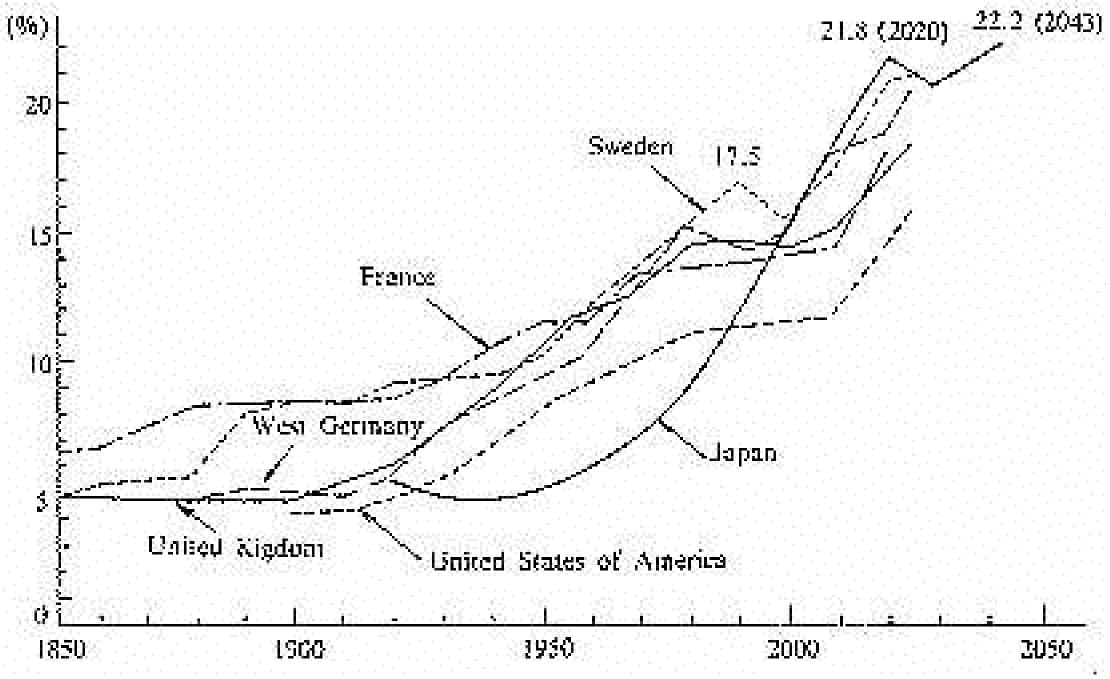
I. Background: The Elderly in Japan

A. The Uniqueness of the Aged Japanese Population

Japan is a small country. Its total territory is almost the same size as the state of

California, but only 21% of this area is inhabitable. The total population is about 118 million, which is just over half of the U.S. population (1982). The Japanese population is only 2.5% of the total world population and Japan's land space occupies only 0.28% of the world. Also noteworthy is the fact that Japan's economic activity is so high that it is consuming 10 times more energy than the U.S. (Health and Welfare Statistics Association, 1985) In this setting, Japan's elderly population is growing rapidly, even when compared with other industrially developed nations (see Chart I).

Chart I. Trend of the Ratio of the Aged (65 years and over) to the Total Population

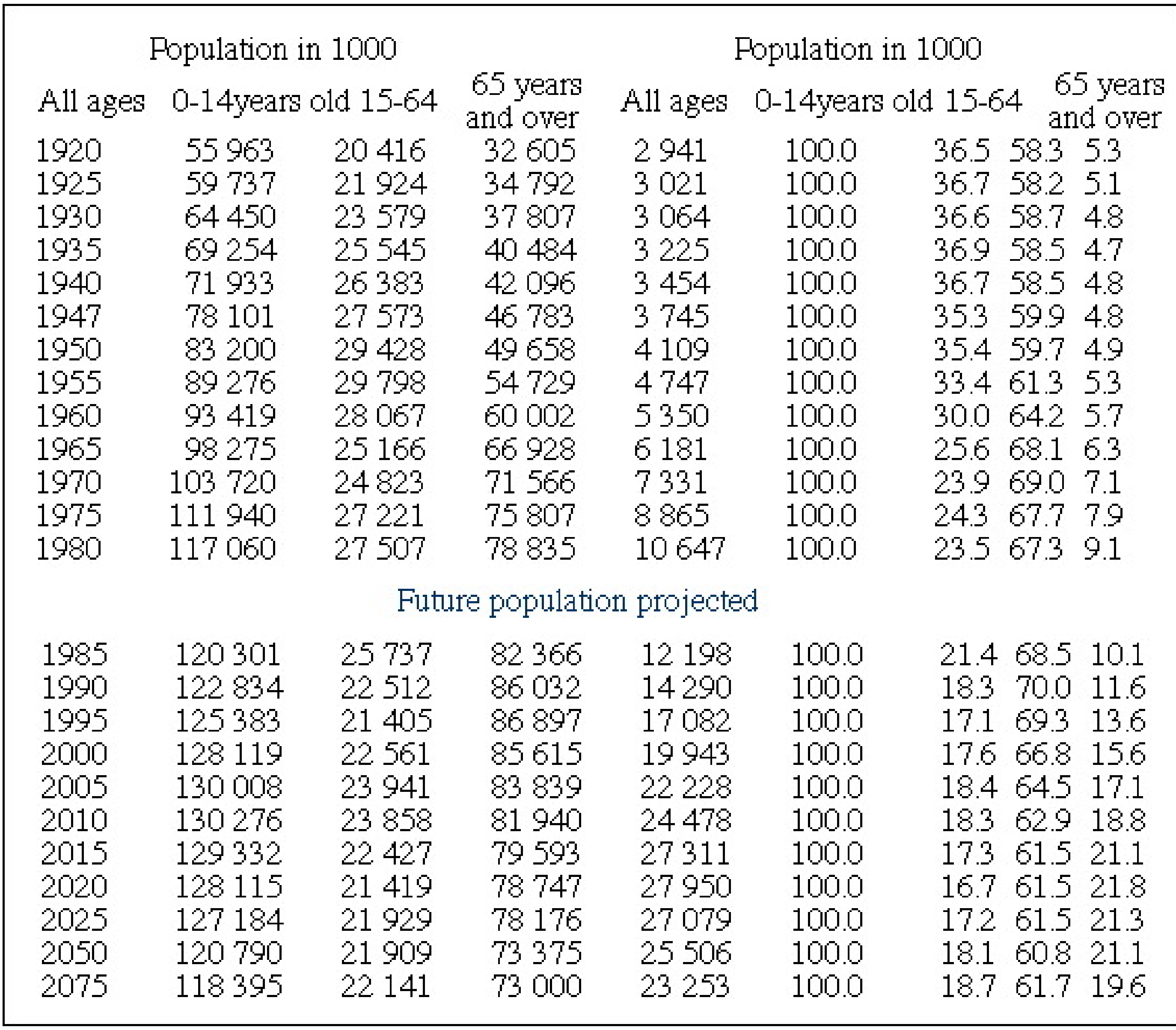


Source: For Japan, from Statistics Bureau, Prime Minister's Office and Population

Problems Research Institute of Ministry of Health and Welfare For other countries, from UN

In 1950, the number of those aged 65 and over was 4,155,000 only 4.9% of the total population. That is, during the 31 years since 1950, the number of those of 65 and over had increased 2.6 times, and the ratio of the aged to the total population had increased rapidly. This tendency is expected to continue, and it is estimated that at the beginning of the 21st century, the total number of those aged 65 and over will exceed 20,000,000, and account for more than 15% of the total population.

Table 1. Population-future population projected-percentage distribution by three broad age groups and sex, 1920-2075 Both sexes

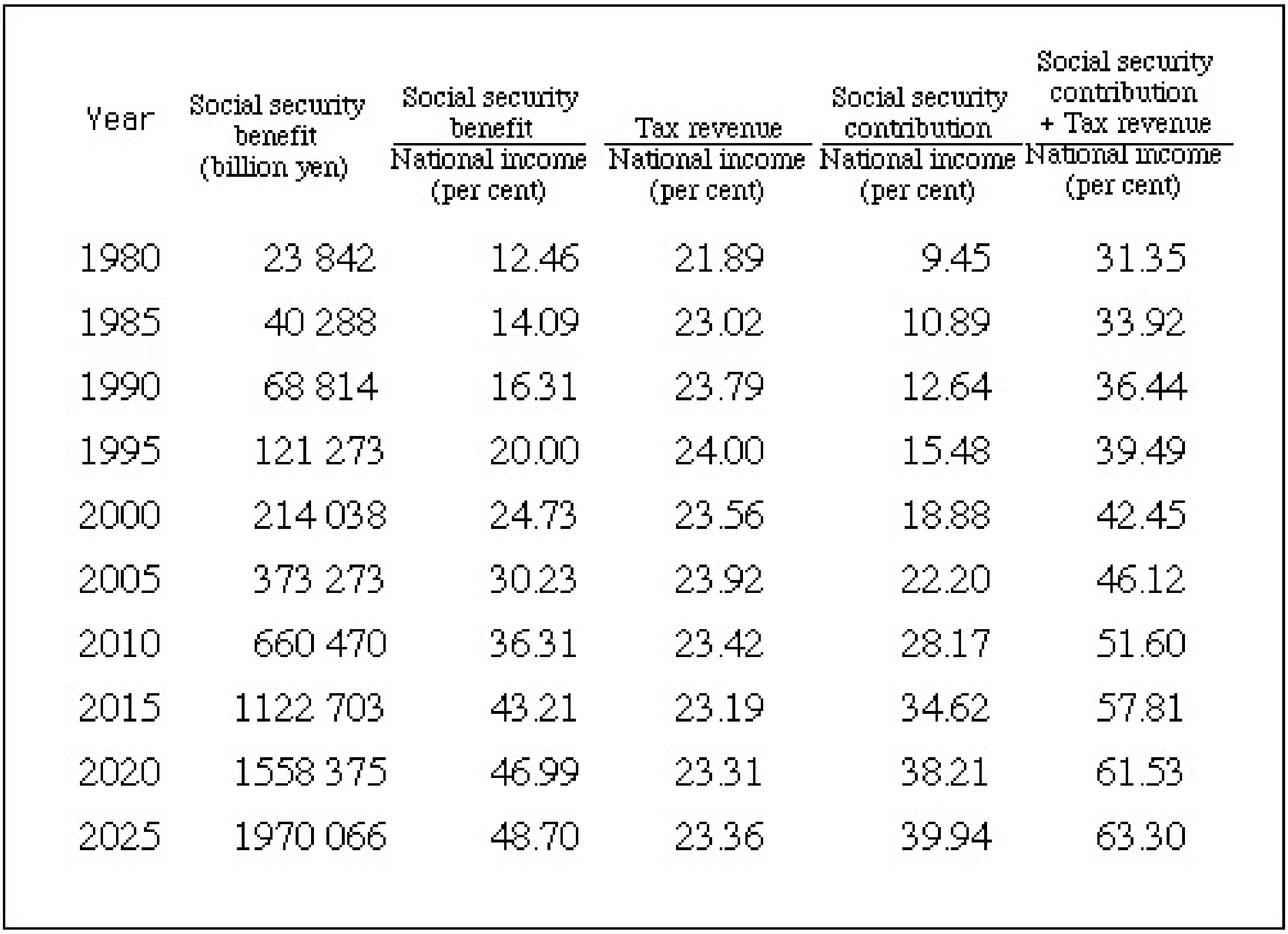


	Population in 1000				Population in 1000			
	All ages	0-14years old	15-64	65 years and over	All ages	0-14years old	15-64	65 years and over
1920	55 963	20 416	32 605	2 941	100.0	36.5	58.3	5.3
1925	59 737	21 924	34 792	3 021	100.0	36.7	58.2	5.1
1930	64 450	23 579	37 807	3 064	100.0	36.6	58.7	4.8
1935	69 254	25 545	40 484	3 225	100.0	36.9	58.5	4.7
1940	71 933	26 383	42 096	3 454	100.0	36.7	58.5	4.8
1947	78 101	27 573	46 783	3 745	100.0	35.3	59.9	4.8
1950	83 200	29 428	49 658	4 109	100.0	35.4	59.7	4.9
1955	89 276	29 798	54 729	4 747	100.0	33.4	61.3	5.3
1960	93 419	28 067	60 002	5 350	100.0	30.0	64.2	5.7
1965	98 275	25 166	66 928	6 181	100.0	25.6	68.1	6.3
1970	103 720	24 823	71 566	7 331	100.0	23.9	69.0	7.1
1975	111 940	27 221	75 807	8 865	100.0	24.3	67.7	7.9
1980	117 060	27 507	78 835	10 647	100.0	23.5	67.3	9.1
Future population projected								
1985	120 301	25 737	82 366	12 198	100.0	21.4	68.5	10.1
1990	122 834	22 512	86 032	14 290	100.0	18.3	70.0	11.6
1995	125 383	21 405	86 897	17 082	100.0	17.1	69.3	13.6
2000	128 119	22 561	85 615	19 943	100.0	17.6	66.8	15.6
2005	130 008	23 941	83 839	22 228	100.0	18.4	64.5	17.1
2010	130 276	23 858	81 940	24 478	100.0	18.3	62.9	18.8
2015	129 332	22 427	79 593	27 311	100.0	17.3	61.5	21.1
2020	128 115	21 419	78 747	27 950	100.0	16.7	61.5	21.8
2025	127 184	21 929	78 176	27 079	100.0	17.2	61.5	21.3
2050	120 790	21 909	73 375	25 506	100.0	18.1	60.8	21.1
2075	118 395	22 141	73 000	23 253	100.0	18.7	61.7	19.6

