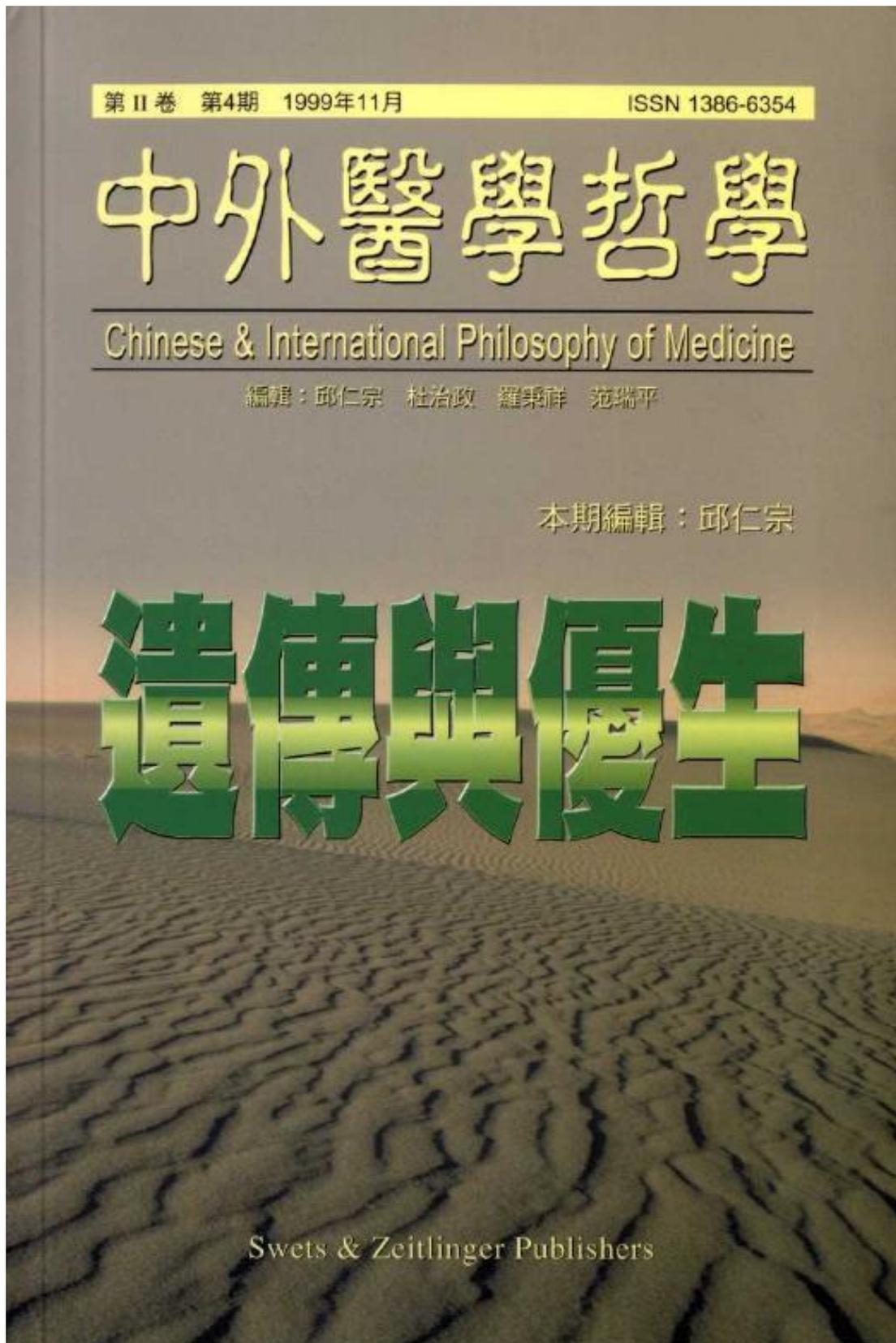


[Table of Contents\(目錄\)](#)

[中文摘要](#)

[Abstract\(English\)](#)



[Order](#)

