

Bioethics in Japan and East Asia

JAPONYA VE DOĞU ASYA'DA BİYOETİK

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Summary

This paper focuses on bioethics in Japan with comparisons to Asia, and global comparisons. There are three ways to think of the term bioethics, one is as descriptive bioethics-the way people view life and their moral interactions and responsibilities with life. Another is prescriptive bioethics-to say what is good or bad, what principles are most important, or that people have rights and therefore others have duties to them. A third is interactive bioethics, which include social consensus-a process of interaction with traditions and social dialogue. The International Bioethics Survey performed in Australia, Hong Kong, India, Israel, Japan, New Zealand, the Philippines, Russia, Singapore and Thailand is used as a background to discuss the issues of bioethics from an Asia perspective. The topics discussed include attitudes to science; privacy, genetic diseases and AIDS; prenatal genetic screening; assisted reproductive technology; the medical profession and medical ethics; euthanasia; brain death and organ transplants; and education. The future of bioethics and universality are major issues in bioethics in Asia today. The bimonthly Eubios Journal of Asian and International Bioethics is on-line on the Internet providing a forum for Asian bioethics dialogue: (<http://www.biol.tsukuba.ac.jp/~macer/EJAIB.html>).

Key Words: Bioethics, Japan, East Asia

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Özet

Bu makale biyoetik alanında Japonya'nın Asya ile ve global olarak kıyaslanmalarını ele alır. Biyoetik terimini üç şekilde düşünebiliriz: Birincisi tanımsal biyoetiktir. Yani, insanların hayata bakışı ve onların ahlaki değerleri ve hayatla ilgili sorumluluklarıdır. Diğer Kuralcı Biyoetiktir. Neyin iyi ya da kötü olduğunu hangi ilkelerin en önemli olduğunu ya da insanların hakları olduğunu ve bu nedenle diğerlerinin de onlara karşı görevleri bulunduğunu bildirir. Üçüncüsü ise gelenekler ve sosyal diyalogun birbirine etki ettiği bir kavram olan sosyal konsensusun bulunduğu birbirine etki eden biyoetiktir. Avustralya, Hong-Kong, Hindistan, İsrail, Japonya, Yeni Zelanda, Filipinler, Rusya, Singapur ve Tayland'da hazırlanan Uluslararası Biyoetik Survi'yi, Asya perspektifinden biyoetik konularını tartışan bir background olarak kullanılır. Tartışılan konular, bilim, gizlilik, genetik hastalıklar ve AIDS, yardımcı üreme teknolojisi, tıp mesleği, ötanazi, beyin ölümü ve organ aktarımları ve eğitimle ilgili incelemeleri girer. Bugün Asya'daki biyoetikte biyoetiğin geleceği ve evrensellik ana konulardır. Asya ve Uluslararası Biyoetik Mecmuası'nın internet adresi şöyledir: <http://www.biol.tsukuba.ac.jp/~macer/EJAIB.html>.

Anahtar Kelimeler: Biyoetik, Japonya, Doğu Asya

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The majority of the world's population live in Asia, and as the economic centre of the world shifts to Asia it is timely to look at the societies and cultures of Asia. While many are developing countries in terms of economics, the regions have long cul-

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tural and social histories and so that term, "developing" is not so appropriate. Japan is economically among the most developed countries not only in Asia, but in the world. As the country in the region with which I have the greatest familiarity, I will focus on Japan with references to Asia and other countries.

Japan has a population over 120 million. The birth rate is at replacement level, with a gradually aging population. Compared to most industrialised countries the application of agricultural biotechnol-

ogy, human gene therapy, organ transplantation has been slow. However, these techniques are being introduced with some bioethical debate, and in vitro fertilisation has been practised for a number of years and is spread over 200 clinics across the country (1). The basic philosophy of the Japanese health care system is universally mandated government provided health insurance coverage. The health care coverage to all the population is a more positive sign of bioethical maturity.

There is little private health care insurance (2).

Descriptive or prescriptive bioethics?

