

# The 'far east' of biological ethics

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**The ethics of biological research, and its general impact, are hotly debated in the West. Japanese silence on the issues is counterproductive. Will the Human Genome Project provide the catalyst for change?**

DURING the past 30 years, everyone has become familiar with ethical issues arising from technological change. Although technological development in Japan since the end of the Second World War has been famously rapid, social change has not mirrored this. When it comes to medicine, for example, fear and suspicion of this paternalistic profession means that 'informed consent' is a little-known concept. The advent of reproductive technologies such as *in vitro* fertilization failed to raise widespread public debate. There are no guidelines on somatic gene therapy, although many have called for them. Will the human genome sequencing project provide a catalyst for general discussion?

Japan contributes about an order of magnitude less than the United States to the Human Genome Project, but about two orders of magnitude less to ethical research on the subject. In the United States, 5.2% of the National Institutes of Health's budget for 1992 has been allocated to research on ethical, legal and social issues and on education. In Canada the figure is 7.5% and in Europe a similar proportion is being spent. But in Japan the figure is less than 1%. The contrast can be seen clearly by comparing funding in 1992: in Japan there are two projects of ¥5 million (\$80,000) whereas in the United States expenditure is \$7 million.

In Europe, scientific research for the Human Genome Project received financial support only after a system was established for funding of research on the ethical issues. In Japan, the only reason any ethical, legal or social research was funded at all was because one scientist decided to allocate 1% of the budget received from the Ministry of Education to set up a study group to organize a seminar on the subject. The 1992 budget was spent on the seminar and publication of the proceedings in English and Japanese (ref. 1). In 1992, a second project was set up by the Ministry of Health and Welfare<sup>2</sup>. This tiny beginning cannot begin to address the ethical problem as a whole.

There have been international bioethics symposia in Japan since 1980 (ref. 3), but despite the participation of some biologists there is still no interdisciplinary dialogue. Scientists in Japan who do see the relevance of ethical studies do not think they should be the responsibility

of natural scientists, but of social scientists or lawyers. But even if social scientists start such research, they may still be unable and/or unwilling to challenge the views of biologists or policy-makers. It is more difficult for non-academics to discuss the views of scientists, even about public policy issues.

In the West, scientists in general have become convinced of the need to gather data and do research on ethical, legal and social issues. The situation in Japan is more related to the structure of its society than to any difference in individual people's attitudes. This can be shown from the results of opinion surveys, for example, my study<sup>4</sup> in which the public, researchers and school-teachers were asked to give their reasoning for their opinions on bioethical issues such as genetic manipulation. Many people simultaneously perceive both benefits and risks; opinions are independent of education, age or profession. The overall statistical results of many of the questions, and the reasoning expressed, were similar to those from surveys in New Zealand, Europe and the United States.

In the same survey I also found that Japanese scientists show less concern about ethical issues associated with animal experimentation, consistent with the lack of guidelines for such experiments. One reason for there being no guidelines is fear of bureaucratic legislation. Japan is a legalistic society, in that behaviour is regulated by law rather than by ethics, and although some individuals recognize the importance of ethical issues, there is no general willingness to build on this concern via self-regulation, teaching courses and so on.

Perhaps the most well-known difference between Japan and elsewhere is the issue of brain death. It has been said that Japanese people would not accept 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 relatives' organs, 31% were unsure and only 16% disagreed. In a similar survey, in 1984, 20% said they would disagree, while 48% agreed to donation<sup>5</sup>. Despite this, only kidneys and corneas are donated from cadavers at present. The view that the Japanese have special cultural barriers to such donations has been dismissed by sociologists and religious groups in the

country. A more serious doubt in the minds of some Japanese people is whether they can trust doctors. Even a committee set up by the Prime Minister that reported earlier this year on the subject and which recognized this problem, was itself closed to the public.

It is therefore not surprising that genetic counselling is also being introduced very slowly. The 1948 Eugenic Protection Act does not officially allow abortions of fetuses because of genetic disease or chromosome abnormalities, yet abortion is easily obtained. Like the brain-death issue, people think that Japanese have different views from Westerners, but in fact they seem rather similar statistically. Japanese people strongly support the use of genetic screening and gene therapy<sup>4</sup>. Genetic screening services are not commonly available or funded by national health insurance; many major medical schools still do not have a genetics department. There is a pressing need for education, and research is required on how to introduce counselling and to reduce the stigma associated with genetic disease.

Ethics demands the recognition of the autonomy of all individuals to make free and informed decisions providing that they do not prevent others from making such decisions. 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. The main theme of Confucianist ethics was the maintenance of moral discipline for the nation, society and the home<sup>6</sup>; this of course was to the benefit of people in authority. It is not surprising that many of the authorities in Japanese society still wish to promulgate the idea that the Japanese are different.

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