Note; * Population census 1920-1980 * Excluding Okinawa-ken for 1947-1970

Sources: "Population estimates of Japan", "1970 Population census of Japan, "1975 Population census of Japan", "1980 Population census of Japan", Statistics Bureau, Prime Minister's Office. Institute of Population Problems, MHW "Future population projected for Japan by sex and age for 1980-2080 Prepared in November 1981" Medium projections of future population as of October 1 of the year stated prepared as of November 1981

Table 2. Future changes in selected social security-related indicators, 1980-2025



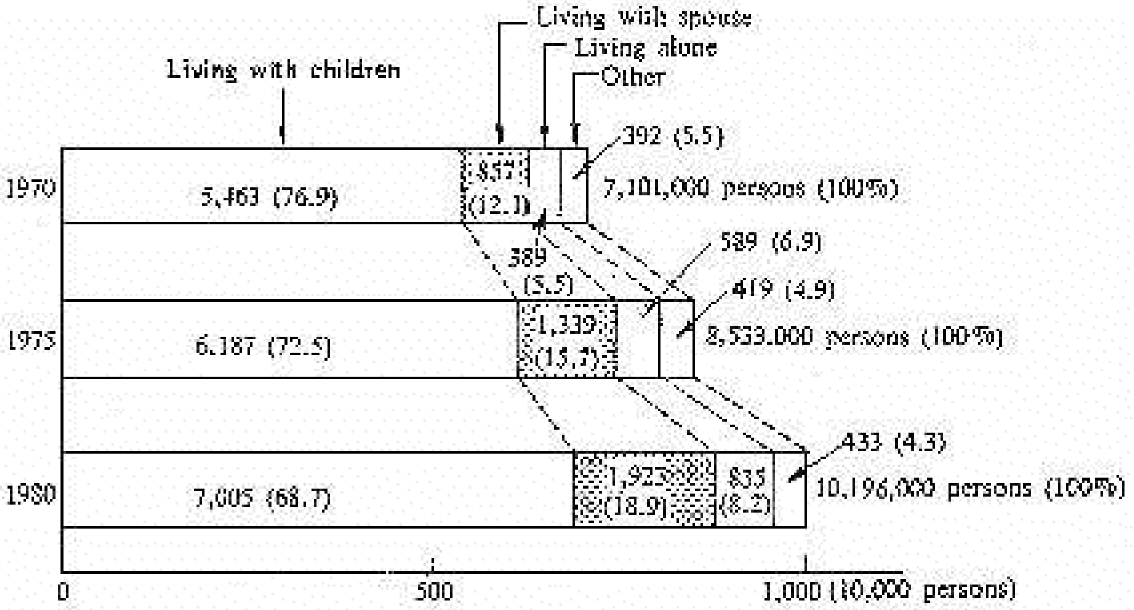
Year	Social security benefit (billion yen)	Social security benefit / National income (per cent)	Tax revenue / National income (per cent)	Social security contribution / National income (per cent)	Social security contribution + Tax revenue / National income (per cent)
1980	23 842	12.46	21.89	9.45	31.35
1985	40 288	14.09	23.02	10.89	33.92
1990	68 814	16.31	23.79	12.64	36.44
1995	121 273	20.00	24.00	15.48	39.49
2000	214 038	24.73	23.56	18.88	42.45
2005	373 273	30.23	23.92	22.20	46.12
2010	660 470	36.31	23.42	28.17	51.60
2015	1122 703	43.21	23.19	34.62	57.81
2020	1558 375	46.99	23.31	38.21	61.53
2025	1970 066	48.70	23.36	39.94	63.30

Source: Ogawa, N., Population in Japan: Ageing of the Population, NPRI Reprint Series, No. 13, Population Research Institute, Nihon Univ., Tokyo (1984), p. 15.

The birth rate in Japan has been slightly decreasing since the 1920s. Since the end of World War II, both birth and death rates have been rapidly decreasing. In 1955, the elderly (over 65 years old) composed 5.3% of the total Japanese population; 7.1% in 1970; 10.1% in 1985 (see Table 1). The second unique fact about Japan's elderly population is the high number of persons who live with one of their married children, usually the eldest son. Even though this traditional life style is changing rapidly, many households contain three generations, particularly in rural areas (see Chart II). Thirdly, because the "aging process" and "old age" are to be respected, Japan celebrates a unique national holiday every September 15th - "Respect-for-the-Elderly Day". This began in 1966. "Respect-for-the-Elderly Day" (Keirô-no-Hi in Japanese) came about, according to some cynical critics, due to the lack of such an attitude in Japan's rapidly changing society (Yoshizawa, 1992). However, the Japanese believe respect remains of prime value even among the young generations as is reflected in their language and social behavior as members in three-generation families.

Because of the vitality of these kinds of social values, the elderly themselves view their future happily as one in a peaceful family setting, playing with the grandchildren and ending their lives surrounded by their offspring within their home-setting and in their own community. However, a trend toward an independent life style (rather than security within family dependency), lack of housing in urban areas in order to accommodate elderly parents, economic motivation for the elderly to continue to work as long as possible (even after retirement), and rapidly changing social values that erode the traditional life style, all cause hardship on the aged.

Chart II. Living Pattern of Persons 65 Years and Over



Source: Statistics Bureau, Prime Minister's Office

Note: Both actual number and proportion are those of ordinary households, not including quasi-households.

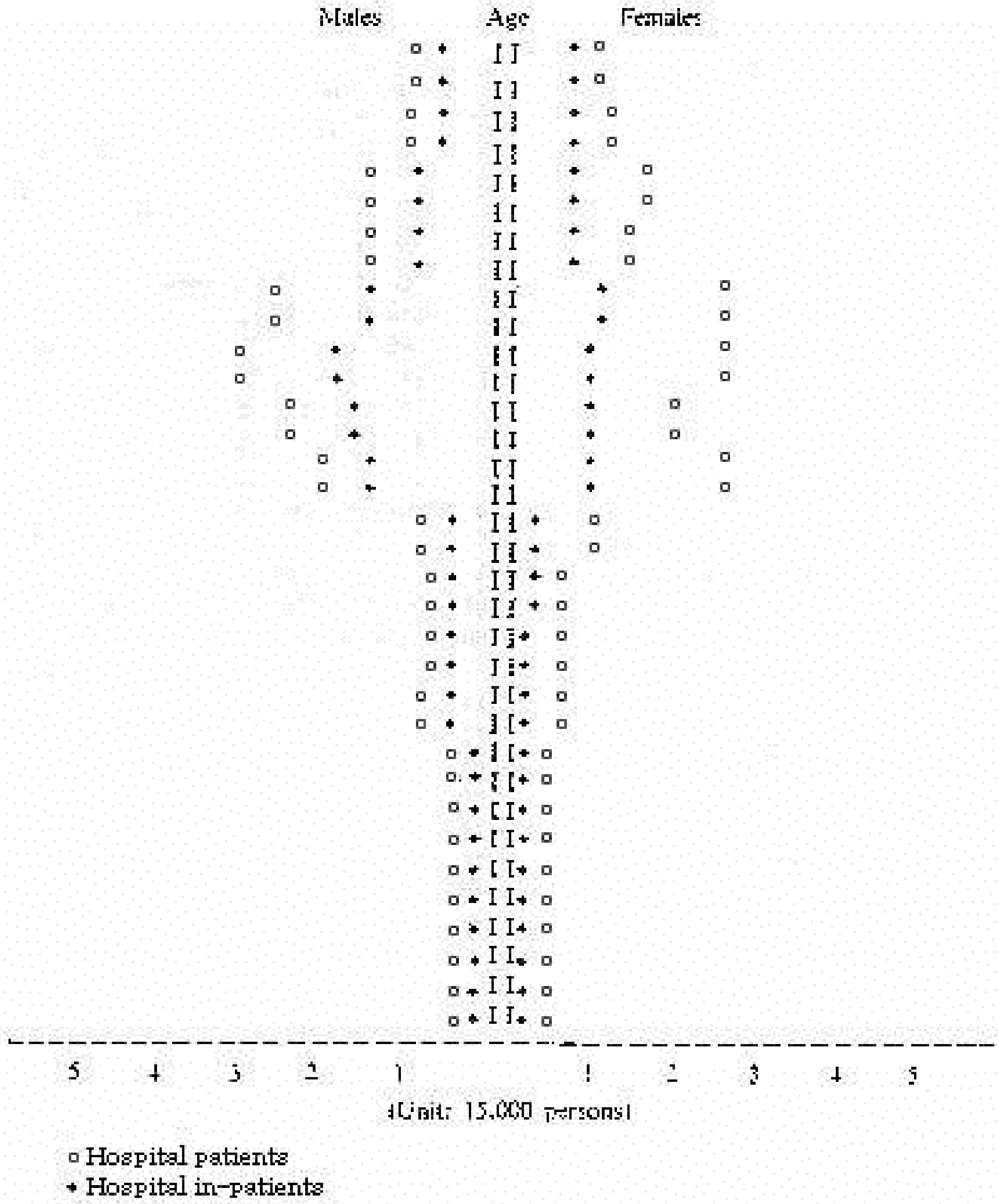
B. Health of the Elderly in Japan

In 1891, the average longevity of the Japanese male was 42.8 years, and 44.3 years for the female. In the 1950s, the longevity for both sexes rose to 60 years and above. In 1984, life expectancy for women was 80.18 years, and 74.54 for males (Ministry of Health and Welfare, 1985). Today, Japan has the highest average life expectancy in the world. Extended average life expectancy, very low infant mortality rate, a decrease in deaths caused by infection, a higher living standard, and the establishment of various public health programs throughout Japan, have made an enormous contribution to the health of the aged Japanese. However, so-called "geriatric diseases" have increased very significantly - from 46% in 1960 to 63% in 1983. Both Great Britain and the U.S. have also experienced an increase in "geriatric diseases" (the most important of these are cardiac disease, high blood pressure, cerebral apoplexy, and cancer), and the death rate has increased very gradually in 60% and over. For many years, in Japan, cerebral apoplexy has been the number one cause of death for the aged, but this has been decreasing since 1970; today cancer has become the major cause of death, followed by apoplexy. (The death rate from cancer is 148.3 per 100 thousand; the death rate from apoplexy is 122.8 per 100 thousand.)