There are three ways to think of the term bioethics, one is as descriptive bioethics—the way people view life and their moral interactions and responsibilities with life. Another is prescriptive bioethics—to say what is good or bad, what principles are most important, or that people have rights and therefore others have duties to them. A third way is interactive bioethics. If we consider prescriptive bioethics, there has been less development of bioethics in Japan and Asia than in Western Europe or North America. In research and application of bioethics Japan may still be considered somewhat isolated (3), but there is still more active discussion of bioethics than in many other Asian countries. There have been attempts to stimulate the discussion of bioethics in Japan (4), and the word itself may be recognised by a majority of people, but the application of bioethics to science and medicine is still at an early stage. When we make cultural comparisons we can look at both aspects. In the sense of descriptive bioethics, recent surveys suggest that the views of people in Asia are not so different from those of people of other regions of the world.

The word “bioethics” means the study of ethical issues arising from human involvement with life, and I have called it simply the “love of life” (5,6). When people talk about bioethics they often are discussing the prescriptive side, which is often more subjective than objective. However, we often read statements, for example “Japanese do not accept brain death”, which may be purely subjective yet are accepted unquestioned by many. One of ways to make social research more objective is to use opinion surveys, though these also have poten-

tial for misunderstanding. In this paper I will report on the results of surveys on bioethics in Asia as a background for considering bioethical issues in Asia.

The International Bioethics Survey was performed in 1993 in ten countries of the world, in Australia, Hong Kong, India, Israel, Japan, New Zealand, The Philippines, Russia, Singapore and Thailand. Questionnaires including 150 questions in total, with 35 open-ended questions, were developed to look at how people think about diseases, life, nature, and selected issues of science and technology, biotechnology, genetic engineering, genetic screening, and gene therapy (5). A simple-style of open question, “why?”, was added to should not lead respondents into set responses, and was added to look at people’s reasoning. The ideas in each comment were assigned to different categories, which were compared.

Knowledge of science and attitudes to science

The public in Asia has a relatively high level of interest in science, and a high level of awareness of specific developments of science and technology (5,7). Less than 10% in all countries in the International Bioethics Survey saw it as doing more harm than good. Overall, most people in industrialised countries perceive more benefit than harm from science. Most people also believe that improved quality of life depends on scientific knowledge.

People support more government funding of science. However, Asian people like people in industrialised countries, are suspicious of safety statements made by scientists, and especially statements made by companies. The question was specifically on the level of trust that people had in authorities who were making a statement about the safety of a product of biotechnology. There was most trust in the government in Hong Kong and Singapore, and least in Australasia, Japan, Russia, USA and Europe. Despite the lower trust shown in the government in Russia, they had a level of trust in medical doctors. The result is most striking when we compare it to Japan, in which doctors were not trusted.

Japanese public were the least trusting of the ten countries in the International Bioethics Survey,

the biggest difference with the other countries was that doctors and university professors were mistrusted, especially so by medical students.

When asked about specific developments of technology, including in vitro fertilisation, computers, pesticides, nuclear power, biotechnology and genetic engineering, both benefits and risks were cited by many respondents. People do show the ability to balance benefits and risks of science and technology (5). Technology that touches life is perceived to be as worthwhile as technology which does not directly affect living organisms, but people may perceive more risks from technology that directly affects living organisms than from those physical science developments which do not. This is similar internationally, with genetic engineering evoking mixed emotions of benefit and risk. People do not have a simplistic view of science and technology, and can often perceive both benefits and risks. This balancing of good and harm is necessary for bioethics, and I have called this one indicator of the bioethical maturity of a society.

In the surveys there were generally no strong trends in opinion with religion, with an exception in the Philippines with significantly higher rejection of abortion. Religion in Japan is interesting, with the number of people registered to different religions over double the total population, suggesting many claim to follow several. A few respondents put many, for example one said they were "Buddhist, Shinto, and I could agree with the idea of Muslims and Christians!" Religion is not very important in daily life, as seen in the survey results and in everyday life. Younger people tended to be more indifferent, as seen in medical students. The Christians were significantly more religious than the Buddhists. In China there is more diversity of religion, and the degree of religiosity is one method to compare people's religious behaviour across countries.

