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Chinese Geneticists' Views of Ethical Issues in Genetic Testing and Screening: Evidence for Eugenics in China

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Summary

To identify Chinese geneticists' views of ethical issues in genetic testing and screening, a national survey was conducted. Of 402 Chinese geneticists asked to participate, 255 (63%) returned by mail anonymous questionnaires. The majority of respondents thought that genetic testing should be offered in the workplace for α-antitrypsin deficiency (95%) and the predisposition of executives to heart disease, cancer, and diabetes (94%); that genetic testing should be included in preemployment physical examinations (86%); that governments should require premarital carrier tests (86%), newborn screening for sickle cell (77%), and Duchenne muscular dystrophy (71%); and that children should be tested for genes for late-onset disorders such as Huntington disease (85%), susceptibility to cancers (85%), familial hypercholesterolemia (84%), alcoholism (69%), and Alzheimer disease (61%). Most believed that partners should know each other's genetic status before marriage (92%), that carriers of the same defective gene should not mate with each other (91%), and that women should have a prenatal diagnosis if medically indicated (91%). The majority said that in China decisions about family planning were shared by the couple (82%). More than half had views that, in China, there were no laws to prohibit disability discrimination (64%), particularly to protect people with adult polycystic kidney disease (57%), cystic fibrosis (56%), or genetic predisposition to other diseases (50%). To some extent, these results might provide a basis for a discussion of eugenics in China, particularly about China's Maternal and Infant Health Care Law (1994).

Introduction

Genetic testing and screening are hot topics that stimulate widespread discussion and debate, not only among genetics professionals, but among clinicians and scientists generally, and increasingly these topics involve the wider public in developed countries. Views are expressed in the scientific and general press, and through other media, about the likely benefits and dangers that may result from genetic testing and screening (Harper and Clarke 1997).

However, there is much less debate about genetic testing and screening in developing countries, where ~95% of the world's future children will be born. To some extent, this situation reflects the lack of genetics services in these countries. A majority (3,330) of the estimated 5,000 specialists in medical genetics worldwide work in developed countries, which have an overall geneticist/population ratio of ~1:222,000, compared with a ratio of ~1:700,000 for eastern European countries and ~1:3,700,000 for developing countries (Wertz et al. 1995). Clinicians, scientists, and the public in developing countries are focused on the struggle to improve basic health care. Given the problems of poverty, illiteracy, low contraceptive use, and high infant mortality (Galjaard 1997), they have relatively little interest in the development of genetics research and services.

China, however, is an exception, having to some extent made genetics a priority. For example, in the 1960s cytogenetics technology was introduced to China, and in the 1970s chorionic villi sampling was performed in some hospitals (Luo 1988). Since the 1980s, molecular-genetic techniques have been used in genetic research and counseling in several national genetic laboratories (Luo 1988; Fu et al. 1995). In 1988, in vitro fertilization, embryo transfer, and gamete intrafallopian transfer were available in several teaching hospitals (Zhang et al. 1988). In 1992, the techniques of enrichment of fetal cells from maternal blood, for prenatal diagnosis and sex determination during the first trimester, were introduced to China. In 1994, China launched its Human Genome Project (Li 1994). Gene therapy for patients with hemophilia B has also been used in clinical trials (Fu et al. 1995).

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On the other hand, according to international standards, genetics services in China are underdeveloped because of a lack of funding and expertise, as well as the large number of people with genetic conditions (Harper and Harris 1986; Luo 1988). Chinese geneticists have expressed their views about ethical, legal, and social issues in genetics research and practice in China. Their concerns are, however, quite different from those of other countries, particularly developed nations (Mao 1996, 1997; Mao and Wertz 1997).

The term "eugenics" has many meanings. Eugenics can be voluntary or coerced, government sponsored or individual, a "science" or a social policy, based on the welfare of individuals or on the welfare of society or a nation (Paul 1992; Garver and Garver 1994; Larson 1995; "Brave New Now" 1997). Most people in developed countries today think of eugenics as a coercive social program enforced by the state for the good of society. Since China announced the Maternal and Infant Health Care Law (1994), it has provoked widespread concern in the international scientific community, because of some of its eugenic content ("China's Misconception of Eugenics" 1994; "Western Eyes on China's Eugenic Law" 1995; O'Brien 1996; "Brave New Now" 1997; Harper and Clarke 1997; Morton 1998). There has, however, been very little international discussion on what eugenics means for Chinese geneticists and why it is alive and well in China. In this article, I will present Chinese geneticists' views of ethical issues in genetic testing and screening and will discuss the likely basis of eugenics in China, particularly China's Maternal and Infant Health Care Law (1994).