Before 1960, the Japanese elderly usually died at home. In Japan, a census questionnaire included items relating to the place of death; according to this survey, in 1955 only 16.5% died in an institutional setting (e.g., hospitals or nursing homes). The situation has been changing rapidly, and in 1975 over 50% died in institutional settings; 63.1% in 1983. These changes are also due to the increasing accessibility of health care for the elderly became almost cost free. According to this data, the percentage of elderly who still die at home is relatively high compared with previous generations. Statistics on causes of death at home reveal the following: 1) rosui (naturally caused "senility" due to old age)=83.9%; 2) cardiac disease=43.0%; 3) cerebrovascular related disease=41.6%; 4) pneumonia and bronchitis=34.1% (Nakamura, 1985).

It is projected that health care costs for the elderly, if recent trends continue (1978-1979), will increase enormously during the period 1980-2025 (see Table 2). The growth pattern of the number of hospital patients per day and that of the number of in-patients per day are described by age and sex for two different years, one in 1980 and the other in 2025 (see Chart III and IV). These computerized charts indicate that the number of aged hospital patients and in-patients will increase enormously in the 21st century when the aging of the population dramatically accelerates. The greatest demand for hospital and clinic services will appear around the year 2020 (see Table 3), if present trends continue.

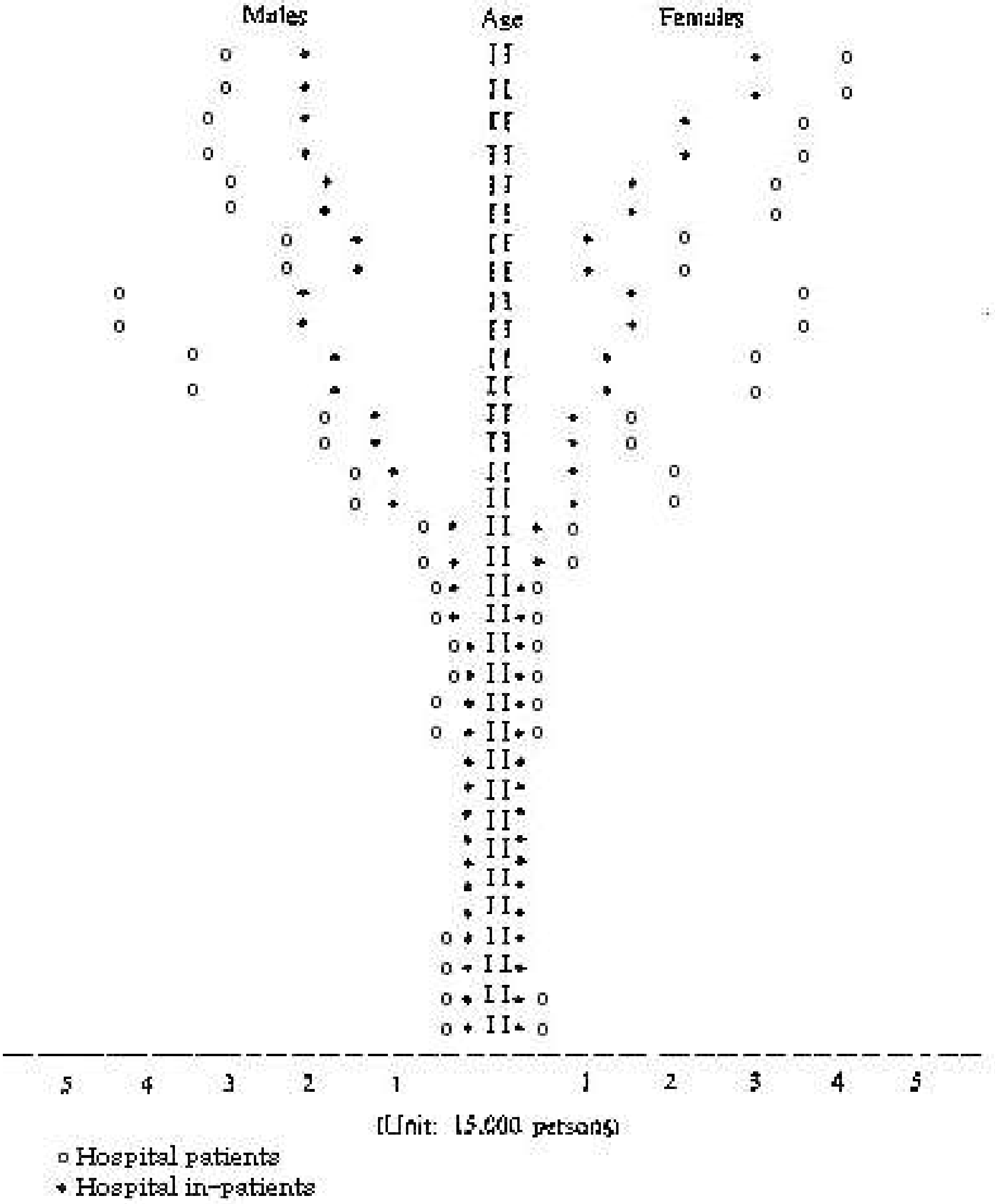
Chart III. Estimated number of hospital patients and in-patients by age and sex per day in 1980



Source: Ogawa, N., Population in Japan: Aging of the Population, NPRI

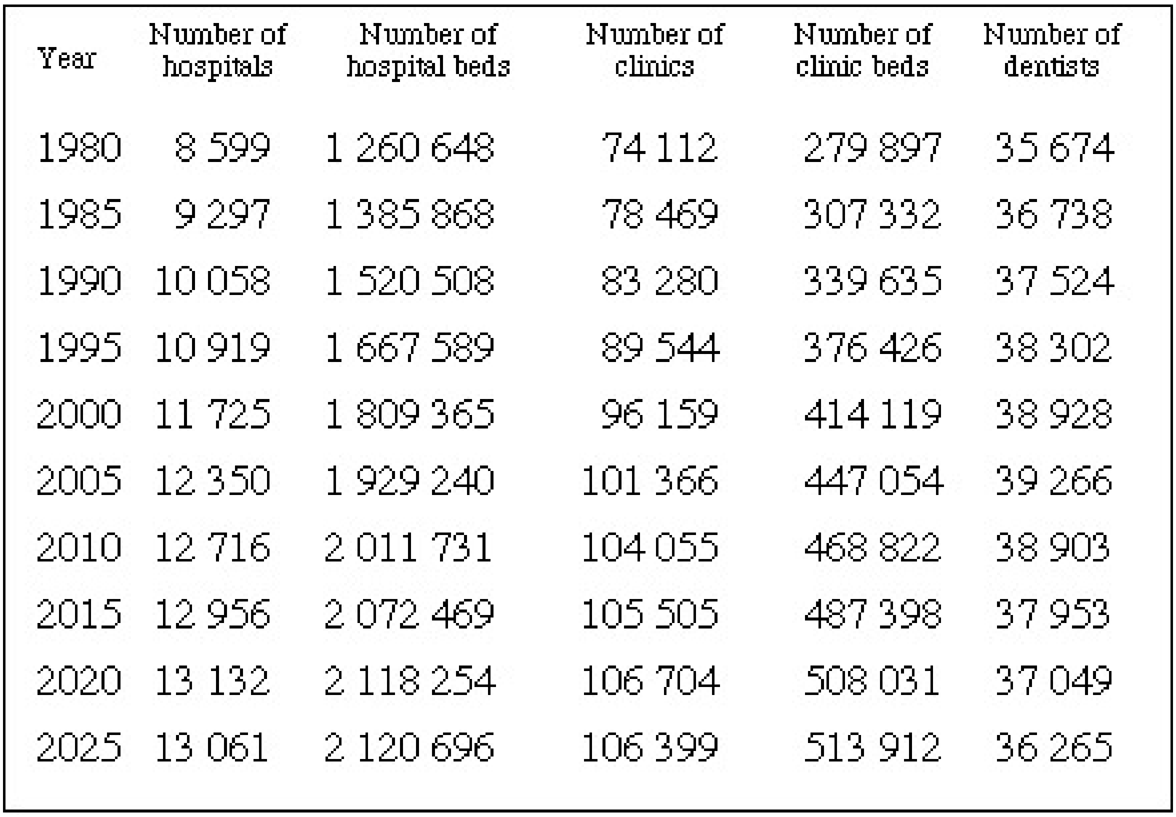
Reprint Series, No. 13, Population Research Institute, Nihon Univ., Tokyo (1984), p. 16.

Chart IV. Estimated number of hospital patients and in-patients by age and sex per day in 2025



Source: Ogawa, N., Population in Japan: Aging of the Population, NPRI Reprint Series, No. 13, Population Research Institute, Nihon Univ., Tokyo (1984), p. 17.

Table 3. Changes in medical services required per day, 1980-2025



Year	Number of hospitals	Number of hospital beds	Number of clinics	Number of clinic beds	Number of dentists
1980	8 599	1 260 648	74 112	279 897	35 674
1985	9 297	1 385 868	78 469	307 332	36 738
1990	10 058	1 520 508	83 280	339 635	37 524
1995	10 919	1 667 589	89 544	376 426	38 302
2000	11 725	1 809 365	96 159	414 119	38 928
2005	12 350	1 929 240	101 366	447 054	39 266
2010	12 716	2 011 731	104 055	468 822	38 903
2015	12 956	2 072 469	105 505	487 398	37 953
2020	13 132	2 118 254	106 704	508 031	37 049
2025	13 061	2 120 696	106 399	513 912	36 265

Source: Ogawa, N., Population in Japan: Ageing of the Population, NPRI Reprint Series, No. 13, Population Research Institute, Nihon Univ., Tokyo (1984), p. 15.

II. Cultural, Bioethical, and Legal Aspects of Treating the Aged

It seems that some physicians still hold onto rather traditional notions of "death criteria", as does the Japanese lay public. According to statistical data on the issue of "brain death criteria" surveyed in 1985, the situation is changing rapidly. Physicians tend to avoid "malpractice" suits or conflicts with the family members of dying patients who accuse them of ceasing treatment before the patient's end of life. One physician regretfully mentioned his own experience of having provided long hours of explanation to family members of a dead patient who accused the attending physician of misconduct (Okayasu, 1983).

There is now a trend to diagnose the death of patients by applying total "brain death criteria" as the accepted standard and thus to cease treatment when this condition arises (Ministry of Health and Welfare, 1985).

The moral, financial, and social aspects of "brain dead" patients have become a very critical problem in Japan. If the family members do not agree with the physician's judgment that the patient is dead, all treatment, including hydration and nutritional support, will be continued. It usually takes three to five days and at the most two weeks after the physician's judgment for the family members to agree that the patient is dead on the basis of "brain criteria" (Ministry of Health and Welfare, 1985).

In many cases almost all Japanese family members agree that aggressive and positive intervention to support the patient's life is a sacred obligation of the society. Thus, faced with the reality of continuous and expensive life support of unconscious, bedridden elderly patients, many serious problems arise.

Japanese physicians educated to defend paternalistic Confucian ideology of medical morality (known as "Jin-Jitsu ") usually think of themselves as final judges in decisions to provide treatment or to withdraw or withhold it. A patient's autonomy and rights are not yet well established values as is the case in the U.S. All the information relating to patients is not necessarily given to the patients themselves, or to their families. "Right of treatment" by physician is an established principle and is recognized by law; the patient's obedience is expected as part of his tacit agreement with his physician. However, there is a trend toward more open, informed, and patient-centered approaches, although change is slow in coming (Kimura, 1981).

So-called DNR orders (do not resuscitate) are not officially accepted among medical professionals even though there has been some agreement to employ DNR coding in each medical professional group which work in the same clinic and hospital setting (Okada, 1985). Application of DNR orders differs among physicians.

A. Foregoing Treatment in Japan: The Legal Problems

There are three unique yet common phenomena among the Japanese which relate to end-stage medical treatment, particularly in the case of terminally ill patients: 1) not telling the truth because of fear of increasing the patient's despair; 2) right to treat which is strongly confirmed in legal cases; and 3) medico-technological interventions up to the last moment of a patient's death; this is expected to be provided and every effort must be made by the medical team (Hara and Chihara, 1983).