Privacy, genetic diseases and AIDS

One of the bioethical issues is privacy, something which is becoming more familiar in the age of computer databases. Overall, respect for privacy of genetic information was similar between Asians and Australians, differing from those in the USA (5). People in all countries are similarly positive

about sharing information with a spouse, with 85-98% saying that a spouse deserved to know if someone was the carrier of a defective gene or had a genetic disease, with 88-98% saying the same for HIV. About 90% of the people in Japan, Singapore, the Philippines or Thailand said that the immediate family deserved to know, more than in Hong Kong (76%), and less in India and Australia (74%), USA (70%) or India (67%). The difference in the family result may represent attitudes to family involvement in disease and how much disease is seen as a family problem. Both genetic disease and HIV had similar results. A family in all countries may support a sick person, but it is interesting to see where the balance between individuals and families is; which is the basic unit of autonomy.

Attitudes to disease are central to how much people will want to "treat" someone, or return to "normal". People were also asked whether they knew someone with a genetic disease or mental disease. The most commonly cited genetic diseases were Down's syndrome, and muscular dystrophy. The most common mental diseases cited were schizophrenia and depression. In different countries there were some different perceptions, for example in Thailand many people said diabetes was a genetic disease, while this was not so common in other countries, and in Japan colour blindness. However, the frequency of some of these diseases is similar in different countries, so their familiarity may be due to other associations. There were six open questions asking people what they thought of people who had the following diseases: hemophilia, muscular dystrophy, AIDS, depression, schizophrenia and neurosis. In all samples the most common response was sympathy and comparison. Other responses included people are the same, understanding, or saying "they would help them". In general there was more expression that the diseases were "their own fault" for mental diseases than genetic ones, as well as less understanding (5). The highest level of rejection was seen for persons with HIV, another common comment being that it depends on how they go it. This is a rather judgmental attitude, as all people make mistakes and AIDS is generally a fatal disease (8). Singapore and Hong Kong students showed the highest degree of rejection.

Support for prenatal genetic screening

The main objective of prenatal screening or diagnosis (also included in the phrase “genetic counseling”) is to remove the doubts in the mind of the mother, and to ensure the health of the fetus, and at the moment only 1-5% of fetuses tested are aborted. Japan has been slow to introduce prenatal genetic screening into its efficient health check program, because of concerns expressed by handicapped persons groups and a lack of an adequate funding mechanism for the screening. Several private laboratories offer genetic services, and a mental serum marker test is being distributed commercially among doctors since 1994.

There was high support for making prenatal genetic screening available under government funded medicine in all countries of the survey (5). About two thirds said that they would personally use it, and a tenth to a fifth said that they would not. The open comments were varied. In the general question on government funding of prenatal genetic tests, many included the comment “health care is a right”, or “should be available to all”. Most other reasons were also given for the personal use of genetic screening, and more people say “don’t know” or “it depends on the case”, than in the general question. About a fifth said the testing would help the family or parents, and other reasons included a desire to know, the quality of life of the child-to-be, and saving the life of the fetus. Only 1-2% in Japan said the fetus had a right to life; 3-4% in Australia and 4-8% in NZ. There was surprising little objection on religious terms in Thailand. There were very few fears of eugenics expressed anywhere.

In Asia there is more blame and shame for the birth of a handicapped child than in Western societies. This will be affected by genetic knowledge, but until education reaches more people it will be more than just bad luck in the minds of many Asian families, rather it will include guilt or shame. However, social acceptance of genetic testing is the high in all countries, and the reasons given are rather similar. In Japan there was the least support for eugenics seen in the open questions on genetic screening among the countries of the International Bioethics Survey. In this survey eugenic ideas found both positive support (genetic screening), and negative reaction (gene therapy for enhance-

ment). Whether eugenic views of improved genes and health for individuals, a positive view in itself, can be separated from the negative eugenic social forces of conformity, and discrimination against people with disease, is a question only time will truly answer. In China there is a “Eugenics and Health Protection” law that attempts to ban the marriage of people with undesirable genes, although it may not be implemented at present. The results of a survey in China among medical staff (9) suggests that many people will support the concept, though perhaps less would support the compulsory nature of the law. About 10% of the respondents in this survey in Russia, and many in India also, gave eugenic reasons for support of genetic screening, more than in the other countries. If we combine this with the economic reasons, we find Australia, New Zealand and Thailand also have significant support for this idea.

Assisted reproductive technology

In vitro fertilisation (IVF) has been practised for a number of years and is spread over 220 clinics across the country. They are guided by voluntary guidelines only, of the Japan Society of Obstetrics and Gynecology (JSOG) (10). However there is a law against reproductive human cloning (11). Some lawyers continue to call for a law on other aspects of reproductive medicine, but it is unlikely. The total number of children born annually was over 11.000 in 1999.