Subject and Methods

An anonymous international questionnaire including 50 questions on ethical issues, which was used in an international study comparing attitudes of geneticists in 37 nations (Wertz and Fletcher 1993), was distributed to 402 geneticists in 30 provinces and autonomous regions in mainland China. These geneticists were registered members of the Chinese Association of Medical Genetics, the Human and Medical Genetics Branch of the Chinese Society of Genetics, or the Chinese Society of Family Planning, all of which are headed by the Chinese Association for Science and Technology but are affiliated with different departments of state (the Ministry of Public Health, the Chinese Academy of Science, and the National Committee of Family Planning, respectively). In all, 255 geneticists (63%) responded. All of the respondents' comments were translated into English. The completed questionnaires were mailed to the Division of Social Science, Ethics and Law, at the Shriver Center for Mental Retardation, in the United States, for statistical analysis. Coded data were entered into the SPSSX program (from Statistical Package for the Social Sciences) on an IBM 3090 computer (Mao and Wertz 1997).

Results

The questionnaire asked whether genetic testing should be offered for job application–related situations; the majority of respondents thought that genetic testing should be offered to workers for α-antitrypsin deficiency in a very dirty workplace (95%) and for executives' predisposition to heart disease, cancer, and diabetes (94%).

The questionnaire listed several ethical issues designed to survey respondents' opinions. The majority of respondents agreed that partners should know each other's genetic status before marriage (92%), that carriers of the same defective gene should not mate with each other (91%), that women should have prenatal diagnosis if it is medically indicated (91%), that genetic testing should be included in preemployment physical examinations (86%), and that governments should require premarital carrier tests (86%) and newborn screening for sickle cell anemia (77%) and for Duchenne muscular dystrophy (DMD) (71%) (table 1). Sixty-five percent agreed with the statement that "an important goal of newborn screening is to identify and counsel parental carriers before next pregnancy."

When Chinese geneticists were asked whether parents should be able to have their children tested for late-onset disorders or predisposition to such diseases, the majority said that, if parents request it, children should be tested for Huntington disease (85%), susceptibility to cancers (85%), familial hypercholesterolemia (FH) (84%), and predisposition to alcoholism (69%) or to Alzheimer disease (AD) (61%) (table 2).

When asked whether there was a prevailing pattern for decisions about family planning, most (82%) said that decisions about family planning were shared by the couple. The minority believed it to be determined by the husband's (10%), doctor's (3%), wife's (2%), husband's parents' (2%), or wife's parents' (1%) views (table 3).

When asked whether there were any laws prohibiting disability discrimination, more than half of Chinese respondents said that there were no such laws in China (64%), particularly to protect people with adult polycystic kidney disease (57%), cystic fibrosis carriers (56%), and persons with genetic predisposition to other diseases (50%) (table 4). Ninety-four percent agreed with the statement that "it is not fair for a child to be brought into the world with a serious genetic disorder if the birth could have been prevented;" 79% thought that some disabilities will never be overcome even with maximum social support, and the majority would not

Table 1

Views on Various Ethical Issues

Ethical Issue	Agree (%)	Neither Agree nor Disagree (%)	Disagree (%)
Partners should know their genetic status before marriage	92	7	1
Carriers should not mate with each other	91	5	4
Woman should have prenatal diagnosis if medically indicated	91	8	1
Genetic testing should be included in preemployment physical examinations	86	12	2
Governments should require premarital carrier tests	86	10	4
Governments should require newborn screening for sickle cell	77	21	2
Governments should require newborn screening for DMD	71	22	7
Woman's abortion decision should be her own	40	19	41
Patients should have right not to know test results	29	28	43
Useless to test if the only treatment is abortion	27	10	63
Prenatal diagnosis should be provided regardless of intended use	13	10	77

support disabled parents' decisions to have disabled children. Ninety percent thought that an ethical code or guidelines for genetics services are needed in China, and 50% said that public education in genetics should be the top priority of the government health budget.