Though this situation is changing gradually, many people still think that the patient's obedience to his physician is mandatory. The patient's exercise of his autonomy is not possible in the Japanese medical setting; even the notion of "informed consent" has not yet become a well-established principle in Japanese medicine (Inagaki, 1985).

Due to the dehumanizing process of recent medical services in Japan, and because of the lack of communication between medical staff and patients over treatment decisions and the use of medical treatment in prescribing medicine and surgical operation (not to mention increasing misconduct of some medical professionals) (Nakai, 1979), malpractice suits are now increasing in number, though the total number of litigations is quite small compared to the U.S. There were approximately 1,400 malpractice suits in Japan by November 1984 (According to the data by the Supreme Court, the medical malpractice suits now in pending are 1,329 cases in the year 1984 and since 1974, there have been around 250 cases in average in each year till 1984). The Japanese people prefer to resolve disputes out of court since medical problems are not usually remedied by resource to legal solutions. The special resolution called "Jidan " (private settlement) is very common by the arrangement of the persons concerned together with medical professional belonging to each local medical association. "Wakai " (reconcilement) and "Chôtei " (conciliation) are also possible in several cases (Nakai, 1979; Kawashima, 1963; Kojima and Taniguchi, 1978).

Actually, almost all patients in Japan are given an opportunity to sign a document at the time of admittance to the hospital usually for a surgical operation, which says "no complaint whatever happens to patients themselves (Suzuki, The Consent Form for Surgical Operation and Patients' Rights)". This is only a matter of formality, according to hospital administrators; however, many patients believe that this has some legal binding power over patients. But appeal to this has been declared void when set forth to justify malpractice litigation and compensation.

The "living will" has not been accepted among the Japanese public, even though the Japanese Euthanasia Association has been active since the 1960s, and has changed its official name - since 1983 it is the Japanese Society for the Right to Die with Dignity. This organization is affiliated with the World Federation of Right to Die Societies and in 1976 organized the first International Conference on Euthanasia in Tokyo, Japan (Fujita, 1980).

There is also a different type of association, which claims the right not to be treated. The official name of this association is the "Association for the Rejection of Medical Treatment (Fujita, 1980)". Even though a member of each organization holds membership which is recognized at the time of an accident or some emergency situation, this person presumably would be treated because this attitude is the physician's professional calling according to their ethical and legal obligation provided by law (Fujita, 1980).

There is no "ethical" or "critical care" committee in Japan, which would provide medical services, or assistance in clinical and moral "decision-making". Physicians are the decision makers in almost all cases, even though the patient's family members would be given some information and given an opportunity to state their opinions (Nishida, 1982). "Persuasive communication" from the side of the physician is quite common, especially when the case is serious. This is an expression of the traditional paternalistic approach by the physician to the patient; this attitude will in all likelihood prevail in the future (Nishida, Sakamoto and Sakanoue, 1983).

A positive attitude of Japanese physicians is found in their strong sense of commitment to their patients and family members; this includes concern for the patient's and family's daily life as well as participating in the funeral ceremony. In some cases this is an expression of professional responsibility considered in wider perspective. It should also be mentioned that the Japanese Health and Insurance System which is controlled by the government includes the prescribing of drugs, thus the over-prescription of drugs, unnecessary surgical operations, and futile efforts to prolong life regardless of the terminal situation of the patient (Hara, 1983). Patients as well as patients' family members might themselves have caused these trends by placing too much emphasis on the dependency and respect for the medical professional to whom many people are reflexively obedient.

For more than 1,000 years, in the Japanese culture, medical and health care was regarded as "Jinjitsu ". "Jin " signals human compassion and love, and "Jyutsu " is art. According to Confucian moral teaching, medical practice should be "art of Jin" (which first appeared in print in 982 A.D. in the oldest existing Japanese Medical Encyclopedia of 30 volumes. The Japanese medical profession has integrated some key religious ideas from Shintoism - purifying the body by washing; from Buddhism - giving mercy to the sick and aged; and from Confucian ethical teaching - to practice the action of love (Kaibara, 1714; Fujikawa, 1941).

Traditional Japanese and Chinese medicine have been well accepted as part of daily health practice: acupuncture, moxibustion, and herb medicine are all based on a long tradition and employed to alleviate particular diseases, such as stomach pain and headaches. In the context of feudalistic Japanese society, respect for the aged as well as respect for those who have extraordinary knowledge and wisdom in the medical arts was presumed. In many cases physicians were regarded as intellectuals who were literate in the Japanese and Chinese classics and the teaching of Confucius.

However, this has been rapidly changing in recent years due to the acceptance of Western medical practice in the mid-19th century. One result has been the government initiated modernization and socialization of Japanese medical services.

There has been a strong undercurrent of traditional Japanese and Chinese medicine even during this recent process of Japanese medical modernization, particularly since the beginning of the 1970s. We today are witnessing a revival of this traditional medicine. It is also evident that Japan's elderly people have a tendency to consult traditional medical professionals for alternative healing treatments.[25] In order to practice Eastern medicine government regulations require the practitioner to have a professional license.

III. Financing Health Care and the Right to Treatment

Japanese Medical and Health Care Legislation for the Elderly : 1963 to 1985

The Law for the Elderly's Welfare was promulgated in 1963. In Article 2 of this law, the fundamental aim of the legislation was stated: "The elders shall be loved and respected as those who have contributed for many years to the progress and development of society, and healthy and peaceful life shall be guaranteed." Article 3 (2) says that in accordance with their desire and ability, elders shall be given opportunity to engage in appropriate work and to participate in other social activities.

In 1961, before the enactment of this law, Japan had established a system of national health and medical benefits for all of its people, regardless of the premium paid (based on income) or financial situation. The original pattern of this plan, under the name of Health Insurance Law, was promulgated in 1922, and had been enforced since 1927. In 1938, a National Health Insurance Law was enacted. Due to the unusual situation during and after the war, however, the government could not implement this law until 1961. The welfare, health, and medical insurance policy became part of the political agenda around the end of the 1950s, and was expanded during the 1960s following Japan's economic growth in world trade (Kimura, 1985).

In Article 25, the Japanese Constitution of 1946 specifies the following responsibility of the State: "All people shall have the right to maintain the minimum standards of wholesome and cultural living." In all parts of life, the State shall endeavor to promote and extend social welfare, security and the public's health. Usually, this provision is regarded as state principle, and people's claim to these rights is guaranteed through the enactment of particular positive laws, which relate to welfare, health, and medicine. The 1963 Law for the Elderly's Welfare was a positive law for the implementation of Article 25, as well as of Article 13 which provides that: "All of the people shall be respected as individuals. Their right to life, liberty, and the pursuit of happiness shall, to the extent that it does not interfere with the public welfare, be the supreme consideration in legislation and in other governmental affairs."

One of the most radical policies for the elderly relates to virtually cost-free medical and health care, which was officially accepted by the Japanese government in 1972, following the success of excellent free medicine and health programs of several local governments. This was one of the most unique welfare accomplishments in recent Japanese history (Kimura, 1985).

In the framework of Confucian ethical principles, the medical profession maintained its strong paternalistic values even after the radical reformation of medical education from the traditional Chinese system to a modern Western one. In pre-war Japan, medical benefits and health services were not regarded as a "right" of the people (Hino, 1984).

One of the earliest movements toward "free health and medical services for the elderly" occurred in the northern mountain province - Iwate Prefecture. Formerly, this region was known as a poor area, with no resident physicians in full service to provide medical and health care. In 1949, in the village of Higoroichi (Kasen-gun) an integrated policy for insurance and medical services was initiated by the mayor, Suzuki; it was expanded to 24 local governments in the prefecture by 1952. The policy was almost abolished around 1955, however.

In the same prefecture, the Sawauchi village started a regional health and medical service system, with the full cooperation of the people, physicians, the medical organization, and the Administration. This is now well known as the "Sawauchi System (Kikuchi, 1968)". In 1960, for the first time in the nation, a totally free program was available for health and medical services for those over 65 and for newborns and infants. In 1961, those aged 60 or older could apply for this program.

The Sawauchi System, initiated by a local people's movement, had a powerful impact on local communities throughout Japan. By the end of 1962, 69 local communities had established a similar system. In 1969, the Tokyo Municipal Government also decided to provide a similar service for people over 70. More significantly, the success of the Sawauchi System led directly to the government's amendment to the Law for the Elderly's Welfare and it endorsed free health and medical care for people over 70 (Hino, 1984).

Until 1982, therefore, there were continuous improvements in the provision of health care for the elderly. The Japanese Constitution, the 1963 Law for the Elderly's Welfare, the amendment of 1972 that provided free medical care for the elderly, and the existence of social insurance, as well as national health system - all were the embodiment of the people's "right to health and medical care".

Social movements in local communities, together with strong endorsements and medical service staffs, were the initial forces behind realizing these rights in the context of Japanese state policy. However, pressure arose to resist socialization of health and medical care, for financial reasons. The equal distribution of health and medical care resources became a powerful item on the political agenda in the 1980s (Hino, 1984).

The Law for the Health of Elderly aims to improve national health and to promote the welfare of the elderly, by implementing a policy incorporating prevention, treatment, and rehabilitation for the aged. This legislation is regarded as one of the positive laws, which fulfills the "right to health care and social security" of the Constitution of 1946. Just as with the Law for the Elderly's Welfare, however, Article 2 (2) of the new law mentions that "the people shall be given the opportunities to receive appropriate health services in order to enhance the health of the aged." There is no positive statement about the "right" of people, including the aged, to state or local government health and medical services. Paternalistic and bureaucratic attitudes can be traced very easily in the legislative process regarding the wording of laws relating to the welfare of the elderly.

According to Article 12 of this law, the following health services for the elderly are provided:

1. Health notebooks, 25
2. Health education,
3. Health consultation,
4. Health examination,

5. Medical services,

6. Rehabilitation therapy,

7. Visits to provide home-care for patients at home, and

8. Other necessary services in accordance with particular ordinances.

These medical services are provided by the local government for those 70 or older, and for those between 65 and 70 who have designated disabilities (according to the Ministry's ordinance and after confirmation by the local authority), and are covered by medical care insurance; public and insurer contributions are used as resources. In the case of outpatient treatment, the cost sharing is 400 yen (approximately $1.60) per month, while the in-patient elderly have to pay 300 yen ($1.20) per day for the first two months (or for the first 50 days for insured persons). The other health services specified in this law are provided for those 40 or older and are arranged at the local level.

There are some problems related to the enforcement of this law. First, not all local governments have a "cost-sharing health and medical care policy for the aged". In 1983, there were still 26 local governments in 9 prefectures that had their "free" health and medical policy for the aged, which was contrary to policy of the central government. The sanction against these local governments took the form of cutting government support for the programs at the local level (Hino, 1984).

The second problem arises with the special limit regarding the elderly's medical costs. Medical treatment and hospital-related expenses have been limited to certain lengths of stay in the hospital. These gradual stages or limits are too rigid and too unreasonable for some patients with chronic, serious conditions.[26] The amount of out-of-pocket expenses for the continuation of such medical care in the future will surely increase (Hino, 1984).

The third problem: the extremely low funding allowed for visiting services to provide home-care to patients, especially the elderly. It was certainly admirable that such a fee was approved for the first time for home-care patients in the community, but again, the time limit for this service affects the quality of care. The elderly are not encouraged to stay in the hospital for long periods of treatment; and furthermore, after they are discharged, they are not given continuous care (Ogishima, 1984).

IV. Technological Issues Related to Geriatric Care of the Critically and Terminally Ill Elderly

Japan's medical practice reflects the values of Japanese society, and is affected by historical, moral, and religious traditions. Medical treatment is usually equally given to all the people according to the need and the urgency, regardless of age, sex, and source of payment. The entire Japanese population is protected by National or government-regulated health insurance. The elderly are shown great respect because they have contributed so much to the society during their long lives. This is one reason which explains the provision of free medical care at the local and National level, and has been supported by public funding since 1983 to those who are over 70 years of age. (The Law for the Health of Elderly, 1983) Even though the idea of cost sharing by the elderly was introduced by amendment to this Law of 1983, the expenses accrued by the elderly are not too burdensome (according to the official statement of the Ministry of Health and Welfare, 1984). There are positive incentives to Japanese physicians who receive elderly patients, and the reimbursement for medical services fees is guaranteed by the National and/or local government-controlled health and medical insurance scheme.