Surrogacy is not permitted, though foreign surrogacy agencies have been used by Japanese clients, and at least two agencies operate for US surrogacy businesses in Japan. Donor insemination is conducted largely through the Obstetrics and Gynecology Department of Keio University, Tokyo.

Preconceptional sex selection has been investigated in Japan, but in a 1993 survey, 76% said that if they had only one child they would want a girl, suggesting that traditional ideas of family inheritance are discounted by many people. The reason why more people wish to have a girl than a boy, which is in contrast to many other Asian countries, may be because girls are considered more cute, or better carers for elderly parents. The Japan Society of Obstetrics and Gynecology and the Japan

Medical Association committees both reached similar guidelines in September 1986. They decided sex selection by Y-chromosome containing sperm concentration should only be adopted to help prevent the conception of a conceptus with severe sex-linked genetic disorders, such as progressive muscular dystrophy or hemophilia.

The medical profession and medical ethics

The Japanese medical profession is in the process of conversion from paternalistic domination to acceptance of informed consent and truth-telling (12-16). Japanese medical ethics is a mixture of Buddhist and Confucian influences combined with Shinto influence, and later Western influences (6,17). From the fifth and sixth century the medical profession has been restricted to the privileged classes. With the centralisation of government in the seventh and eighth centuries there was a bureau of medicine established, with the Yoro penal and civil codes creating an official physician class. Because of shortages of doctors there was room for some others. After the Heian period the government-sponsored health service was replaced by professional physicians. One code of practice was similar to the Hippocratic code. It required that physicians should always be kind to people, and devoted to loving people. There is a very strong paternalistic attitude by doctors even today. There was also a directive to keep the Art secret, and to form a brotherhood. There was concern about quacks also. Modern Japanese medical thinking has been influenced by western ideas, however the revolution of the 1960s in American and Western medical ethics is taking a long time to be accepted in Japan.

Certain features of the Hippocratic tradition, especially the reinforcement of the eliteness of the medical profession, have been readily accepted by the medical profession in Japan (3,18).

In October 1990 the Prime Minister's Office (N=2209) interviewed members of the public throughout Japan, who were 20 years old or more. They asked people if they thought that some new medical techniques from a list required special ethical consideration. 75% said that some fields do, 6% said they did not, and 19% said they did not know. The following issues were raised, and the percentage of the total people that were interviewed who thought that these fields require special ethical

consideration were brain death (47%), organ transplantation (35%), terminal care (26%), in vitro fertilisation (24%), gene therapy (24%), and prenatal screening (20%). The people who thought that special ethical consideration was needed (75% of the total), were then asked how this could be done in practice (by choosing between options". 24% said that a multidisciplinary committee should assemble, to make a social standard, 23% supported the use of a special committee of doctors, who should make nation-wide standards, 9% supported individual hospitals and universities making their own individual standards, 37% supported case-by-case decision-making involving the patient, with family and attending physician, and 7% said they "don't know", with 0.1% saying something else. There is support for nation-wide standards by 47% of the people, but also there needs to be room for individual case decisions. In any event, a code of professional ethics needs to be accessible to the general population because it applies to them. In questions concerning informed consent. 63% said that informed consent is necessary and needs to be emphasized more, and 23% said it is necessary but is already used. Only 5% said that it was not especially necessary, and 8% said they did not know. There was more support among the young, though even among people older than 60 years more than 80% said informed consent was necessary, and only 6% said that it was not especially necessary. Even if of these 5% of the people who do not think informed consent is necessary say to a doctor you should do what you think is best, it still does not mean the doctor should not talk to the patient about something major. In modern medicine there are often many alternative therapies, which present the doctor with such dilemmas. There are scientific studies to show that effective doctor-patient communication has a positive influence on health outcomes (19) though we still hear some doctors saying that they are avoiding anxiety to the patients by not informing them.