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遺傳與優生
Genetics & Eugenics

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邱仁宗 Qiu Renzong	導言 Introduction
吳秀瑾 Wu Shiuching	基因資訊——文化與後現代倫理觀 Genetic Information and Everyday-Life Choices——A View from the Postmodern Ethical Perspective
Ted Peters	“扮演上帝”與生殖系干預
楊煥明 Yang Huanming	人類遺傳學家的社會責任 The Social Responsibility of Human Geneticists
Rosamond Rhodes	遺傳聯繫、家族關係和社會紐帶：面對遺傳知識的權利和責任
胡新和 Hu Xinhe	中國文化視野中遺傳知識的應用 The Use of Genetic Knowledge in Chinese Culture Context
Eric T. Juengst	在遺傳醫學中能否區別增強與預防？
邱仁宗 Qiu Renzong	科學與政治：遺傳學歷史上的辛酸教訓 Science and Politics: Lessons from the History of Genetics
Ellen Wright Clayton	對兒童進行遺傳檢測

摘要

作者在論述對基因科技的不同觀點後，指出在兩極化的爭論中，雙方的後現代倫理觀背後均隱含相同的預設，即個人自主性與同意原則背後的線性思考、還原立場和全體是部分的總合的機械觀。作者提出了另一種非線性、非還原的後現代觀點，並將嘗試從非線性思考中推論出對道德觀的可能蘊涵。作者根據非線性的後現代道後立場，提出吾人面臨基因科技作出因應的道德指導方針。

目錄

“扮演上帝”與生殖系干預**Ted Peters****摘要**

對於新聞記者來說如此熟悉的短語“扮演上帝”在關於生殖系的遺傳干預的爭論中顯現出重要的意義。雖然在“扮演上帝”這個短語中蘊含著人類自鳴得意所帶來的危險，但在這裏特別注意基督教的那種按神的形象創造的人的觀念。人類被賦予了“被創造的創造夥伴”的稱號。有鑒於此，在考查和反駁禁止生殖系干預的倫理時，以一種開放的態度來讓這一世代對我們後代擔負創造性的責任。

目錄

摘要

作者首先指出科學是一把雙刃劍，科學家是鑄造和掌握這把雙刃劍的人。因此有責任去關注對科學技術的正當使用，使之有益於人類。中國人類遺傳學家當前有四項責任：加速研究並應用於衛生保健；最大限度減少/ 避免遺傳信息和保護措施的誤用/ 濫用，其中尤其是要堅持知情同意/ 知情選擇和保護隱私原則；積極參與 ELSI 爭論；以及教育臨床醫生、公眾和自己。他強調，更重要的是我們必須充分地認識到通過遺傳學措施提供給特定個人的具體幫助與“改良人口質量”的本質區別。我們必須探索隱藏在 30 億城基對內的秘密，我們人類和我們社會一直是依靠這些城基進化和發展的。我們必須努力工作來更新我們關於我們基因的知識，並應用這些知識於人民的衛生保健和我們的社會。

目錄

遺傳聯繫、家族關係和社會紐帶：面對遺傳知識的權利和責任

Rosamond Rhodes

摘要

目前，涉及遺傳聯繫的一些意義大的道德問題與遺傳知識有關。在這篇文章中，我沒有著眼於通常提到的專業或公共機構對個人負責的問題，而是著手談論就遺傳知識而言，個人應相互負有的責任。我提出：個人在不提供社會的群體遺傳學知識、不增加他們的家族的遺傳歷史知識、不發現關於他們自己和他們後代的遺傳信息的情況下，是否具有追求自己目標的道德權利。這些問題引導我們考察對遺傳未知的推定權利並探究各種各樣的社會紐帶。根據上述考慮我分析了幾個案例，從而導致了一些意想不到的結論，觸及了廣為人們接受的遺傳諮詢規則，也獲得了對典型問題的倫理學洞察力，並且進一步引發了未被答覆的面對遺傳知識個人所負何種責任的問題。

目錄

摘要

本篇論文由四部分組成。第一部分旨在探討那些在猶太—基督教文化中形成的有關遺傳學問題的倫理學原則，在被應用於非基督教文化傳統中的這些問題時的情形；第二部分將討論有關遺傳知識應用的某些價值和預設；第三和第四部分中，要分析在遺傳知識的應用中，尤其是遺傳檢測和基因治療中的某些具體倫理問題。