A. End Stage Renal Disease (ESRD)

The most recent data relating to chronic haemo-dialysis treatment, published in 1984, shows an increasing number of patients in higher age groups. The average age of dialysis patients in 1983 was 51.9 for males and 52 years for females. In 1983, the oldest patient receiving dialysis treatment was 98 years old, and in addition, in the same year, 164 patients over 80 years of age began dialysis treatment (The Society for the Study of Artificial Dialysis, 1983).

There were 48 dialysis machines in 1966 and in 1983, 24,474 machines were working (with a maximum capacity to assist 68,813 patients). In 1968, there were only 215 dialysis patients in Japan, and in 1983 the number of patients was 53,017, about 246 times more than in 1968. In comparison to other countries, the number of dialysis patients is very high in Japan. There are 404.2 patients per million in Japan and 237.0 in the U.S.; 25.0 in Canada; 350.0 in Europe, respectively (per million population) (Sakai, 1984).

Because it is still unexplained why so many Japanese dialyzed, it may be that this technology is being used more than is necessary.

There are no criteria other than need in order to receive dialysis treatment in Japan. All those who need dialysis were totally compensated by one insurance scheme; they applied to all Japanese citizens until 1984. Amendments to the Health Insurance Law of

1984 require dialysis patients to pay partial costs of treatment, up to 10,000 yen (approximately U.S. 50 dollars per month). The rest is paid by the insurance scheme to which each patient belongs.

One of the reasons for the increase in use of dialysis machines is the comparatively easy access to dialysis centers that are readily accessible in Japan's major cities. A network is also provided for prefectures. Thus, a patient finds it possible to go to a center for dialysis treatment several times a week that is within a short distance from his or her home.

Dialysis treatment is also available at home. Only 132 persons (0.2% of total dialysis patients) were dialyzed at home as of December 1983. But this number of patients is now increasing given the use of the relatively new popularized method of Continuous Ambulatory Peritoneal Dialysis (CAPD). In 1985, 1,400 patients were using CAPD because of the official endorsement for insurance policies by the Ministry of Welfare and Health, and 800 patients were receiving this CAPD at home. CAPD use is much more convenient for many patients due to the simplified method of dialysis, less cost, and flexible application according to the working and life styles of individual patients (Sakai, 1984).

Because of this national insurance incentive, even though medical treatment fee by point for this CAPD is not enough according to some critics (consultation and advising fee for CAPD patients at home was decided at 1,500 fee points limited twice a month only; total amount per month would be around U.S. 160 dollars), this CAPD would be used more and more in Japan. There are now approximately 500 institutions (as of 1987) throughout Japan which offer CAPD patients' affiliation due to the notice issued by the Director of Medical Service Section of the Ministry of Welfare and Health (Medical Service Section's Notice, 1984).

Under the present scheme of health insurance, Japanese men and women, young and old, utilize opportunities for the treatment by dialysis at various regional centers. A very recent policy to provide home treatment of dialysis is the result of a policy shift from financially expensive hospital care to moderately inexpensive home care. However, in order to make home care more available to those who prefer to stay at home rather than remain in hospital, elderly patients need an effective support system which must include the establishment of a "visiting nurse" network; this began only recently with the endorsement of the Ministry of Health and Welfare. It applies to those patients who are under the care of medical institutions but who stay at home. The independent "visiting nurse" service cannot be reimbursed by the insurance policy under the central control of government (Sato, 1985).

On the other hand, from the point of view of the elderly's family, there is a kind of tendency to place elderly patients in hospital, since in hospital all treatment is provided by the national and local government. (Law for the Health of Elderly, 1983) It is convenient for the supporting family to have its elderly family members in hospital because here there is easy accessibility to regular medical treatment, lack of housing space for totally bedridden elderly, and inexpensive cost. In the case of elderly dialysis patients, one of the family members (usually a non-employed female family member) becomes extraordinarily busy bringing the patient back and forth three times a week, and additional time for the dialysis treatment. This is one of the reasons dialysis centers have many available beds for hospitalization which were in the past fully occupied.

There are very few cases wherein a family member of an 80-year-old kidney patient decides not to bring this person for treatment. According to a nurse in charge of dialysis, this is a very rare case. Generally speaking, Japanese family members who have elderly patients bring them in and ask what treatment should be done at the time. Later, they will be faced with continuous arrangements for treatment by dialysis. If there are no beds available under the government insurance plan, people will pay an additional amount to fill the gap between the cost of the insured bed and the private bed. This system is called "Sagaku Chôsei " - collecting payment for the gap in costs (Niki, 1985).

Kidney transplantation is available, but is not widely performed, due to the lack of available kidneys. Neocortical brain death criteria have not yet been accepted. However, in 1982, an advisory board on "life and ethics" was formed and attached to the Ministry of Health and Welfare; it is dealing with this issue of "brain death criteria" as one to be studied. There is also a special task force for determining "brain death"; it was established in 1983 as one of the advisory groups to the Ministry of Health and Welfare (Otani, 1985).

Due to the absence of an officially formulated policy - except for professional criteria established by the Japanese Society of Brain Wave Research (Committee on Brain Death) in 1974 - organ transplantation is proceeding rather slowly in order to avoid legal disputes over traditional notions of time of death (Yokoyama, 1984).

This lack of official policy had led to one of the unique phenomena in the Japanese situation, in which large numbers of organ donations (mainly kidneys) are from living human bodies (Neomorts). As of December 1982, the total number of kidney transplantations was 2,457, of which 1,949 were from living donors and 508 were from cadavers (Yokoyama, 1984).

There are now nine active kidney transplantation information centers in Japan on which 3,562 patients are registered as candidates for future kidney transplants. Retrieval searches were accomplished 84 times by May 1984, the opening date of this information system; 42,285 persons were registered as possible kidney donors, according to the data provided by the Association for the Promotion of Kidney Transplantation (The Society for the Study of Artificial Dialysis, 1983).

There have been several cases where kidneys were acquired from the U.S. due to the lack of available cadaver kidneys in Japan. In the case of two hospitals in Sendai City (Miyagi Prefecture in northern Japan), at Sendai Social Insurance Hospital and Tohoku University's 2nd Surgery Department, 33 cadaveric kidneys air-transported from the U.S.

were used for transplantation as of December 1983. Since 1981, kidney transplants using cadaveric kidneys have increased compared to preceding years. One reason for this increase was the special arrangement to acquire cadaveric kidneys from the U.S.; another reason is the changing attitude of the public (Sasaki, 1984).

However, there are large gaps between those who are waiting for kidney transplants and the actual transplants performed. Around 25-48% of the dialysis patients expressed their wish to have kidney transplants even though less than one percent of such transplants goes on annually (Sasaki, 1984).

B. Nutritional Support

Nutritional support for elderly patients is generally one of the most well provided life-sustaining technologies in Japan. Some serious problems relating to nutritional support are: 1) cases of terminally ill, elderly patients; 2) cases of prolonged unconsciousness; and 3) cases where patients reject nutritional support.

1. The situations are very different from case to case in providing nutrition and/or hydration to terminally ill patients. All of these treatments have received endorsement by the Ministry of Health and Welfare and count in computing medical fee points. Only

since early 1985 has nutrition support (by Central IV outside the hospital) been accepted as official medical treatment under the direction of physicians and operated by the patients themselves: 70 points (around U.S. 40 dollars) is counted for consultation and advising fee for this treatment (The Government Notice from the Director, Medical Service Section, Ministry of Health and Welfare, 18 Feb. 1985).

In the case of terminally ill cancer patients, symptomatic treatment, such as pain relief, should be done, while active and aggressive intervention, such as chemotherapy and radiation therapy, would be withheld. Because during this end stage of cancer both chemotherapy and radiation treatment usually cause side effects, and patients get weaker. IV nutrition support would also be undesired by many patients at this terminal stage. If "the Performance Status" is classified "under 3", all positive interventions would be regarded as more disadvantageous for the patient. The end-stage patient who is terminally ill and unconscious, should not be given aggressive medical intervention if it would only serve to prolong the dying process; this would violate the dignity of the patient as some physicians see it (Ishikawa, 1985).

Another physician, working in a pioneering Japanese "hospice", has mentioned that even the dying patient should receive nutritional support, including hydration, up to the last moment. Patients as well as family members who want to have the elderly patient live as long as possible should be given that opportunity, according to some physicians (Hara, 1983).

2. Patients suffering prolonged unconsciousness are usually given nutritional support regardless of age and sex, as cases in Number 1. There are various causes for these kinds of prolonged losses of consciousness; in many cases nutritional support would be given to these patients by naso-gastral tube, mouth, or IV. The nutritional support is given as part of the integrated treatment to the patient, but under the strict control of the medical care team.

3. Patients sometimes reject nutritional support by intentionally removing the naso-gastral tube or IV tubes. The rejection of any kind of medical treatment, knowing death will follow, is not common among Japanese patients, even though there now exists a patients' rights movement which claims patients are autonomous and have a right to reject treatment. Patients are expected to obey the physician and many health regulations reflect this paternalistic tradition. Unjustifiable rejection against the treatment given by

physicians is supposed to be reported to the local authorities, under the Law for the Health of Elderly (1983); Article 37 and 38 provide non-treatment and non-benefits for medical services in cases where patients act "maliciously" or intend criminal acts or where patients cause their own sickness or wounds due to misconduct like fighting and intoxication.

There are cases, such as the case of an elderly patient (83 years old, male), who was admitted to the ICU for treatment of shock caused by myocardial infarction and pulmonary edema. After one week of treatment, the patient had another shock, and then he requested that all treatment cease and he removed all life-support tubes himself. Because of his clear diagnosis of fibrosis of the lung and the difficulties of his recovery, following tracheotomy, the patient was discharged from hospital; he died of dyspnea at home three days later. In this case it took 38 days of painful and aggressive treatment, including nutritional support at the penultimate stage, thanks to various technological interventions. The physician in charge of this patient had serious reservations, and expressed his doubt regarding the value of this expensive and aggressive treatment (Aochi, 1985).

Public debates in Japan are now taking place on various issues related to bioethical problems. One of the most important issues is the need for a coherent public policy on "brain death" in the context of the gradually changing social values rooted in bio-technological achievements. The nutritional support technology should also be reexamined in terms of a patient's dignity and his right to medical treatment; it is a reasonable balance to the notion of patient's autonomy for final medical and ethical decision-making to have a peaceful dying process in more humane care environment without having aggressive, painful and extraordinarily expensive intervention.

C. Resuscitation

In the case of elderly, terminally ill cancer patients, there are rare cases where resuscitation is required. One of the reasons for resuscitation in Japan is the traditional attitude toward the dying patient who should be seen by his relatives at the moment of death. It is an important Japanese ceremonial event to have the closest persons at the bedside of a patient. So, in order to maintain this tradition, patients are resuscitated even though hopeless; sometimes this practice is accomplished with the ceremonial support of members of the medical and nursing hospital team.

According to a survey by the National Cancer Center of Japan, approximately 74% of dying patients had a resuscitation attempt (Kakikawa, 1985).

Age and sex have never been factors for deciding who should be resuscitated, whereas a complete diagnosis of a patient's medical status might reflect that the decision to resuscitate should be made with the patient's or family member's consent.

D. Ventilation

Mechanical ventilation is widely available in Japan. In many cases hospitals and nursing homes have the necessary equipment.

According to the amendment of a recent regulation issued by the Director of the Medical Service Section, Ministry of Health and Welfare, Government of Japan (Notice No. 11, 18 Feb. 1985), ambulatory oxygen use at home by patients was officially endorsed and should be counted in the medical practice fee for 700 points (U.S. 35 dollars).

