



THE CHINESE PERSPECTIVE ON THE USE OF GENETIC KNOWLEDGE

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The Twentieth International Conference on the Unity of the Sciences
Seoul, Korea August 21-26, 1995

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This paper consists of four parts. In the first part we will approach the issue of how the ethical principles that address ethical issues in genetics shaped in a Judeo-Christian culture could be applied in a non-Judeo-Christian culture. In the second we will discuss some values and presumptions regarding the use of genetic knowledge. In the third and fourth we will address some particular ethical issues in the use of genetic knowledge, especially the genetic screening/testing testing and gene therapy.

Tensions between Western Ethical Principles and Non-Western Cultures

The solutions or resolutions of ethical issues in genetic screening and testing as well as in other fields are shaped by a framework of ethical principles. Now the three (or four) basic ethical principles, i. e. beneficence (or plus nonmaleficence), autonomy and justice ^[1] which were developed in a medical context of Judeo-Christian culture have been widely accepted in the world as well as in some countries with non-Judeo-Christian culture. So it can be said that these principles form a common framework in the international community, and more or less became universal principles in the world.

However, when applying these principles to address ethical issues in developing countries there are some tensions between the principles and traditional values emerging there.

Each belief system or value system outlines an ideal world in which people behave according to the norms shaped by the system. Belief systems or value systems in different cultures outline different ideal worlds that are overlapping, but never identical. If we are not mistaken, the three basic ethical principles were developed mainly in a personal medical relationship between physicians and patients under an individualism-oriented and right-focused socio-political philosophy. Beneficence prescribes that the action physician takes should be in patient's individual best interest, autonomy - physician should respect patient's individual self-determination, and justice - physician should treat individual patient equally. However, even in the western context the priority of these principles has been controversial (e.g. which should be the first? Beneficence or autonomy), and they seem to be inadequate in some circumstances (e.g. in the prevention of HIV/AIDS pandemic) especially after medicine became a social institution. In the most of developing countries whose cultural traditions are non-Judeo-Christian the individualistic orientation and right approach are underdeveloped and emphasis is put more on collectives (family, community, society) and duties, and their priority of values and understanding of these ethical principles are different from their developed counterparts.

Case 1: In the responses to a notorious case in USA where physicians and ethicists had serious debate on a case in which a patient told his psychiatric doctor that he would kill his girl friend, however, the doctor failed to timely inform the girl or other people, and then the girl was killed, Chinese physicians and ethicists were curious at the debate taken place in

USA or other western countries. For them there is nothing to debate: Absolutely the doctor should timely warn the girl.

Case 2: Chinese colleagues also had a clear-cut answer to the question about a case in which a HIV positive male asked his doctor to keep his serological status confidential to his girl friend, because he wanted to marry her. The answer for Chinese is definitely no.

What is the difference between Western and Chinese colleagues? For Westerners, the balance between confidentiality and risk to the third party is needed. But for Chinese there is no controversy arisen not only because it involves the third party whose health and life will be at stake, but also because the motive of both patients is selfish. The latter point matters to Chinese, as they learnt from Confucianism in books or social conventions, the demarcation between a human being and an animal lies in whether he/she takes the other's interests into account or only care himself/herself. This is why Chinese traditional ethics is the one to teach people how to be a human being. Although we are born as human beings biologically, but it is not necessary to be human beings morally. To be a human being, has to learn ethics. "You are an animal" or "you are a beast" is a very serious curse for Chinese, it means you are not a human being morally, despite of you being a human being biologically. If a man behaves as an animal, any other has right to intervene with it and make efforts to protect others from the harm his behavior may bring to them. So for Chinese both patients' intention in these cases have gone beyond the limit of keeping confidentiality and talking about keeping confidentiality would become a disguise of being murder's or wrongdoer's helper.