目錄

在遺傳醫學中能否區別增強與預防？

Eric T. Juengst

摘要

對使用人類基因轉移技術治療健康問題與使用該技術增強或改善正常人遺傳特性加以區分已成為討論基因治療倫理學的標準。一些人對這一區分的規範力提出質疑，認為這忽視了如何在醫學上合法使用人類基因轉移技術預防疾病。例如：用基因工程增加免疫功能，改進 DNA 修復功能或增添細胞受體獲得和處理膽固醇的功能。一些批評者認為，如果疾病預防是醫學的正當目標，使用基因轉移技術增強人類的健康維護能力將有助於實現這一目標。然而，“治療 / 增強”的區分法不能對合法基因治療進行界定。我論證在基因治療的預防與增強(以及在基因治療醫學方面的正確使用與基因治療非醫學方面的使用)之間能夠劃一條線，但只有你願意接受以下兩種老式的主張：1)一些健康問題最好被理解為體現在生物系統中各種過程或部分的實體，至少具備了像受抑制的功能一樣的本體論客觀性與理論意義。2)合法的預防性基因保健應該限於努力保護人的不受更強有力的病理實體的侵襲，而不是改變他們的身體以逃避社會的不公平。

目錄

摘要

18屆國際遺傳學大會達到的八點共識具有重要意義。這一共識實際上總結了遺傳學歷史的教訓，也指明了在遺傳學及其應用問題上不同文化之間如何解決它們之間分歧的最佳途徑。納粹德國的優生實踐和蘇聯李森科學派的興衰都給我們留下了不可忘記的教訓。圍繞中國母嬰保健法的爭論反映了科學、倫理和政策的交叉。我們提供遺傳服務是為了增進個人的健康和促進家庭的幸福，而不能也不應以減少殘疾人口為目標。在提供遺傳服務中必須堅持知情同意原則，由於醫患雙方價值觀念未必一致，甚至經常發生的不一致，當事人的自主決策尤為重要。

目錄

對兒童進行遺傳檢測**Ellen Wright Clayton****摘要**

在這篇文章中，作者主要論述了在給兒童作遺傳檢測問題上，父母與醫生誰更有決定權。她認為，父母應該更有理由判定遺傳檢測對於他們的孩子是否有好處。而且他們在作選擇時，可以適當考慮其利益(除了孩子利益之外)。然而，醫生認為，遺傳檢測會對孩子為生極大危險時，他們可以拒絕執行父母對於該孩子進行檢測的要求。對於一系列的討論將說明在此問題上如何平衡父母與醫生對此問題的控制。對父母要求檢測攜帶者的狀況和對遲發疾病的遺傳傾向，通常有理由加以拒絕。作者通過討論為甚麼隨著孩子年齡的增長而逐漸遵從他們的意見是適當的這一問題對她的分析做出了總結。

目錄

**Genetic Information and Everyday-Life Choices —
A View from the Postmodern Ethical Perspective**

Wu Shiu-Ching

Abstract

If machine engine is the emblem of the industrial age, computer for the advanced industrialization, it would be safer to say that genetic information revealed through decoding genome can be an emblem of the ongoing postmodern age. Leaving safety and availability issues aside, the rapid development of genetic technology, including artificial reproduction, genetic therapy, genetic engineering and cloning, opens many choices never thought before. Likewise, it also radically challenge our traditional way of handling with giving birth, enhancing health, curing disease and improving farming productivity. Many questions arise, such as, would it be moral to reproduce by way of 'unnatural' means? would it be moral to manipulate our human nature at one's will? Or, would it be moral to play God? All and all, these questions lead to the final one, i.e., where will genetic technology may lead to? - the brave new world or humanity's extinction?

The aim of this paper is to investigate two leading postmodern ethical perspectives and their different moral implications toward technology in general, and genetic development in particular. I will point out that both positions represented by Engelhardt and Bauman, although being the same at criticizing Enlightenment reason and modern universalization of morality, are bifurcated at our moral attitudes toward genetic technology. The bifurcation, as I argue, becomes clearer, if we read Engelhardt through Silver's *Remaking Eden*, and read Bauman through Fox's *Superpigs and Wondercorn*. The alliance, as I understand, helps us to see that, while Engelhardt/Silver pair sees new possibility developed through genetic technology, including refashioning one's nature, thus, a brave new world, what Bauman/Fox pair sees, on the contrary, is the possible catastrophe created by manipulating the very same techniques. Which direction should we lead to?