One of the embarrassments of the Japanese health care system is the corruption that is implicit in the way drug prices and reimbursement is made, and the contributions from pharmaceutical companies to doctors who use their drugs. Japanese are the world's highest spenders on prescription drugs (20). Almost all general practitioners and hospitals have their own pharmacies for outpatients. Every

two years the MHW sets "official" prices for all drugs, which are used to determine the charges to patients and the national health insurance systems. However, pharmaceutical companies offer drugs to hospitals at a discount. The permitted discount is 10%, which means even official sanction of the scheme to have financial reimbursement for dispensing prescription drugs. In practice the current discounts are 20-30%, or more in competitive markets. This means that hospitals and doctors benefit from prescribing drugs, and explains why the consumption of drugs is so high. For example, antibiotic prescriptions around 1990 were about 15 times greater per person than in the U.K. There is also financial incentives to use newer more expensive broad spectrum antibiotics because the profit for the hospital is greater than dispensing older cheap antibiotics. This source of income is regarded as essential for private hospitals and clinics, in the absence of government subsidies, if the current wage system is to be maintained.

A medical treatment to reduce or remove pain which may also cause an earlier death is considered lawful under several conditions (from a 1962 Nagoya High Court ruling): 1) The patient suffers from an incurable disease as judged from contemporary medical knowledge and technology, and death is impending. 2) Physical pain is unbearably extreme and without any other means of relief. 3) There is consent or a contract based on the true will of the suffering person; in the case where the consciousness of the patient is not clear enough to express his wishes and there is no hope of recovery, the consent or earnest request of the immediate family is sufficient. 4) A generally practiced medical act is to be employed to this end.

The Japanese Medical Association recommended that there be general legislation allowing doctors to withdraw life-sustaining treatment if patients wish to do so in cases of terminal illness. They want the law to recognise living wills, but opposed legalising euthanasia. Different religious groups appear to have similar views on terminal care in Japan (15).

A Japanese court decided that a man who helped his terminally ill female partner die in response to her requests, in 1991, did so out of deep love, so he was only sentenced to 1 year with a 2 year stay of execution (Asahi Newspaper (1 Jan 1993), 31). In a case of physician-assisted active

euthanasia in Japan, a doctor at a Tokai University injected KCl into an incompetent patient at the pleading of relatives. The University Committee judged it unethical. The Yokohama District Court ruled in 1995 that the conditions for euthanasia are the same as those judged in 1962, and sentenced the doctor to a two year suspended sentence. However, it has exposed the inadequacies of Japanese terminal care, where many patients who have pain remain in pain because pain killers are not completely covered by the national health insurance.

Brain death and organ transplants

Perhaps the most well known difference in bioethical policy between Japan and abroad is the policy regarding brain death (21-23). People have been told that Japanese people rejected organ transplantation from brain dead donors. However, in a 1990 opinion poll of 3,000 adults, 51% of the respondents agreed with donation of their brain dead relative's organs, while 31% said they did not know, and only 16% disagreed. In a similar 1984 survey, 20% said they would disagree, while 48% agreed to donation (24).

There has been some trend towards further acceptance in this time, but about half the people have been willing to donate organs for about a decade. The consent rate in Western countries is only somewhat higher, as is the refusal rate, with the rate in practice being much lower than in theory (3).

Here we have a case of misinformation in the face of statistics. Various theories were proposed to explain what were claimed to be different attitudes to organ donation in Japan. The argument was that Japanese have special cultural barriers to such donations, which has been dismissed by Japanese sociologists and religious groups. In every culture one can find people who reject removing organs from bodies, of their own or family members, and their views should be respected. The debate continues in Japan, and the law recognising brain death and allowing organ donations from such bodies has been before the Parliament since 1994. In the meantime, many potential recipients will continue to die while the misguided efforts of lawyers and politicians to "protect" people from being judged brain dead continue, in the name of saving lives.

A more serious doubt in the minds of some people is whether they can trust the doctors who

make the decisions about transplantation (3,5). The conclusions of a 1992 Prime Minister's committee report on the subject was principally concerned about the process to ensure that consent is obtained from donors, although the meetings of that committee itself were closed to the public. This points us the major problem of Japanese medicine, effective doctor-patient communication, and the idea of informed consent. Perhaps the awareness by some physicians that the era of consenting organ donors may herald the entrance of informed consent into more general areas of health care is one reason why some in the medical profession object to allowing willing physicians perform such operations with "willing" donors and recipients.