Discussion

Genetic testing, which is offered to individuals and families who are at high risk, is either the analysis of a specific gene—and/or its product or function—or other DNA and chromosome analysis, to detect or exclude an alteration likely to be associated with a genetic disorder. Genetic screening is applied to large population groups with unknown excess risk to individuals. Screening is frequently part of government-sponsored public-health programs and may be a preliminary procedure that identifies people at elevated risk of genetic disease, but it does not provide a definitive diagnosis (Wertz et al. 1995; Harper and Clarke 1997).

In this survey, questions about newborn genetic screening were asked. This is because newborn screening for phenylketonuria (PKU) and hypothyroidism has saved many thousands of infants worldwide from these two severe disorders and therefore has created a large store of goodwill and ethical credit in favor of genetic screening programs (Harper and Clarke 1997). This survey shows that 77% of Chinese respondents thought that the government should require newborn screening for sickle cell disease (table 1). The figure is higher than those for the United Kingdom (13%) and the United States (11%) (Wertz 1995). One explanation for this difference might be that Chinese geneticists believe that identification of parents and newborns who are heterozygous carriers is important, since sickle cell disease is very common in China. Although newborn screening for DMD fails to meet the established World Health Organization guidelines for the adoption of a screening program (Wilson and Jungner 1968), it might be helpful to avoid diagnostic delays and to permit families to seek genetic counseling before they embark on another pregnancy. The mothers of infants in the United Kingdom appeared to have more enthusiasm for newborn screening for DMD, since 94% of them would accept such screening (Smith et al. 1990). When geneticists around the world were asked whether the government should require newborn screening for DMD, 71% of Chinese respondents, 64% of respondents in the United States, and 49% of respondents in the United Kingdom thought that the governments should do so (table 1) (Wertz 1995). On this issue, the difference between geneticists in China and the United Kingdom may be that Chinese geneticists believe that newborn screening for DMD is a public-health issue, and that, because it is very expensive in China, it must be government sponsored. Geneticists in the United Kingdom are concerned about the state directing genetic decisions, rather than individuals making the choices (Harper and Clarke 1997). In addition, the majority of European, North American, and Chinese geneticists would recommend newborn screening for cystic fibrosis, FH, fragile X, and thalassemia if

Table 2

Views on the Testing of Children for Late-Onset Disorders

	CHILDREN SHOULD BE TESTED[a]	
DISORDER	Yes (%)	No (%)
Huntington disease	85	15
Susceptibility to cancer	85	15
FH	84	16
Alcoholism	69	31
AD	61	39

[a] For gene for either adult onset or predisposition.

Table 3

Views on Family Decision Making

	Agree (%)
Couple should make decision	82
Husband should make decision	10
Doctor should make decision	3
Wife should make decision	2
Husband's parents should make decision	2
Wife's parents should make decision	1

automated DNA diagnostic techniques were available on newborn blood spots, even though there is no proof that the newborn benefit from such screening (Wertz 1995). It may still be reasonable to offer such screening if the disease has its onset in childhood and if the child's family finds it helpful to have an early diagnosis (Harper and Clarke 1997).

The advent of DNA-based testing across a wide and increasing range of late-onset genetic disorders is a challenge to conventional thinking about medical tests. This is because those individuals receiving an abnormal result are sometimes considered, by themselves and others, to "have the disease," even though they are still presymptomatic. Testing children for late-onset genetic disorders may have serious ethical and social implications. This survey shows that most Chinese geneticists thought that children should be tested for susceptibility to cancers and FH (table 2). Most geneticists in Europe and North America expressed the same view, since they saw early diagnosis and early treatment of these disorders as being a potential benefit to the child (Wertz 1995). However, most of them thought that testing for Huntington disease, alcoholism, and AD provided no medical benefit to the child (Wertz 1995). They opposed the testing of children, on the grounds that testing was an affront to the autonomy of the child, who, on reaching adulthood, should be allowed to make his or her own decisions on whether to be tested. Most Chinese geneticists favored such testing (table 2), on the grounds that parents should be able to decide for their children and should have the power to direct their children's lives. This cultural division reflects the extension of individual autonomy in developed countries, to include preservation of the autonomy of minors. In China, the child is often seen as part of a collectivity (the family), rather than as a potentially autonomous individual.