My main thesis in this paper is to argue that underlying the bifurcation is the same theoretical assumption, namely, linear and reductive thinking pattern regarding part-whole relations. Likewise, their respective postmodern ethics shares the very same starting-point, i.e., the concept of freedom based on linear and reductive reasoning. Likewise, either based on the free choices of moral person to refashion human nature (Engelhardt/Silver), or based on 'the duty to visualize the

future impact of action' (Bauman), I see that both alternatives are one-sided. As I will continue to argue in this paper, there is an alternative way of understanding postmodernity defined by nonlinearity, nonreductivity and top-down causation. The moral implication of nonlinear and nonreductive thinking, I hold, is a paradigm shift from moral theory based on linear and reductive thinking. Likewise, I would also suggest that, from the standpoint of nonlinear postmodern ethics, we don't have to choose between either overaction through individual freedom uninhibited by the state authority, or simply choose to do nothing because of fearing unintentional consequences in the long run. Instead, as I would conclude in the paper, we can work out different ELSI(ethical, legal, social issues) guidelines in terms of different degrees of individual perturbations and genetic risks with respect to various time periods.

Table of Contents

Abstract

The advances of the world-wide Human Genome Project and other research in this field have led to the explosion of knowledge about our genes which are so widely and deeply involved in our lives. The knowledge and related technologies have already made a great impact on the whole society.

Science is only good when it is applied to the society in a proper way. Science has proved itself a double-edged sword. The sword is in the hands of the scientists who should be closely observed by the public. As human geneticists, we should be the best to know that genes and their related technologies would be the most dangerous if they were abused or misused, while we expect all good from them. The reason is very simple: we are dealing with the nature and essence of ourselves. It is the moral, professional, and social responsibility for us, human geneticists, to pay serious attention to the ethical, legal and social issues (ELSI) related to the genes which we are playing with, to make sure that the knowledge and technologies about the genes will serve the people, instead of harm to the society presently and in the future.

I would like here to propose four responsibilities for discussion with my colleagues both home and abroad, even my topics are limited to my own country.

1. To develop research and apply genetic knowledge and technologies to health care

2. To minimize/avoid the abuse/misuse of genetic information and measures by our own common sense and moral responsibility

a. The 'demand-driven effect' of the urgent need for genetic services

b. The 'amplification effect' by the huge population and enormously large number of clients

c. The 'historic lessons'

I here try to list two principles which, I think, have been widely accepted as common senses for people like us, as well as our moral responsibility in our career.

a. The principle of 'informed choice and informed consent'

The first application of this principle is to research, for example, when we take a blood sample or other genetic material from a donor. The second application of this principle is to offer counselling or diagnostic or even therapeutic measures. Counselling is non-directive, because finally the client should make the 'informed

choice' by himself/ herself, without any threat or pressure presently and afterwards, and sign the 'informed consent form' before a genetic measure is offered. It is also simply common sense that we cannot do everything at the request of a client, e.g. sex determination of a fetus, or cloning of herself/himself. Anything that is not allowed to be done by law in the developed countries will absolutely not be allowed to be done in China. China will never be the test field to which some unethical experiments will be transferred. China will never be the place to host any 'Jurassic Park'.

b. The principle of privacy

All human geneticists and clinicians who are involved in genetic services, no matter how, when or where they were trained, should have the common sense in their career about how to protect the privacy of patients. Genetic information is generally related to their health in the whole life and fate in the society, and is the ultimate privacy of a citizen. No genetic information can be released to any other individual, any organization, or any department of the authorities, without the 'informed consent' and specified legal procedures. Needless to say it is not allowed to be released to the places related to dignity, marriage, employment, insurance of the clients. The client's 'right not to know' should also be respected.

3. To debate on the ELSI

In the past years, through the effort of Chinese ethicists and geneticists, the discussions about bioethics have started. Three good examples are public debates on cloning of humans and on the protection of genetic resources, as well as the recent serious debate on the ELSI at the 18th International Conference of Genetics, August, 1998, Beijing.

4. To educate the clinicians, the public and ourselves

It is urgent and extremely important to educate the clinicians, the public and, at the same time, ourselves. The Chinese Human Genome Project will include an education programme. The education of an army of clinicians in different medical branches who are directly involved in genetic service every day is even more important and urgent. It is they who are dealing with the genes related to human lives and the society and waving the 'double-edged swords'. It is they who are applying the genetic knowledge and measures to the people. It is they who are given the power to issue the 'certificate of marriage' or 'certificate of permission to give birth'. It is they who are responsible for the present and future society by avoiding or minimizing the abuse or misuse of genetic information or measures. The educators should be educated first. We have to soberly realize that

we still know so little about our genes, the direct and observable effects of the genetic measures and those long-term and unobservable and unpredictable effects on the human society and the future. We are even unable to clearly distinguish 'good genes' from 'bad genes', 'normal genome' from abnormal or 'disease genome'. We don't understand the potential positive significance of the 'bad alleles' present in our bodies and in the population. We don't know the nature of natural gene therapy of the genetic diseases. Most importantly, we have to fully realize the substantial differences between specific help offered to a specific individual and 'improvement of the population quality' by means of genetic measures. We have to explore the secrets hidden in the 3 billion base pairs on which we human beings have been evolving and our society is developing. We have to work very hard to update our knowledge about our genes and apply it to the health care of the people and our society.