The underlying assumption of these attitudes is a socio-political philosophy distinct from their Western counterparts. For Chinese, a person is

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not an individual atom in the community, but an inseparable part of it, as a water drop in the sea. A person can survive and his/her life can be extended only relying on mutual help and mutual support with other members of the community. So the ideal society for Confucianists is "Great Harmony" in which "people bring up others' children just like their own's, and support others' parents just like their own's", and the central principle of Confucian ethics is *ren*, which means "loving others" - from own parents and children, brothers and sisters to friends, neighbors, strangers, foreigners, animals and plants - "Harmony between Nature and Man". [2]

Case 3: In a Sino-American Program in Prevention of Neural Defects staff members tried to obtain the consent from women in some villages to be human subjects in a research project. They explained them that the participation in the project is in their best interests. But they were indifferent. After explaining that if the research is successful, it will benefit a great number of children and contribute the welfare of a great number of families in the world, women were willing to be human subjects. And the consent from all women is obtained after their negotiation with their family. [3]

Case 4: A woman patient, a computer scientist in Beijing, with breast cancer at terminal stage asked to withdraw the treatment from her because the treatment was useless to her, and she wanted to leave expensive and rare medicines to other patients whose conditions were hopeful. And she also asked to take active euthanasia for releasing the intractable pain from her and the physical and emotional burden from her husband and son. After obtaining support from her husband and son, she applied for it to the hospital. She died painlessly and peacefully. Her action was praised as "her death as noble as her life". [4]

These two cases show that

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1) for many Chinese intellectuals as well as many ordinary Chinese, his/her own action should not be only out of his/her own interests, or cannot be justified ethically only by the interests the action would bring to him/herself. In some cases, they are even willing to make sacrifice to save the other's life or release the other's suffering. As R. Dworkin [5] pointed out, there are some people in the West who refuse needed medical treatment because they believe that other people, who would then have to go without it, need it more. This action expresses one's own integrity and own character - values, commitments, convictions, and critical as well as experiential interests. In some cases we can even say that he/she is willing to be mere means for the other's end but not for his/her own end from his/her own free will but not by coercion. Perhaps, we should say that the end of his/her life is for the other's end. It seems to challenge Kant's ethical axiom to the effect that a person should never be treated as a mere means without his/her own end. Because he/she is treated by him/herself as a mere means and his/her own end is for the other's end.

2) As shows in clinical settings a patient's decision is rarely an individual personal decision, but usually a family decision. Sometimes, the community is also involved in the decision. So we can say that in any medical decision there are individual, personal elements as well as collective elements (family, community). It does not exclude the extremes: an exclusive individual decision or an exclusive collective decision as case 5 shows:

Case 5: A Chinese American woman patient was admitted into the hospital of NIH. When her doctor disclosed the medical information to her, she refused to listen and, instead, asked him to disclose it to her husband and obtain consent from him. It put the doctor into embarrassment. When the bioethics group consulted me, I suggested them to respect her preference. [6]

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This case also shows what a difficulty is when applying an ethical principle or rule which was developed in a Judeo-Christian context to a patient who was grown up in a Confucian context.

There will be no tension if the interests or preference of individual and that of the community are compatible. But in many cases there is tension between individual and community, the compromise between them has to be reached. Both individualistic orientation and community orientation are inadequate. We have to guard against over-individualistic orientation in developed countries where individual freedom has been abused, and against over-community orientation in developing countries where collective power abused. When there is a conflict between individual and community, no rule - neither individualistic rule which prescribes that the priority should be always put to the individual, nor communitarian rule which prescribes that the priority should be always put to the community - is universally applicable. What the priority is put to should be judged case by case. [7]

Values and Presumptions Underlying the Use of Genetic Knowledge

Before we discuss the ethical issues in the use of genetic knowledge, we first should address the issues on why we use it and how can we use it.

There will be no dissent on the answer to 'why' problem: we use genetic knowledge to improve human existence and quality of life. The following values can be promoted by the use of genetic knowledge:

- (a) Treat genetic diseases;
- (b) Prevent genetic diseases;
- (c) Reduce the occurrence of non-genetic diseases;

- (d) Enhance human traits;
- (e) Promote individual and family happiness;
- (f) Save resources for the society.
- (g) Respect well-being of future generation.