Although, thus far, employers' requests for employment-related genetic testing have been few (Harper and Clarke 1997), questions on whether such testing should be offered were included in this survey because there is an ethical conflict between the individual's rights and the employer's interest. More and more Western geneticists have expressed their concerns on the likelihood of misuse of such testing, which would cause harm to those employees with genetic conditions (i.e., genetic discrimination; Harper and Clarke 1997). This survey shows, however, that most Chinese geneticists agreed that such testing should be offered as a part of a routine physical examination. This result may demonstrate that Chinese geneticists hold strong social views on genetics services (Mao and Wertz 1997).

One purpose of genetics services is to provide accurate, full, and unbiased information that individuals and families may use in making decisions. Traditionally, China has been a paternalistic society and parents have had absolute power to make family decisions. To explore the current situation of family planning in China, questions on this issue were asked. This survey shows that, of 255 respondents, 51% were female (Mao and Wertz 1997). Most of them thought that family planning was currently shared by the couple. This figure is quite similar to that in developed countries (Wertz 1995) and, in part, may reflect socioeconomic changes that have occurred in China during the past 4 decades.

In 1994, China's population reached 1.2 billion. Now China is pushing on with its goal of ensuring that the country's population is ⩽1.3 billion by the end of the century and <1.4 billion by 2010. The basic means of reaching the goal are birth control and the "one couple, one child" policy, which stipulates that each Chinese couple is legally allowed to have only one child (Wu 1994). Ironically, China has paid a huge socioeconomic price for ridiculing the theory and practice of birth control and family planning during the 1950s and 1960s. On the other hand, according to a national sampling survey in 1987, there were 51.64 million disabled people (4.9% of the total population) in China. Of these, 54.3% (i.e., 2.66% of the total population) were children. The majority of these disabilities (64.91%) are due to postnatal diseases and injuries, whereas 35.09% are due to birth defects and genetic diseases (Chen and Simeonsson 1993; Ming and Jixiang 1993). One aim of this survey is to investigate geneticists' attitudes toward the social and legal aspects of genetics. It would be necessary to

Table 4

Views on Laws Prohibiting Disability Discrimination

	COUNTRY SHOULD HAVE LAW	
INTENT	Yes (%)	No (%)
To prohibit disability discrimination	36	64
To protect people with adult polycystic kidney disease	43	57
To protect cystic fibrosis carriers	44	56
To protect people with genetic predisposition to other diseases	50	50

ask whether there are laws or regulations in China that prohibit discrimination against people with disabilities. This survey shows that more than half of Chinese respondents thought that there were no such laws or regulations in China, particularly to protect people with genetic conditions. This may be because, although the rights of people with disabilities have been protected constitutionally in China, there are no Chinese laws specifying whether people with genetic conditions should be protected as disabled people. This survey also suggests that most Chinese still regard disabilities as a severe burden for both family and society. Population and disability issues are universal. As the history of the Western eugenics movement has shown, these issues are to some extent likely to produce a social "medium" or environment for the "birth and growth" of eugenics (Paul 1995).

Historically, cost effectiveness appears to be one of the major issues concerning Western eugenicists. A typical example of this was seen in 1923, when the American Eugenics Society tried to justify the expense of building enough institutions to house and separate all the mentally retarded people by calculating that the $25,000(U.S.) spent on segregating the original mentally retarded persons for life would have saved the state >$2,000,000 in later costs. It also added that sterilizing the original mentally retarded people would have cost <$150 (Larson 1995). Although it is questionable whether economic calculations would really work in genetics, some Western geneticists still regard cost effectiveness as an important factor in genetics services. This is because the clinical genetics services already available have been shown to be highly cost effective, mainly because of the high costs of medical and psychosocial care for the chronically handicapped in Western countries. For example, in the Netherlands seven regional clinical genetics centers involved in pre- and postnatal chromosome analysis, biochemical and DNA diagnosis, and genetic counseling supported by the national health insurers cost ~$50 million/year. As a result of their combined activities, the birth of 800–1600 severely handicapped children is avoided every year. The costs of their medical and psychosocial care would have been $500 million–$1 billion during an average life span of 10 years (Galjaard 1997). Moreover, it even has been predicted that the most enforced codes of medical practice, particularly in genetics services, may be based on cost-effectiveness analysis rather than on ethical considerations for the future (Wertz 1997).

