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Psychological and sociocultural barriers to cancer genetics and prevention: the Asian viewpoint

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I propose to look at a number of reasons why Japan appears to be lagging behind the US and a number of European countries in its willingness to apply new genetic approaches in the identification and treatment of cancers.

I believe that one reason why Japan is lagging behind other developed countries in this respect is that we have never felt the necessity for such strategies. This, in turn, is probably because we have not generally been concerned about the issue of genetics itself. There are probably a number of factors — you might almost say barriers — why we should have been reluctant to respond to the future promise offered by cancer genetics.

One suggestion for our hesitation has been that the incidence of genetically-related disorders is probably lower in Japan than in some other countries: there are, for instance, no or fewer cases of cystic fibrosis or sickle-cell anaemia. In addition, the incidence of breast cancer is lower in Japan than it is in Europe and America. It is said that mutation of the BRCA-1 gene is observed in 5–10% of breast cancer patients in Europe and America, whilst in Japan mutation of this gene is found in a lower percentage of women suffering from the disease. Although there are differing opinions, it has been suggested that 70-80% of women in Europe and America with a mutated BRCA-1 gene develop breast cancer at some time during their lives, whereas in Japan the figure is generally lower. It may be these facts have persuaded the Japanese people that they do not need to take cancer genetics too seriously.

There may also be a number of social rather than medical factors responsible for the lack of interest in cancer genetics among the Japanese people. Throughout the world, the social position of medical doctors is very high, and amongst the various medical fields, pathologists wield the greatest power; this is particularly true in Japan. In such a situation, those already in strong posi-

* Tel.: +81-11-222-1506; fax: +81-11-222-1525. *E-mail address:* scs-hk@phoenix-c.or.jp (H. Kobayashi). tions might resent and resist the development of a new science, such as cancer genetics, which they might perceive as threatening their position. In fact, very few departments of cancer genetics have as yet been set up in Japanese universities and colleges, and training for geneticists is not widespread or eagerly undertaken. Moreover, while members of the co-medical staff are simply assistants to the medical staff, they none the less have considerable power of their own, and unfortunately neither the doctors nor their assistants will welcome geneticists.

Furthermore, cultural differences may play their part, whereas American-European people are descended from hunting races, the Japanese were in the past primarily a farming race. Influenced perhaps by Buddhism, they have always enjoyed such unassertive and selfnegating cultural activities as flower-arranging, the tea ceremony, playing musical instruments like the koto, and so on. They are not willing to share their feelings with those outside their own cultural world and give the highest regard to the preservation of the peace and harmony of their society. When anything disturbs that harmony, or appears likely to, then they become very nervous. Thus, when something unknown or about which they have little information appears, they will hesitate at first to accept it into their safe world. Even if they do accept something new, they will try not to allow it to disturb their established peace and harmony. However, if whatever is new is considered (or believed) to be destructive of the old order, they will isolate or

It is also possible that they might agree with Glenn Hoddle, the former England soccer coach, and believe that a genetic disease is the outcome of a curse placed upon an ancestor or a punishment for some evil act of their own committed in a previous lifetime. I am not saying that such a belief is now commonly held by the majority of Japanese people, but I can not deny that a number of people in remote areas do still hold such a belief

We might at this point consider the notion of informed consent, since this again raises the issue of the status of doctors and the traditional relationship between doctors and their patients. Unfortunately, the doctrine of informed consent has not been welcomed with open arms by the Japanese people. Traditionally, doctors have always been expected to receive the respect and thanks of their patients, and they often say "please leave everything to me". This was a good habit in the 'good old days', when most of the population was illiterate. However, today it is not an acceptable attitude. The doctor–patient relationship is, of course, a two-way relationship, and both doctors and patients bear some (if not always equal) responsibility for its continuance and success. However, Japanese patients are often extremely reluctant to ask their doctor questions since they fear that this may harm the relationship of trust between them.

Consequently, if children are diagnosed as suffering from cancer, the parents do not like to ask the doctor about any genetic causes or associations: it can be said that they lack the courage to ask such questions. This may, I believe, be a Japanese trait, buried in their subconscious minds. As a result of such unwillingness to raise controversial questions, they have had very little chance of discussing these issues in public, as people in the US are in the habit of doing.

At the same time, such words as 'hereditary', 'inheritance', 'inherited' may, in the English language, have positive meanings not only with regard to the notion of a son being his father's heir, but also when applied to the field of genetics: the Japanese term 'iden', however, will, in genetics, carry negative meanings without any sense of inheriting valuable property.

Such facts mentioned above can probably not be attributed as common to all the people of Japan. Additional social or immediate environmental factors may also play a part in enforcing whatever innate predispositions they may be supposed to have.

A good example may be provided by the recently conducted organ transplants from a living body —

from, that is, a person who is brain-dead. In 1968, Japan's first heart transplant operation was performed without adequate scientific consideration of the brain death of the donor. This caused great public distress at the time, and the bitter memory of that original mistake has caused the medical profession to be very very cautious in its assessments or prescriptions of brain-death. No further organ transplants from brain-death donor were carried out for another 30 years.

This reluctance on the part of the Japanese medical profession to pronounce on the conditions of braindeath may have been a consequence of a medical error and the memory of that unfortunate operation may have subsequently tied the doctors' hands, yet I have to recognise that many people still do not agree with the claim that when a person's brain is dead that person is in fact dead. At any rate, it would not be easy to conclude that such a state of mind was induced by inherited genetic traits or by the influence of some historical or environment event.

Since I am unfortunately not sufficiently well-versed in the genetic or bioethical viewpoints to be found among Japan's Asian neighbours, I have been forced to concentrate only upon those in Japan and how they compare with those in Europe and North America. I trust that you will excuse the enforced narrowness of my narrative.

Broadening my viewpoint a little, I should like to conclude these necessarily sketchy remarks by saying a little more about bioethics. My own belief is that in spite of wide differences in race, culture and religion, the world must abide by a universal code (or creed) of medical bioethics. Whilst we must respect each country's own history and cultural context, we must, nevertheless work towards the establishment of just such a universal code. Medical doctors in every country will have to subscribe to a common set of agreed upon principles, which must, at their most basic and general, fulfil a number of conditions. "We must leave to a more general discussion the actual nature of these principles and their conditions. All I can say now is that we shall most certainly need them".