Any action of using genetic knowledge is predicated on the presumptions of these dichotomies, such as nature vs. nurture, biological determinism vs. social determinism etc. With the development of human genetics and the success of genome mapping project, more weight seems to be put on the innatism and biological determinism or genetic determinism of the balance. And the radical or hard determinism [8] claims that all human diseases, traits and behaviors be determined by their genes, and leaves no room for environment and individual's free will. However, except a few human diseases and traits, many of them are the result of interaction between multi-genes and environment. For some of them, such as mentality, the role of socio-cultural environment cannot be ignored. It is well-known that even the gene which control the brain is the best, if the baby is isolated from its interpersonal relationship or social environment, it will never become an intelligent child. Also the genes which cause the onset of some cancers have been known, but nobody can deny the role the human behaviors or environmental factors play in it, such as smoking, radiation and cancerogenic chemicals.

Radical genetic determinism also leads to medical solution of social problems. If all human behaviors are predetermined by genes, then not only at risk behaviors but also unethical and illegal actions can be explained by abnormal genes and can be corrected by gene therapy, not by health education, moral education or correction institutes. It will also raise some ethical and legal issues on whether offenders should be responsible or accountable for their unethical or illegal actions, because they have no choice

accountable for their unethical or illegal actions, because they have no choice by their free will. Genetic determinism in general, radical version in particular, will produce over-expectation to genetic knowledge and over-ambitious genetic program, and in turn make genetics be discredited as eugenics has been.

As for the enhancement of human traits, it raises no less issues. First, which kind of human traits should be enhanced, it will be a problem to which there will be no agreed answer among human beings. Second, when we reach an agreement of which kind of human traits should be enhanced, it may not be avoidable that people with the opposite and undesirable traits which are not to be enhanced will be stigmatized or discriminated. Third, there is no guarantee that the enhancement of human traits will not lead to eugenic practices such as in Nazis Germany.

These issues discussed above are only a few among the others. However, the discussion is to show that the view on what genetic knowledge can do and what it cannot do depends on these values and presumptions. So we should make them clear first before we turn to the more practical issues.

Ethical Issue in Genetic Screening/Testing

1. Voluntary vs. Compulsory

Genetic screening and testing should be voluntary in general according to the principle of autonomy or respect. However, "voluntary" means informed choice. If people are not informed, voluntary is meaningless. If we believe genetic screening and testing will benefit people and their family, and genetic services will become part of universal health care and genetic knowledge will become part of everyday life, geneticists and institutions concerned have

obligation and responsibility to provide genetic information and education to people. However, if people choose to not take genetic screening and testing after informed and educated, we have to respect their choice. But a) screening newborns can be compulsory when treatment is available for those affected by genetic disorders, because both parents and medical professionals have the obligation to protect the health and life of newborns; b) testing the sex of the fetus, unrelated to genetic diseases should be prohibited. [9] Although Chinese Ministry of Public Health has promulgated a prohibition on sex selection by genetic testing in January 1989, but this practice is still illegally going on, it is an important factor in sex imbalance.

I don't think we should absolutely exclude any compulsory genetic screening or testing if we recognize we have responsibility for the well-being of next generation. If I were a suspect of a dominant genetic disease, then my child will have 50% chance to get the disease too. I would feel I have the obligation to be screened or tested. Otherwise, my child contracting the disease would sue me of wrong life at the court when he/she know the truth. So this may form a moral basis to do compulsory screening and it will be in the best interests of my own, my child, and my family. And I believe that with the spread of genetic knowledge and the change of ethos leading people to more sense of responsibility for the health and life of our future generation, either the compulsory screening for some diseases will be generally accepted, or it becomes unnecessary because all people are voluntary to have it.