This oxygen treatment would be given by the patients themselves, while at home, and mainly for those having chronic pulmonary problems but who are in rather stable condition when discharged from hospital. Physicians then should be responsible for giving particular directions for home treatment by patients, and hospitals should be prepared to have these patients rehospitalized in case of emergency.

Because of the acceptance of this home treatment as official medical practice, the cost for the treatment is covered by health insurance according to the proportion required by each insurance scheme (Ministry of Health and Welfare, 1985).

Ventilation machine treatment in the ICU is very common, and expenses are also covered by insurance.

A Critical Care Committee has not yet been formed in many medical service institutions, and generally speaking physicians who are in charge of a particular patient's care and treatment would decide what the medical treatment should be.

There are no common guidelines to be applied where ventilation treatment is in question.

E. Antibiotics

In Japan, chief causes of death have been drastically changing during the past ten years. Formerly, particularly before World War II, various infectious diseases were the common causes of death; now, various "geriatric diseases" are the chief causes of death

(Health and Welfare Statistics Association, 1985).

However, the causes of death in the elderly population, particularly at home, are called "Rôsui " which means the "senility" and "weakness" caused by old age. In this case, it is quite common to have infectious diseases weaken the patient's physical condition and lead to weakness and death. In this case, it is quite common to have infectious diseases weaken the patient's physical condition and lead to weakness and death.

So-called "influenza" combined with secondary types of pneumonia, are increasingly high among the elderly in recent years. This clearly reveals the very sharp contrast of the infant and the elderly mortality due to influenza and/or pneumonia (Health and Welfare Statistics Association, 1985).

The use of "antibiotics" is very common for the treatment of influenza and pneumonia. However, in order to avoid the negative reaction of the elderly patient, a very careful selection of "antibiotics" should be made. Sometimes the prescription for "antibiotics" will be construed as a preventive treatment against pneumonia. The elderly are often regarded as being a high-risk group; some have suggested the elderly be given an injection to immunize against influenza, but on a voluntary basis (Amano, 1985).

In the case of terminally ill cancer patients, the statistical data show that antibiotics are commonly used for symptomatic treatment. These data were gathered at the hospital of the National Cancer Center of Japan during six months between June and November 1982. Chemotherapy was given to 48.4% of the patients, and antibiotics were used in 75.5% of the cases. In most terminal patients, the positive intervention by the medical team for prolonging life has been going on frequently. Only 29% of the patients at this hospital with terminal cancer had symptomatic treatment rather than aggressive intervention (Mizuguchi and Hiraga, 1985).

All of these medical interventions require chemotherapy as well as surgical interventions and were done within one month of the patient's death. It is frequently necessary to refrain from positive and aggressive medical treatment if the patient's situation and symptoms do not bring about a reduction of pain or amelioration of the disease (Mizuguchi, 1985).

The Japanese are now facing both a radical change in traditional values, including attitudes toward health and rapid technological changes which call for everything possible to be applied in the clinical medical setting.

Technological interventions - such as life-sustaining technologies - now impact on other issues of economics, ethics, and public policy.

By emphasizing Japan's traditional value system and value of family and communal relationships, which more and more influence everyone's daily life, a new and fundamental shift in health and medical policy-making is taking place though initiated by government policy planners of the Ministry of Health and Welfare. Yet there is not enough public involvement. Elderly people are now expected to pay for increasing costs and to share as is not required by the recent amendment of the Law for the Health of Elderly. Those who are insured in Health Insurance Societies, under government control, are now obligated to pay 10% of the total cost of medical treatment, which had been free of charge since 1927 (Health Insurance Law) amended and enforced from 1st Oct. 1984). On the other hand, and in the name of cost containment goals, private patient incentives are now being introduced. Multinational health and medical industries, as well as large insurance corporations, are currently seeking to expand their market in Japan - a policy which is unprecedented (Hino, 1984).

This critical turning point in Japan's health policy requires the Japanese public to take a more active role, participating in open debate on these issues, in order to achieve a more secure and excellent level of health and medical services in Japan.

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B. Bioethical Issues of Long -term Care Policy in the Context of Long-term Care Insurance Law of 1997

On December 9, 1997, an epoch making new law, Kaigo hoken ho [Long-term Care Insurance Law], was passed by the Japanese Diet. Some media reports also refer to this new law as kôteki [i.e., public] kaigo hoken, indicating the emphasis on the public and social elements of the new long-term care system, in which around 50% of the expenses are "public funded" by the support of central and local governments. In international publications, the Kaigo hoken ho is usually translated as "Long-term Care Insurance Law" because of its concern for public care in replacing the traditional family-supported care system. It is very important to mention here that although this law has been passed, various types of services, mechanisms, funding, human resources, and systems provided for in this law are at present not functioning in an integrated form.

The law will be effective and fully implemented on April 1, 2000. As it is the base for the institutional and functional elements of the care for the elderly, tremendous efforts are being made by the Japanese people and government to prepare this new system of care for the elderly. The law is regarded as a response to as well as a social re-evaluation and integrated system of welfare policy for the social reality of an increasing number of elderly in Japan (Rôjin Hoken Fukushi Shingikai 1996).

According to the information in the media, including the White Paper issued by the Ministry of Health and Welfare (Kôseisho 1997), the underlying reasons for the need of elderly care has been constantly featured as one of the greatest tasks of the "aging society" (kôreika shakai) of the next century. These reasons are as follows:

First, because of the rapid increase in the number of aged people, the number of people who will need care naturally will also increase. The level of care needed will be more intense and longer-term. Second, due to the change in the "traditional" role of the family in care for the elderly, it is now difficult to support the elderly as before. Third, the general public is aware of the insecurity and expresses concern for the care of the elderly. Fourth, care for the elderly would mean an excessive burden on the family in many cases. Fifth, around 80% of the Japanese, according to a survey, would like to see the establishment of a new unified system of assisted care because of the limited access in the present system in which it is difficult to choose an individual style of service and care (Kôseisho, 1997).

Even though the Ministry of Health and Welfare as the government organization responsible for dealing with the new law is stressing very positive elements, many individuals concerned - welfare professional workers or local governments officials - are still skeptical about the implementation of the law and the future plans for the care of the elderly under the new system (Yomiuri Shinbun, 1997).

In this article, I will raise some of the critical aspects of this new law in the socio-cultural context of Japanese society from a bioethical point of view. Further, I will point out that there were also several positive elements, which evolved during the process of public policy-making, which led to the enactment of this law.

I. Shifts in Welfare Policy Due to the New Kaigo Hoken ho

As I have mentioned above, there is a social need for some sort of system to provide care for the elderly in Japan. Particularly, in more concrete public policy terms, the reasons for proposing the Kaigo Hoken Ho and its aim could be summarized as follows (Ihara and Amaike, 1997):

First, regardless of family situation and income level, elderly people should be entitled to utilize home care services and institutional services according to their own needs and wishes, without feeling any reluctance. Further, the independence of the elderly should be fully supported by this new system. Second, the two systems presently existing - the elderly welfare system and the national medical insurance system for the elderly - should be integrated with the new law in order to create a unified care system for all elderly people above the age of 64. Third, the law should encourage the private sector to play an active role as a service provider in this integrated system. These services are currently supported by the public and semi-public sectors. Fourth, the idea of "care management" which is a rather new notion in Japanese health care, should be introduced in order to provide a variety of services required by the elderly

On the one hand, generally speaking, all of these aspects relating to the care of the elderly are very much welcomed by the Japanese public. On the other hand, the law itself as well as these four positive aspects have also been criticized (Mainichi Shinbun 09.10.1997: 5). In the following, I would like to point out several unique changes or shifts in the concept of social welfare expressed by this law which, according to my analysis, can be clearly recognized as shifts in a positive or negative way:

"From status to contract" through service industries

I used this very popular phrase invented by a famous legal historian, Sir Henry S. Maine (1888: 165). He coined this phrase to explain social trends in the legal status of the individual from ancient to modern times. A shift from "status to contract" is exactly what the Kaigo Hoken law effects.

The former Rôjin fukushi-ho [Law for the Welfare of Elderly] promulgated in 1963, provided administrative measures (sochi) for the care of the elderly in order to make arrangements of various welfare services such as home help services, day services, and short stay services for the elderly including the providing or rental of special appliances such as wheelchairs, canes, and hearing aides for daily use. Sochi also applied to the admittance of elderly care to institutions. Sochi were basically decided by local authorities, but, legally as well as administratively, they were not regarded as claim or right of the elderly person in need of services or institutionalization (see Ogasawara et al. 1997: 52-53). In order to gain the benefits of sochi, private information relating to family relations, income, or other property matters would eventually be disclosed. Those elderly who needed sochi and were recognized, as an "object" of welfare services would be taken care of by the social welfare system of the government. In the Rôjin Fukushi Ho, tax money was used for the support of needy people. However, as a matter of fact, people were feeling reluctant about obtaining that "status". With the new Kaigo Hoken Ho, the notion of this sochi was abolished. A shift from state responsibility to individual care by the establishment of an insurance system can be clearly recognized in this law.

- "From family to society" through mutual assistance

Both care and social assistance supplied by the Japanese welfare systems have had a negative image and faced difficulties because of the traditional emphasis on family care. Usually those who receive welfare services are categorized as poor and without family support, and this has been one of the reasons why people have been reluctant to be in that "status" and become an "object" of socialized welfare services. Until very recently - and still today in many Japanese rural areas - the family has taken care of their elderly members (Kimura 1988: 175-186). Therefore, it is quite an embarrassment for many elderly to receive public welfare services, particularly if they live alone and are separated from their family.

A recent article on elderly life that appeared in the Asahi Shinbun (16.12.1997: 26;

17.12.1997: 34) reported these strong ethical and moral sentiments of the elderly against utilizing social welfare services. The people interviewed expressed traditional attitudes like "a parent has to be taken care of by their children's family members, particularly by the wife of the eldest married son". Recently, however, it has become more and more difficult both in urban and rural communities to care for elderly family members due to changes in the function of the family. Further, statistical data show that there is a rapid increase not only in elderly parents but in elderly children as well.

The new law stresses the positive idea of insurance as a mutual assistance framework so that people would not feel any reluctance to utilize it. All people beyond the age of 40 are required to pay premiums from their income to prepare for the possibility of being taken care of after they have reached 65 years of age. This is a practical solution to cope with the possible increase in the number of elderly who might not be taken care of through the family or relative networks of support.

According to the Report on the Survey Concerning Aging issued by the Prime Minister's Office in January 1998, only 38% of the middle-aged (40-59 years of age), and 46% of the elderly (beyond 60 years) responded that if family members became bedridden, he or she should be taken care of by other family members. By contrast, around 47% of the middle-aged and 31% of the elderly expressed the need to utilize public welfare services or even institutions in case of a bedridden family member. However, in the case of ordinary care for the elderly, only 9% of the middle-aged group and 10% of the elderly responded that they needed to be institutionalized rather than utilizing public welfare services in their home environment (Sômuchô Chôkan Kanbô Kôrei Shakai Taisakushitsu 1998).

· "From state to individual" through community support

According to the Kaigo Hoken Ho, each individual will be supported in his or her care by community-based local agencies. As mentioned above, emphasis is not put on the government to intervene for the care by application of "Sochi", but on each individual to utilize community-based care services after having consulted a care-manager. Furthermore, the law encourages the use of private sector organizations in the community, which are usually business-oriented welfare services. It is a totally new notion for many Japanese to utilize these services which many people would otherwise not have been able to afford.

In my opinion, this shift from welfare as a state obligation to individual choice with regard to the care-provider can be recognized in a very positive way. It signifies a very dramatic change in Japanese welfare legislation.

·"From bureaucrats to the people" through public deliberation

The official statement of the Ministry of Health and Welfare assures us that as soon as the new long-term care system as a mutual assistance insurance mechanism supported by local governments and communities is well understood by the people, elderly people will be ready to claim their rights and utilize this system in a positive way. However, there must be a change in the mentality and attitudes of welfare bureaucrats as well as the people in the local community in order to accomplish this objective.