Table of Contents

Abstract

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 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. The 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. 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.

Cases show that 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. 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). 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.

Any action of using genetic knowledge is predicated on the presumptions of these dichotomies, such as nature vs. nurture, biological determinism vs. social determinism. With the development of human genetics, innatism and biological determinism seem to prevail. However, except a few human 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 ignorable.

Genetic screening and testing should be voluntary in general according to the principle of autonomy or respect. However, "voluntary" means informed choice. 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; testing the sex of the fetus, unrelated to genetic diseases should be prohibited. The potential benefits of genetic screening and testing must outweigh the potential harm, risks or costs according to the principle of beneficence. 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. 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; it is inappropriate to screen for conditions that do not seriously affect health and/or which fall within the normal range of human traits; and 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. 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: XY genotype in a female, and 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 counselling and education according to the principles of beneficence and autonomy. Counselling should be non-directive according the principle of autonomy. However, non-directive counselling 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. Efforts should be made against genetic discrimination in insurance and employment, delivery of genetic services, and eugenics abuse. Any action the state may take to protect collective "gene pool", or "genetic cleansing", or positive eugenics should be prevented. 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 programme to develop genetic services step by step but steadily, insistently, and progressively.

The following suggestion was discussed either: Somatic gene therapy is permissible, regulated as an experimental therapy. Its use for enhancement purposes may be widely prohibited, but it should not be categorically disapproved as unethical in all imaginable circumstances. Germline gene therapy is indefensible at present, but it should not be categorically disapproved. The use of germline gene therapy for enhancement purposes should be categorically prohibited.

Abstract

What happened in Nazi Germany or Nazi Genetics and eugenics left us a grave lesson we should never forget. We must keep in our mind that everybody is ethically and legally equal regardless of race, healthy or ill, smart or retarded, and enjoy equal rights including life, health, marriage and reproduction. Calling retarded "inferior" is a discriminatory action. Science, medicine and genetics aim at "better life for all", should not do harm to anybody who comes to seek help. Technologically possible does not amount to ethically obligatory. Technological imperative is untenable and harmful. State intervention into private affairs such as marriage and reproduction should be minimum. The lesson left by the event of Lyshenko in the former USSR is that it is necessary to distinguish between academic issues and political issues. But this distinction does not mean that science can be free from value. Scientific knowledge and especially its application involves social, ethical and legal issues that science alone cannot resolve. The episode around the 18th Congress of Genetics in Beijing highlighted the involvement of genetics with political pressure, cultural prejudice, misleading conceptions and linguistic barriers. However what cannot be excluded is that some ethicists, geneticists and officials have confused conceptions on several important issues.

The original meaning of eugenics in Greek is similar with Chinese 'yousheng', 'healthy birth'. But the practice of eugenics in Nazi Germany and other European-American countries turned the term 'eugenics' into the meaning of a social program imposed by the state. When the term 'eugenics' is used in literature, the meaning is different to different people. 'Yousheng' in Chinese language means to help parents to give birth to a healthy baby by means of genetic services. It is completely wrong for anybody to try to impose this program to Chinese couples. Genetics is the art of ren as well as medicine. Ren means caring and doing good to people. In some documents, articles or books mentally retarded is called 'inferior' and it was said that there are four groups who have no value for reproduction, there was a law to limit the reproduction of 'inferior' or compulsorily sterilize mentally retarded in some provinces, all these practices are ethically wrong and legally invalid. It should be made clear that the purpose of providing genetic services is to improve individual health and promote family happiness. The attempt to use genetics to reduce disabled population is ethically

unjustifiable. In any case, especially in the matter of marriage and reproduction the principle of informed consent and informed choice should be upheld and genetic counselling geneticists provide should be non-directive. Only in the case that we fully learn lesson from the history and uphold the ethical principles mentioned above genetics will achieve its noble goal: better life for all.

Table of Contents