As an observer, I think the lesson from the genetic screening program for Tay Sachs Disease in Jewish community in USA as well as in other countries is that screening program will benefit a lot to the community. It is appropriate to respect Black people's decision to reject the genetic screening program for sickle cell anemia in the present socio-cultural context in USA

where black people are still more or less discriminated, vulnerable or marginalized. However, I believe one day the Black people will accept it.

2. Benefits vs. Harm

The potential benefits of genetic screening and testing must outweigh the potential harm, risks or costs according to the principle of beneficence. I would like to add that if genetic screening involves a group or some groups the benefits and costs should be distributed fairly intra-group or inter-groups according to the principle of justice. Any unfair distribution in which the benefits are unproportionally given to some people or some groups and the costs are unproportionally borne by the other is unjust.

I agree with the opinion that (a) Genetic screening and testing should be restricted to conditions that seriously affect the health of the individual and may be particularly appropriate to those conditions that result in death before adulthood; (b) it is inappropriate to screen for conditions that do not seriously affect health and/or which fall within the normal range of human traits; (c) it will be appropriate to screen for late-onset diseases for which preventive treatment is available, but it is unlikely to be appropriate for any testing to be done before adulthood in most cases.

3. Information: Disclosure vs. Withholding

All clinically relevant genetic information to patients and family members after screening or testing should be fully disclosed to them, except two kinds of cases: a) XY genotype in a female, and b) a woman's husband being not the biological father of her child, and the disclosure of genetic information to patients and family members should be followed counseling and education according to the principles of beneficence and autonomy.

If the patient refuses to disclose proven risks of harm to family members, the obligation of preventing harm to others will override the obligation of keeping confidentiality according the principle of beneficence or/and nonmaleficence. [9]

4. Counseling: Non-Directive vs. Directive

Counseling should be non-directive according the principle of autonomy. However, non-directive counseling does not mean geneticists should take a passive attitude to their clients. On the contrary, they should help their clients to know all relevant facts, understand their implications to them and their family, and encourage them to consider the facts in the context of their beliefs and values according to the principles of beneficence and autonomy. However, directive counseling can be ethically accepted in the case with incompetent patients, especially when genetic harm to others is great according to the principle of beneficence. [9]

5. Genetic Discrimination

Efforts should be made against genetically discrimination in insurance and employment, delivery of genetic services, and eugenics abuse. [10] It is right that the genetic screening of employees for increased occupational risks will be rarely necessary and efforts should be made by employers to improve occupational health conditions and reduce occupational risks, however, when the danger cannot be significantly reduced by the employer it becomes acceptable to screen employees and move those susceptible to a more safer, but any action of discharge from the employer should be legally prohibited. Any action the state may take to protect collective "gene pool", or "genetic cleansing", or positive eugenics should be prevented. However, negative

eugenics, i e. reduction and prevention of genetic diseases with genetic programs can be ethically accepted, but they should be implemented with clients' informed consent.

6. Access to Genetic Services

The state or society has the responsibility to provide genetic services including genetic screening and testing which are accessible, quality-guaranteed, effective, and affordable to its people. However, in the developing countries with rare resources it can only be achieved gradually. They should have a program to develop genetic services step by step but steadily, insistently, and progressively. And a program for sharing the genetic knowledge and expertise between developed and developing countries and for collaboration between them has to be developed. [11]

Ethical Issues in Human Gene Therapy

1. Definition

It is acceptable to define human gene therapy as: Human gene therapy is the deliberate alteration of the genetic material of living cells to prevent or treat disease; somatic cell gene therapy is defined as the procedures that alter the DNA of the body's differentiated cells, that is cells that lack capacity to transmit genetic material to children; and germline gene therapy is the therapy that changes the DNA of reproductive cells. [12]

Before we discuss ethical issues in human gene therapy we have to make clear the criteria of how to establish an action is obligatory, prohibitive, and permissive. The criteria are: If the result of an action taken will get the present world situation better with certainty according to certain belief

system, then the action is obligatory; if the result of an action taken will get the present world situation worse with certainty according to certain belief system, then the action is prohibitive; and if whether the result of an action taken will get the present world situation better or worse with uncertainty according to certain belief system, then the action is permissive. However, when we apply these criteria to gene therapy, we have to take other variables into account.