·"From tax to insurance" through cost-sharing

The new law proposes a shift in expenditure from tax money to insurance money in order to share the cost for the care of the elderly. Therefore, the biggest problem many people will have with this new system would be expenses, which are expected to increase in the future.

Even though people will have to pay premiums for this insurance, they will not have a chance to utilize this service if particular criteria are not met. Even if people are lucky enough to be grouped into the standard-care category after having passed an evaluation process, they will still have to pay around 10% of the total cost as a user fee. This means that the Japanese will pay an insurance fee, tax money, and a user fee. One of the mechanisms to collect money for insurance premiums is automatic deduction from pension incomes through the administrative channel of local governments.

Cost-sharing for the benefit of elderly care is naturally a good idea. Nonetheless, there are many people who have worries by saying "hoken atte mo kaigo nashi", which means "there is an insurance system but no services will be available" due to the different level of services according to the situation in each local community.

II. Bioethical Approach to the Long-term Care Insurance Law

Bioethics is an interdisciplinary subject relating to the value judgment of life and death in the social and human environment (Kimura 1986: 248-249). It embraces various traditional disciplines like biomedical sciences, ethics, law, philosophy, religion, or public policy. Various grassroots movements of the 1960s dedicated to civil rights, women's liberation, consumer protection, patient's dignity, and other human rights were the creative force behind the formation of bioethical ideas. In this socio-cultural context, it seems obvious to me to look at the issue from four different angles, which reflect bioethical ideas (Kimura 1987). These are (1) the public policy perspective, (2) the human rights perspective, (3) the equality perspective, and (4) the "do-no-harm" perspective.

The public policy perspective can be usefully employed as a good criteria in analyzing bioethical aspects in the making of new laws regarding issues such as organ transplants, the definition of brain death, or guidelines for genetic tests. The Kaigo Hoken Ho should also be scrutinized in this public policy perspective.

From the time the law was proposed to the House of Representatives (139th Session) on November 29, 1996, there has been much deliberation among the general public on the long-term implications of this policy. One criticism was that the law focuses on elderly persons who need care, while someone who might become disabled at a younger age would not be covered. According to the law, from age 40 people are required to pay a compulsory premium, but benefits will, in principle, only be given from the age of 65 after undergoing a qualifying evaluation by an expert. Only in exceptional cases, those younger persons who became ill and disabled as a result of the biological aging process may also receive benefits. This clearly is unjust from the perspective of the younger generation.

One focus of the public debate during 1997 was one of the most basic issues of the system, i.e., whether the benefits should be funded by an insurance system or a taxation system. If the principle of mutual support is fundamentally important, it is quite obvious that a taxation system is much better suited because it is fairer.

However, without sufficient exchange of opinions among the public, the insurance system was finally adopted by policy-makers as the better choice. The reason for this was that almost all political parties refrained from pursuing tax raising-policies in the face of general elections. In a sense, then, the Long-term Care Insurance Law became a victim of political compromise, and, in my opinion, a great opportunity to reconsider fundamental notions of public policy with regard to mutual care for needy people was lost.

Care should be provided as a commitment of the social community regardless of age and generation, and be based on the needs of disabled people and their family. The government, however, insisted that cases covered by the Welfare Law for the Disabled should not be integrated into the Long-term Care Insurance Law.

The human rights perspective can be used to analyze legislation, as it is essential to have criteria whether a certain law will have positive or negative implications regarding the dignity and rights of the people. In the Long-term Care Insurance Law, there are several key expressions such as "support", "care", "welfare", "choice", "service", "mutual support", "cost-sharing", and "independence". However, there is not a single word expressed as to the "rights" of the person in need of services. This law still strangely bears the sense of obligation and a paternalistic welfare-state flavor usually practiced by Japanese bureaucracies. If it is truly important to support the independence of the elderly, as is exactly stated in this law, one has to recognize, first of all, the right of the elderly persons as individuals to have access to various services mentioned in this law as an extension of their constitutional rights.

An equality perspective is an essential element in the process of value judgment when one looks into details of the law's application. There is a possibility of inequality in service provision, reflecting differences in the conditions of local communities. For example, even though the care-manager of a particular community may be able to make plans for the elderly, home care or even institutional care might not be available due to the lack of human resources. This is an unequal and unethical situation which might lead to the creation of "migrant social welfare recipients" moving around from one particular area to another in search of local communities that provide adequate services.

One of the problems relating to the equality perspective is the gender issue. Japan is a strongly male-oriented society in which around 85% of the home caregivers are still women. Ironically, several Japanese feminist groups have rejected the idea of cash payment for full-time care-giving at home. They felt that such cash payment could be a plot against women, confining them to the home and depriving them of their social, business, and professional opportunities. The final decision of not providing cash payment to full-time home caregivers also deprived male family members of being in such a care system on a full-time basis. Obviously, the equality principle is violated with this law. Equal treatment should be accomplished to all possible and available caregivers in the family.

The "Do-No-Harm" perspective can also be regarded as one of the criteria in making value judgments on issues related to bioethics. Here the main problem is that those who have been paying insurance premiums might not necessarily get care services later in life.

Usually, insurance means that the payers will get benefits whenever they are in a particular situation (such as sickness, unemployment, etc.) because they have been paying to insure against a future risk. In this sense, the new law is not implementing insurance at all. This is simply harming the insured that expect to receive proper services when they will need them. The Long-term Care Insurance Law does not automatically guarantee care because it imposes a barrier of qualifying standards. In addition, it is not clear whether an appeal can be filed within a particular time limit.

An additional problem for the elderly can be seen in the current situation in which most hospitals accept elderly patients who have difficulty managing by themselves at home. In Japan, this hospitalization for the elderly occurs very often due to the lack of vacancies in appropriate elderly institutions and is usually called "social hospitalization" (shakaiteki nyûin) because it is not meant to cure a disease, but rather to care for the elderly patient in an institutional setting but which is eventually consuming great amounts of medical resources (Kôseisho, 1997). Following the application of the Long-term Care Law, these patients will be eventually discharged. This will cause tremendous harm not only to the patients themselves, but also to their families, if there is no system prepared for the care of these elderly.

III. The Kaigo Hoken Ho in the Public Policy Process: The Citizen's Positive Role in Making Proposals

I briefly mentioned above that the bioethical public policy perspective played a significant part in the making of the Long-term Care Insurance Law. In this section I will focus on this point by introducing the activities of civic action groups initiated by conscientious people in the process of making this law.

There was a high degree of open debate and public policy-making relating to this law that caught the attention of many people because it was believed to have various implications for Japan in the 21st century in political, economic, social, and family terms. The media usually reports issues such as elderly care in the social or family and women's feature sections. In the case of this law, however, there were many articles of support or criticism that appeared on the front pages of national newspapers. The topic became headline news on radio and television programs with reports on the political, economic, financial, and government issues focusing around this bill. Thus, it evolved into one of the most crucial political issues in Japan that integrated all existing systems for welfare and medical care in local communities.

As the legislative body, the Diet itself had a series of special sessions by inviting experts in the Welfare and Health Committees on the issue of long-term care. Further, special public hearing sessions were even held in cities outside the capital region.

In my opinion, however, the formation of a citizen's social action group in order to support the fundamental idea of long-term care insurance was even more remarkable. This group was established in 1996 and named Kaigo no Shakaika o Susumeru Ichimannin Shimin Iinkai (Ten Thousand Citizens' Committee to Realize a Public Elder-Care System; in the following abbreviated as KSSISI). It has made tremendous efforts to make concrete and positive proposals for the legislating process of the law. Among other things, the group presented policy alternatives, made recommendations, administered surveys on elderly care, sent questionnaires to Diet members on the proposed law, and collected resources, documents, and drafts related to the law. KSSISI's name reflects the purpose of this organization, as founding members planned to gather 10,000 citizens to join this committee with a membership fee of 10,000 yen. They suggested that this national organization would raise a 100 million yen fund to support activities which allow for an input from the ordinary Japanese citizen's point of view on the care of the elderly.

In the statement on the establishment of KSSISI, the emphasis was obviously on citizens' input to influence the making of the law and presenting positive proposals on various points such as the following: 1) Citizen's participation in the policy-making process to plan for care-related infrastructure; 2) assurance of receiving services by setting a target year in order to avoid the situation of compulsory insurance payments without receiving benefits; 3) insurance fee payments from age 20; 4) deletion of the provision stating "necessity of care caused by the aging process" and expansion of benefits to all people with disabilities including younger people; 5) the establishment of a Care Insurance Managing Council consisting of an equal number of male and female representatives of the insured in order to protect the human rights of the insured. This council was also intended to be provided with an "ombudsman" function so that it would have the power of "investigation, recommendation, and public disclosure" (KSSISI 15.09.1996: 7-8).

The KSSISI group received a great deal of attention during the two years since its establishment. They appeared in the news media whenever they held symposiums, seminars, and general assemblies. Its role as a citizen's public policy-making body was, for the first time in Japan, very well accepted by government policy-makers, candidates for the Diet at the time of the 1996 general election, and the people in general.

One of the most remarkable features during this public policy process was the publication of a series of newsletters which carried valuable information on survey results, data, and proposals. From issue 1 to 7 (including an extra issue immediately after the passing of the bill in the Health and Welfare Committee of the House of Councilors on December 2, 1997), the group gave a very positive input and even exerted strong pressure to consider amendments in the final process of law-making (KSSISI 02.12.1997: 2-3).

IV. Disappointments and Hopes for the Future

I have discussed the remarkable process of public debate on the long-term care issue and its implications from a bioethical point of view. This debate was in many respects the first of its kind in Japan, yet not many Japanese recognized its grave importance for particular bioethical concerns, such as care for those in need, in the public policy-making process. Democratic efforts were made through nationwide public hearings held in certain prefecture, such as Okayama, Fukushima, Hokkaidô, and Niigata, organized by the Welfare Committee of the House of Representatives, and in the prefectures of Yamanashi, Kôchi, Ôita, and Aichi, organized by the Health and Welfare Committee of the House of Councilors.

However, the most encouraging approach of public participation that enjoyed the strong support of both the people and the media was the formation of special citizen's interest groups on the care issue. One of the most influential groups was the KSSISI that organized more than 18 meetings, seminars, symposiums, public gatherings, and press interviews, including publication activities supported by members and the general public. As of February 10, 1998, the KSSISI claimed a membership of 2,320 of which around 60% were women, 37% men, and 3% associations. The whole process of making the Kaigo Hoken Ho gave new hope for many people as the KSSISI's proposal for amendment was seriously taken into account:

On May 22, 1997, the general meeting of the House of Representatives of the Diet passed the Long-term Care Insurance Law that included the following amendment:

"Local municipalities should be given the necessary administrative discretion in order to get a feed-back from the insured whenever they make a plan or intend to change services provided by the care insurance policy" (KSSISI 01.06.1997: 1-3). The concrete content and meeting of "administrative discretion" was suggested as "1) the establishment of a planning policy committee, consisting of people with learning and experience and experts from the fields of health, medicine, welfare, and insurance; 2) a public hearing or briefing including the insured should be held" (Kôseishô Kaigo Hoken Seido Jisshi Suishin Honbu 1998). This amendment shows the actual influence of KSSISI's movement, and one cannot deny its role in the public policy process for the new care insurance system.

With regard to the fundamental concept of people who are entitled to receive care, however, the group was unable to influence the legislators. The Kaigo Hoken Ho clearly stipulates that people will be only eligible according to the care-category they are classified in, and on the condition that they are suffering from certain symptoms of disability or a condition caused by the "aging process", this particularly in the case of people between 40 and 64 years of age. It is important to note that the original draft of the law did not have such a sentence mentioning kôrei ni tomonatte shôzuru [caused by the aging process] but only kaigo o hitsuyô to suru hito [those who need care]. In spite of the opposition to keep the latter wording in the law, it was passed using the former phrase. The KSSISI and the majority of the public consider the phrase absurd and are concerned about the serious implications this would have for those who need care because they suffer from a symptom or a disease that is not related to the aging process.