The concept of cost effectiveness may have different meanings for Chinese geneticists. This is because, unlike Cuba, where a free health care system including genetic testing and screening covers the entire population (Heredero 1992), genetics services in China are not free and are expensive for most Chinese people. For instance, in 1987 the average income of a Chinese worker in a factory or university was ~$30/mo, whereas the cost of cytogenetic testing was $6–$20. On the basis of the population prevalence of chromosomal diseases in Sichuan province (31.5/100,000) (Zhang et al. 1991), it is estimated that there would be 346,500 persons with chromosomal disorders in China at that time (in an overall population 1.1 billion). If all of these cases were diagnosed cytogenetically, it would cost $2,000,000–$7,000,000, which is equivalent to 69,300–231,000 workers' monthly incomes. The costs of genetics services have increased very rapidly in recent years because of inflation and health-care reform, although such services in China are still underdeveloped and fall far short of the needs of people with genetic disorders.

The prevalence of PKU in the Chinese population is ~6/100,000 people (Liu and Zuo 1986). Thus, there would have been ~72,000 people with PKU in 1994, when the population was 1.2 billion. A Chinese study analyzed the cost benefit of newborn screening for PKU and estimated that the 10-year cost of screening, diagnosis, medical care, and dietary therapy for each PKU case identified would be $4,000. If PKU infants were not diagnosed and treated, the estimated cost of living for one untreated, mentally retarded individual with a mean life span of 40 years also would be $4,000. Income loss, special education costs, and inability to contribute to society would cause a total loss of ⩾$20,000. The long-term estimated benefits due to early screening, diagnosis, and treatment, minus the cost of screening and treatment, therefore is ~$20,000. Thus, the ratio of benefit:cost ratio would be ~5:1 (Zhou 1995). It is a pity, however, that China is still unable to produce a low-phenylalanine diet in quantities large enough to provide adequate therapy for most affected babies (Luo 1988), even though the PKU test is cheap and newborn screening for PKU seems to be cost effective in China. All of these actual situations most likely will lead Chinese thinking to consider the use of other radical means, such as abortion and sterilization, to reduce the incidence of PKU (Mao and Wertz 1997).

The word "eugenics," which currently is used more widely in China than in the West, when directly translated into Chinese, is "yousheng" and "youyu," which mean "well bear" and "well rear." The view most widely held by Chinese geneticists is that eugenics implies processes designed to ensure that children who are born are, as far as possible, "normal." How to achieve this, in the context of strict family limitation, has emerged as the most significant difference, in the approach to medical genetics, between China and the West (Harper and Harris 1986). This survey was conducted in 1993, 1 year before China promulgated the Maternal and Infant Health Care Law (1994). In their comments, almost all respondents said that the goal of human genetics was "improvement of the population quality, decrease of the population quantity, and furtherance of eugenic principles" and agreed that "an important goal of genetic counseling is to reduce the number of deleterious genes in the population" (Mao 1997, p. 20). Chinese geneticists also were extremely pessimistic about directive counseling after prenatal diagnosis for almost all genetic disorders (Mao and Wertz 1997). The majority of them would advise voluntary surgical sterilization for a single blind woman on welfare who had a 50% risk of blindness in children (88%), for a woman with fragile X who was living in an institutional setting (73%), and for a cystic fibrosis carrier-carrier couple (52%) (Mao and Wertz 1997). This survey reveals that most Chinese geneticists thought that partners should know their genetic status before marriage, that carriers of the same defective gene should not marry each other, and that women should have prenatal diagnosis if medically indicated. These views were expressed, to some extent, in the Chinese Maternal and Infant Health Care Law (1994).

The contentious articles of the law are cited as follows (Maternal and Infant Health Care Law 1994):