2. Somatic Cell Gene Therapy for Treatment

First, gene therapy is only at the stage of experiment, lots of things are uncertain. In the case of somatic cell gene therapy, we know in theory that it is very likely that the therapy can result in the cure of certain genetic diseases. However, during the therapy, we cannot categorically exclude the possibility of that after the domesticated retrovirus used as a normal gene carrier has been integrated into the host's somatic cell, it will be activated and cause virus infection in the host, or activate other pathogenic factors, such as dormant cancer-causing genes, although it is not very likely on the basis of present experiences. And so far animal model which will help us to know what really happens in the host after the domesticated retrovirus enters into it has not been successfully created yet. So somatic cell gene therapy is permissible and now is better used as an experimental treatment which can only applied to a serious disease caused by the gene we exactly know and treated by no other therapy, and cannot be widely applied to many other diseases. And even somatic cell gene therapy is permissible, therapists have the obligation to obtain informed consent from patients, go through strict review procedures before the therapy, and carefully monitor the patient's conditions during the therapy with necessary precautions and safeguard.

3. Germline Gene Therapy for Treatment

Second, in the case of germline cell therapy for treatment, there are more complicated factors apart from those uncertain in somatic cell gene therapy, because it involves the uncertain changes which can be transmitted to future generation, and it is uncertain that these changes will be in best interests of our offspring and will be consented by them if they are able to make choice by themselves. This is new variable and raises a new ethical problem: What is our responsibility for our future generation. Is it permissible for us to leave such uncertain changes in the body of our future generation? There are no sufficient reason to permit us to do so. We agree that germline gene therapy is indefensible at present. [12] But we don't agree that it should not be categorically disapproved. [12] Because the meaning of the phrase "categorically disapproved" is ambiguous. If it means that in the long run the germline cell therapy applied to humans will be able to become defensible one day. We believe it will happen one day. If so, we agree. But if it means that although the germline gene therapy is indefensible now, however, in certain circumstances we can try it. Then we don't agree. Because at all times we are obliged to do good with certainty to our future generations, and not permitted to leave so many uncertain and even probable bad to them.

4. Gene Therapy for Enhancement

Third, in the case of gene therapy for enhancement, there are much more variables. First, which traits are to be enhanced? What is the criterion to select which traits should be enhanced and which are not? One of Chinese geneticists said that 1.6m in height is most desirable, because it will save so much resources for the society. His criterion is to see which trait can save

resources. However, the officials in the department of sports and many coaches would say that 2.5m is most desirable, because it will help our sportsmen and sportswomen to win more golden medals in Olympic Games. How to solve their conflict on how much height should be enhanced? Or, is any individual permitted to enhance one of his/her traits, such as height, weight, skin or eye color, power of muscle, speed of running, and others? Does the enhancement of one trait will disturb the balance within his/her body established before the enhancement, or even leads to weakening of other traits? The use of gene therapy for enhancement will be a slippery slope leading to eugenic practice and to stigmatization or discrimination against those who bear traits which are not to be enhanced. So playing God will lead to lots of unexpected and negative consequences which may be difficult to be remedied. So we agree that the use of gene therapy for enhancement purposes may be widely prohibited, and the use of germline gene therapy for enhancement purposes should be categorically prohibited. But we don't agree that the "but": it should not be categorically disapproved as unethical in all imaginable circumstances.^[12] As we have argued above, what, does it mean by "categorically disapproved" is ambiguous, so is "in all imaginable circumstances". It should be specified that which are imaginable circumstances. Up to now the use of gene therapy should be prohibited until there is new emerging condition which provides sufficient reason for us to consider it again. [13][14]

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