A time of change in Japanese and Asian "society"

Bioethical decision-making involves recognition of the autonomy of all individuals to make free and informed decisions providing that they do not prevent others from making such decisions. This is consistent with democratic principles, and the extent to which a society has accepted this is one criteria of the success of bioethics. However, the structured paternalism of Japanese society is built on the idea that only the views of so-called experts (*sensei*) should be heard. It also means that their views should not be questioned, in accordance with the traditional paternalistic Confucian ethos. Medicine is "an art of *Jin*", the expression of loving kindness (*Jin*) by the health care professional. The main theme of Confucianist ethics was the maintenance of moral discipline for the nation, society and the home; and it was to the benefit of rulers and family leaders (16). Therefore, it is not surprising that many of the authorities in Japanese society share this ideal because it means respect for them, and hence reject autonomy-centred bioethics. They may promulgate the idea that Japanese are different as an attempt to prolong the Confucian ethic. Similar ideas are seen in other Asian countries also.

This guiding ethic is in conflict with the principles of civil rights that lead to bioethics debate in Europe and North America, and it is unlikely that the bioethics process will succeed in Japan until enough individuals raise their voices. On the positive side, the bioethics debate may be the catalyst required to transform Japan from a "paternalistic democracy" (3). One success of bioethics may be

that by 1992, all 80 university medical schools in Japan had established medical ethics committees, though there are very few women, non-physicians, and perhaps no public representatives, on these committees. Thus, while the process of decision-making is being widened, it tends still to exclude the views of the broader public, and sometimes still even those of the patient.

It is understandable that there may be the feeling that it is good to maintain some character of traditional Japan as it continues to be Westernised. People of any country may resist the rapid change and globalisation of ethics, ideals and paradigms, as ethnic and national identities may be changed, or lost, especially countries with such a long history of culture. How countries approach globalisation is a fundamental question, but many individuals in countries with access to common news media have already answered the question by their converging lifestyles and values. To the extent that human rights are more respected, this trend is to be encouraged, providing that individuals recognise more their duties to other beings on the planet, and those to come in the future. Surveys suggest that people in many countries do share the same hopes and fears, which strengthens the call for international standards.

In Japan, there has been concern about bioethical issues such as environmental pollution, suspicion of the medical profession and its paternalism, and the question of brain death. However, this concern is only just beginning to give rise to public discussion of bioethics. This delay may be more related to the structure of Japanese society than to any difference between individual person's attitudes in Japan and Western countries. This can be shown from the results of opinion surveys, for example, when individuals were asked to give their reasoning for their opinions over bioethical issues such as genetic manipulation of humans or animals, there was at least as much variety in opinions expressed by members of the general public in Japan as in other countries (5). Many people perceive simultaneously perceive both benefits and risks from science and technology. The diversity of reasoning exposed in the survey was independent of education or age, and similar diversity of reasoning was found among members of the public, high school biology teachers, and scientists. At the same time, the over-

all statistical results of many of the questions in that survey were similar to results of surveys in New Zealand, Europe and the U.S.A.

The media have a large responsibility to communicate science, and scientists should also inform people about science. The media also has a responsibility to present balanced information, on the benefits and risks of alternative technology and to do this independently of commercial interests. There is also a strong consensus for the inclusion of discussion of the ethical, social and environmental issues associated with genetic engineering in school and University curriculum. There is a role for the academics, and although there is relatively little research in bioethics, many are interested in it, with nearly 1000 members of the Japan Association of Bioethics. Although there are very few universities offering research in bioethics, there are a growing number of university courses on aspects of bioethics.

The future of bioethics in Asia looks interesting, with the founding of the Asian Association of Bioethics (4,25), and the bimonthly Eubios Journal of Asian and International Bioethics being on-line on the Internet (<http://www.biol.tsukuba.ac.jp/~macer/EJAIB.html>). The biggest challenge is the discussion of how universal bioethics is, and facing the modern cultural values which are often different to those of the past (1,5,26-28). There are also issues that have not been dealt with, such as the atrocities committed by Japanese doctors in China in the Second World War (29). Different countries may want to express national identity, however, the people are diverse in every culture, and a balance must be found to allow expression of the choices of people while preserving harmony and justice in society. These are questions that every culture in the world must face, and people must ask themselves do they want to look for similarities or differences with others around them. This is why I call bioethics love of life.

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