> *Article 8.*—The premarital physical checkup shall include the examination of the following diseases:
>
> 1. Genetic diseases of a serious nature;
> 2. Target infectious diseases;
> 3. Relevant mental disease.
>
> *Article 10.*—Physicians shall, after performing the premarital physical checkup, explain and give medical advice to both the male and the female who have been diagnosed with a certain genetic disease of a serious nature that is considered to be inappropriate for childbearing from a medical point of view; the two may be married only if both sides agree to take long-term contraceptive measures or to get the ligation operation for sterility. However, a marriage that is forbidden as stipulated by provisions of the Marriage Law of the People's Republic of China is not included herein.
>
> *Article 16.*—If a physician detects or suspects that a married couple in their childbearing age suffers from genetic disease of a serious nature, the physician shall give medical advice to the couple, and the couple in their childbearing age shall take measures in accordance with physician's medical advice.
>
> *Article 18.*—The physician shall explain to the married couple and give them medical advice about termination of pregnancy if one of the following cases is detected in the prenatal diagnosis:
>
> 1. The fetus is suffering from genetic disease of a serious nature;
> 2. The fetus has a defect of a serious nature;
> 3. Continued pregnancy may threaten the life and safety of the pregnant woman or seriously impair her health because of the serious disease she suffers from.
>
> In these articles, "genetic diseases of a serious nature" refers to diseases that are caused congenitally by genetic factors, that may totally or partially deprive the victim of the ability to live independently, that are highly possible to recur in generations to come, and that are considered medically inappropriate for reproduction; "relevant mental diseases" refers to schizophrenia, manic-depressive psychosis, and other mental diseases of a serious nature.

The international opinions on the Chinese law vary. Some Western geneticists have fiercely criticized the law as an "abuse of genetics" and a "violation of human rights" (Morton 1998). Others have said that "in a country where millions of female children vanish, and many children with developmental abnormalities are left to die, the law might represent an improvement" (Beardsley 1997, pp. 33–34). Frankly speaking, in China too there is opposition to the law, from some geneticists who did their training in Western countries. For example, they oppose some radical measures such as "sterilization of people with IQ less than 60" and the use of term "eugenics" in the early draft of the law. Interestingly, voices of Chinese geneticists are heard defending the law. Some examples are "China now has a population of 50 million handicapped. Without effective action, China will have an even larger population with serious hereditary diseases and it will naturally impose a grave social problem as regards their livelihood, social and cultural development as a whole and even the quality of the whole population" ("Opportunity for Depth in Chinese Eugenics Debate" 1998, p. 109); "the law was terribly misinterpreted"; "the law was needed to supplement the one-child policy and had no intention of enforcing eugenic aspects" (Takebe 1997, p. 89); "the law only facilitates practices common for decades in Western countries, and there is no similarity between what is practiced in China and Hitler's concept of eugenics" (Maddox and Swinbanks 1995, p. 549). The survey results do, however, suggest that social, economic, and cultural differences most likely will give rise to a disagreement between China and the West, on the issue of eugenics.

Public education in genetics is thought to be an effective approach to reduce the incidence of genetic diseases, although it needs a huge and long-term investment from the government (Harper and Clarke 1997). This survey suggests that at least half of Chinese geneticists appear to realize the importance of the issue. On the other hand, genetics education in China has not covered any ethical issues yet (McCaffrey 1989). One ethicist who advised the drafting of the Chinese law admitted that bioethics has just started to be discussed and was not considered seriously when the law was drafted (Takebe 1997). This survey, however, reveals that most Chinese geneticists think that ethical guidelines are necessary for the improvement of genetics services in China. Although the Ministry of Public Health of China published a brief ethical code for medical professionals in 1988 (Qiu 1993), at the moment there are not any ethical guidelines for genetics services in China. A group of experts from both developed and developing countries, including China, sponsored by the World Health Organization, has drafted international guidelines on ethical issues in medical genetics and on the provision of genetics services. The guidelines not only provide ethical principles for genetics services and research but also emphasize respect for cultural, social, and religious diversity (World Health Organization 1998). It therefore is expected that the guidelines will be introduced into China and will serve as a framework for Chinese geneticists in their practice and research. Perhaps in this practical way, such guidelines could bridge the social and cultural gap between Chinese geneticists and their Western counterparts, could help to clarify the nature of eugenics, and could allow a consensus on the ethical, legal, and social issues of genetics in the future.