Nevertheless, through activities including concrete proposals for amendments of the law, the Japanese public experienced direct participation in the democratic political process. Because of the importance the issue of care for increasing numbers of people in need has, many people felt that it was their own issue. It relates to their life in the community and to images of mutual caring, the family, welfare, and medical services. This new trend in Japan will also have positive implications for realizing the "Health for All in the Year 2000" global agenda initiated by the World Health Organization (WHO) of the United Nations (Kimura 1997).

In order to determine the necessary level of care for people in need, international comparisons should be made and concerted efforts initiated to solve these issues, which are usually considered domestic problems. On not a few occasions we have learned that a breakthrough in unsolved and difficult problems can only be made by investigating and looking at the issues from different socio-cultural and bioethical perspectives.

Naturally, the trend toward socializing care for the disabled as full members of their community in each region of the world should not discourage any form of traditional values that emphasize care in the family and community. Rather, we enter a new era of care and support with additional mechanisms that were influenced by international bioethical guidelines brought in during the course of a public policy-making process.

However, it should not be forgotten that there is a need for continuous cooperation beyond national, generational, and gender gaps. We need to safeguard the clear image of respecting the autonomous decision of those people who need care. Participation, commitment, and voices of the people who are in a situation of disablement or of providing care are crucial when making bioethical public policies for building communities in which humane care is fully realized (Kimura 1995).

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Conclusion: Bioethics as a Prescription For Civic Action

Japanese society and culture are changing rapidly.

As I mentioned in each of the chapters of this doctoral thesis, in this era of rapid change, it is timely to examine the dynamics of bioethics development in Japan. I have examined the unique features of Japanese culture in the context of Bioethical decision-making in genetics, death and dying, organ transplants, aging, public policy, and human experiments and speculated on the profound impact bioethics will have on the future of Japan's civil life, health care delivery, and culture change.

In the context of growing concerns and interests in cross-cultural aspects of Bioethical studies worldwide, the first Asian Bioethics program affiliated with Georgetown University within the Joseph and Rose Kennedy Institute of Ethics was formally established in 1980. The first and the second Japan-U.S. Bioethics Symposium convened in Tokyo and Kanagawa in August 1985 and 1986, with the support of the Institute of Medical Humanities of the Medical School at Kitasato University, Japan. Kitasato Medical School, since the mid-1970s, has been the pioneering institution in Japan for the study of the philosophy and ethics of medicine.

Waseda University’s Bioethics Project established at the Center for the Advancement of Human Sciences has organized a series of International Bioethics Conferences beginning in the 1980s and the1990s. The theme of the conferences were different from time to time, but focus has been “ Patient-centered Medical Care. “

In the year 2001 and 2002, Waseda University’s Bioethics project and International Institute of Bioethics and BioLaw have been organizing a series of conferences (supported by the grant from Japan Foundation Center for Global Partnership) to follow the dynamic situation of Bioethics development and its changing situations. These series of conference had a central focus on the comparative cross-cultural study of Bioethical Decision Making Processes in Health Care.

As I have analyzed in each chapter, a unique characteristic of bioethics is its bearing on a "civic action movement". In the U.S. and Jaapan, the concern for life, death, and the environment has been affected by civic and community activities opposed to social, economic, racial, and political injustice. In this sense, Bioethics is the result of these human rights movements and various expressions of civic action. Some of these include the women's liberation movement, access to equal opportunity, patients' rights, informed consent of an entire community for the opening of gene manipulating laboratories, and campus protest groups who question the meaning of academic neutrality. All of these movements have spread to various nations of the world, including Japan according to my analysis.

Since 1980, the lay public and scholars called attention to the serious implications of bio-medical technological developments in Japan. Of course, we should acknowledge some of the very positive and commercial applications of bio-medical technology. However, we should also consider the negative effects that include the failure to adequately protect the welfare of the people. This is particularly true in Japan, where the Japanese suffered the tragedy of Minamata disease that was caused by one of the leading nitrogen fertilizer companies in southern Japan.

Japan’s lay public still has negative feelings toward a too hasty advance of science and growth of technology as I explained in chapters two and three. Perhaps this is due to Japan's first national experience in the world having monumentally suffered from the extraordinarily 'successful achievement' of science and technology in Hiroshima and Nagasaki in 1945.

Since the early 1980s, the dynamic development of Bioethics has been leading to the formation of citizens’ networks in various cities such as Tokyo, Hamamatsu, Nagoya, and Kyoto. They are composed of some one hundred nurses, housewives, students, and physicians, some of whom have become very active as volunteer worker, for example in the psychiatric department of Azumi Hospital in Nagano Prefecture in central Japan. Based on the notion of patient-centered services, volunteers work together with the medical and nursing staffs of the hospital in order to 'humanize' the milieu of the psychiatric section by applying the practical notions of Bioethics. Licensed acupuncture specialists are also quite active as volunteers and serve this purpose successfully. This shows one of dynamic changes in the practice of alternative medicine in the context of Bioethical concern for patient centered medical services applied in the psychiatric Azumi Hospital.

One of the more interesting experiences for these volunteers, as well as patients are professionals who conduct this bioethical activity in the hospital setting, is the newly rediscovered importance of natural rhythms and the feeling of being within nature. Washing and cleaning the feet of the patient; followed by a barefoot walk outdoors have an extraordinary and positive effect on the patients' mental state).”Bioethical activities” such as these have been developing in local community hospitals, but are still in the beginning stages in Japan. However, it might be useful to note that more and more holistic approaches to health, environment, life, and nature have become evident, and the notion of 'bioethics' itself has been interpreted within a totally new holistic approach to life, death, and virtually all health issues.

Given these continuous concerns of the lay public, which involves issues bearing on their own lives, environment, and community, one very important dimension of Bioethics has been developing: the very distinctive difference between 'medical ethics' for physicians and professional ethics for professional people. And the lay public, the latter group, must depend on a fair amount of information from experts and professionals, but it is not necessary that they follow the opinions or decisions made by physicians from the perspective of their own value systems.

The lay public's concern in democratic decision-making calls out to be respected, and reflects a newly formed public policy that should help professionalize clearly value-laden (and often prejudicial) decisions by health professionals. Until quite recently, the medical profession has enjoyed enormous power and professional discretion with regard to medical treatment. The Japanese are accustomed to authoritative structures and paternalistic attitudes, due in part to the fact that physicians have been nurtured in a traditional Confucian ethos - "Jin', traditionally developed in China. Medicine was regarded as 'an art of Jin", and viewed as an expression of loving kindness (Jin) by the physician, and given to people who were not to ask any sort of questions. Although the Japanese have developed socialized medical service and social insurance medicine, and physicians work within this system even in their private medical practices, they still abide by the traditional notion of "Jin' as the basis for their services.

However, Bioethics, which is "supra-interdisciplinary," according to my definition, goes beyond the traditional closed realms of the academic disciplines in order to accomplish its task. For example, in the quasi-didactic, traditional, paternalistic relationship between physician and patient, the notion of "patients' rights" could not be meaningfully formed. Bioethical concerns have altered the image of the patient by applying the notion of "rights" from the legal traditions that might be rejected as indifferent notion in medicine according to its logic of health and medical care. "On behalf of the patient', and 'for the patient's benefit" are phrases that emerge according to criteria set by the attending physician. However, this has gradually been changing in Japan, especially with respect to the new Bioethical emphasis on the patient's framework of values in making final decisions concerning medical treatment. The principle of 'informed consent' applied in clinical medicine is also a recent development in Bioethical decision-making during these 20 years.

An earlier series of articles on Bioethics and Patients' Rights, which appeared in the Japanese Journal of Hospitals, were the first of their kind, and had a significant impact on physicians as well as on patients. The Japanese Hospital Association, in 1983, took the issue seriously and announced its version of the principle of patients' rights in their official handbook for hospital physicians. The first national conference on "Patients' Rights Declaration" took place in December 1984, in Tokyo.

Bioethical decision-making has given greater emphasis to each patient's right to make particular decisions based on his/her own values and moral standards. Of course, this has been viewed by lawyers and Bioethicists as an expression of the principle of autonomy and the patient's moral right to make his or her own treatment decisions.

However, the concept of "right' (Kenri) can be traced to the Dutch word 'regt' and later found in Japanese by using a Chinese character (this occurred around one hundred years ago). It is originally an alien notion for the Japanese, and hence not only the notion of 'patients' rights', but also the notion of sharing information" and "shared decision-making" between patients and physicians is still quite radical for many Japanese patients and particularly for many paternalistic Japanese physicians (Kimura, 1986).

A majority of Japanese often noted that the notion of autonomy, one of the fundamental principles of Western-oriented Bioethics, does not apply suitably to the Japanese socio-cultural tradition, particularly within the paternalistic medical tradition. In Japan, each human being as well as all living beings is dependent in that every person has to suppress his egoistic self. However, this was proven wrong as I prospected before in expressing the accepting of the idea of autonomy and informed consent positively integrating into Japanese medical settings.

A more delicate sense of 'relatedness' is thus the key element in the recovery of one's true humanity within nature, including the entire living being. The Japanese are influenced by the important traditional Buddhist teaching of "En” (relatedness). All fellow beings are related to one another as well as to nature (Fujiyoshi, I 984).

Thus in facing with these dynamic developments in Bioethical concerns among the lay public, the Japanese need to change their profoundly paternalistic attitude, which is reflected in their medical tradition into more positive ways of 'sharing" information, trust, treatment between medical professionals and patients. This is the importance of the Bioethical principle of 'sharing' in Japan - sharing life with others, including all living beings who suffer, are sick, or aged. This positive, creative, living principle is critical to human empathy and grounded on 'En" (relatedness) (Tamaki, 1982).

The lay public in Japan is becoming more and more interested in all areas of the life sciences, which are increasing the boundaries of medicine, science, and technology. By sharing information and working together, they hope to protect and develop their lives as we progress in this era of Bioethics.

In reviewing the development of civic action and interest in the dynamics and change of Bioethics in Japan dealt in each chapter, I can also claim that Bioethics has become an established academic discipline. It is a totally new discipline for Japanese academics and lay public, if not for the medical profession in general. But the dynamic development of Bioethics as a civic action will provide enormous help and change very positively, to health care professionals, as well as government policy makers since these set of Bioethical issues have been of central concern for some twenty years in Japan.

As I have dealt in this doctoral thesis and analyzed in each chapter, in conclusion, I can say it is quite natural, that Bioethics as a prescription for civic action as well as an established academic discipline is now in the process of incorporating itself into Japan's cultural value system in its dynamism and change.

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These previous works have been integrated into the theme of my dissertation “Dynamics and Change of Bioethics in Japan”. In the bibliography section, all the sources of my previous works used in this dissertation have been listed according to the title, date, and publication.

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Summary

Rihito KIMURA

The emerging new discipline of “Bioethics” since its formative era at the end of 1960’s has greatly impacted the medical services and health consumer movements world-wide.

Particularly in Japan, the original movement of Bioethics has been developed by civic action groups in various social sectors in 1980’s concerned with health, medicine, and environment protection.

The idea of Bioethics has been very influential not only in biomedical clinical settings but also in many spheres of Japanese social life with special relevance to the serious problems such as pollution, medical malpractice, and human rights issues.

As the field of Bioethics has developed in Japan, I have been continuously writing articles and books focusing on the cultural diversity and its dynamic aspect of Bioethics in Japanese social context.

In this thesis, I first give a general overview of the Japanese situation of Bioethics in chapter one. Then, I address genetic issues in chapter two, the issues of death, dying and organ transplants in chapter three, and issues of ethics committees and human experimentation in the chapter four. The aging and Bioethics public policy-making issues are dealt with in the chapter five. Finally, in the final chapter, I conclude by putting forward the notion of Bioethics as a Prescription for Civic Action.

In this thesis, I have intended to demonstrate the dynamics of Bioethics as well as its radical changes during its formative era in Japan.

I have claimed that the most important aspects of Bioethics could be well understood in the framework of its “supra-interdisciplinary” character which should have its base in the civic action movements to ensure the protection of Human Rights and Human Dignity.