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References

Beardsley T (1997) China syndrome. China's eugenics law makes trouble for science and business. Sci Am 276:33–34

Brave new now (1997) Nat Genet 15:1–2

Chen JH, Simeonsson RJ (1993) Prevention of childhood disability in the People's Republic of China. Child Care Health Dev 19:71–88

China's misconception of eugenics (1994) Nature 367:1–2

Fu JL, Chu EHY, Tan JZ (1995) Perspectives on genetics in China. Annu Rev Genet 29:1–18

Galjaard H (1997) Gene technology and social acceptance. Pathol Biol (Paris) 45:250–255

Garver KL, Garver B (1994) The human genome project and eugenic concerns. Am J Hum Genet 54:148–158

Harper PS, Clarke AJ (eds) (1997) Genetics, society and clinical practice. Bios Scientific, Oxford

Harper PS, Harris R (1986) Medical genetics in China: a Western view. J Med Genet 23:385–388

Heredero L (1992) Comprehensive national genetic program in a developing country—Cuba. Birth Defects 28:52–57

Larson EJ (ed) (1995) Sex, race, and science: eugenics in the deep South. Johns Hopkins University Press, Baltimore

Li YQ (1994) China launches genome project. Nature 365:200

Liu SR, Zuo QH (1986) Newborn screening for phenylketonuria in eleven districts. Chin Med J (Engl) 99:113–118

Luo HY (1988) Medical genetics in China. J Med Genet 25:253–257

Maddox J, Swinbanks D (1995) When is prenatal diagnosis 'eugenics'? Nature 378:549

Mao X (1996) Chinese ethics. Nature 384:404

——— (1997) Ethics and genetics in China: an inside story. Nat Genet 17:20

Mao X, Wertz DC (1997) China's genetics services provider's attitudes towards several ethical issues: a cross-cultural survey. Clin Genet 52:100–109

Maternal and Child Health Care Law (1994) Order of the President of The People's Republic of China, no 33. People's Daily, October 27

McCaffrey MC (1989) Genetics education in the People's Republic of China. Am J Hum Genet 44:608–610

Ming G, Jixiang M (1993) Demography of people with disabilities in China. Int J Rehabil Res 16:299–301

Morton NE (1998) Hippocratic or hypocritic: birth pangs of an ethical code. Nat Genet 18:18

O'Brien C (1996) China urged to delay 'eugenics' law. Nature 383:204

Opportunity for depth in Chinese eugenics debate (1998) Nature 392:109

Paul DB (1992) Eugenics anxieties, social realities, and political choices. Soc Res 59:663–683

——— (1995) Controlling human heredity: 1865 to the present. Humanities Press, Atlantic Highlands

Qiu RZ (1993) Chinese medical ethics and euthanasia. Camb Q Healthcare Ethics 2:69–76

Smith RA, Williams DK, Sibert JR, Harper PS (1990) Attitudes of mothers to neonatal screening for Duchenne muscular dystrophy. BMJ 300:1112

Takebe H (1997) Human genetics and bioethics in China. Paper presented at the UNESCO Asian Bioethics Conference, Kobe/Fukui, Japan, November 4–8

Wertz DC (1995) Geneticists' ethical views: a survey in 37 nations. Paper presented at the European Society of Human Genetics, Berlin, May 24–27

——— (1997) Society and the not so new genetics: what are we afraid of? Some future predictions from a social scientist. J Contemp Health Law Policy 13:299–345

Wertz DC, Fletcher JC (1993) Geneticists approach ethics: an international survey. Clin Genet 43:104–110

Wertz DC, Fletcher JC, Berg K, Boulyjenkov V (1995) Guidelines on ethical issues in medical genetics and the provision of genetics services. Hereditary Diseases Program, Division of Noncommunicable Diseases, World Health Organization, Geneva

Western eyes on China's eugenic law (1995) Lancet 346: 131

World Health Organization (1998) Proposed international guidelines on ethical issues in medical genetics and the provision of genetics services. Report of a World Health Organization meeting on ethics issues in medical genetics, Geneva, December 15–16 1997

Wilson JMG, Jungner G (1968) Principles and practices of screening for disease. World Health Organization, Geneva

Wu JP (1994) Population and family planning in China. Verh K Acad Geneeskd Belg 56:383–402

Zhang LZ, Liu B, Li MZ, Wang XY, Yuan H, Jia JW, Liu P, et al (1988) Pregnancies following in vitro fertilization and embryo transfer and following gamete intrafallopian transfer. Chin Med J (Engl) 101:303–304

Zhang SZ, Xie T, Tang YC, Zhang SL, Xu Y (1991) The prevalence of chromosome diseases in the general population of Sichuan, China. Clin Genet 39:81–88

Zhou Z (1995) Recent advances of perinatal medicine in China. Chin Med J (Engl) 108:387–389