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Chinese Geneticists Are Far from Eugenics Movement

To the Editor:

The article by Dr. Xin Mao (1998), published in the September 1998 issue of the *Journal,* came to our attention just recently. Unfortunately, it misrepresented in many ways the real attitudes of many of the medical geneticists in China. We feel that it is necessary to speak out for ourselves. For instance, sickle cell anemia is as rare among Chinese as it is among whites. The statement that "sickle cell disease is very common in China" (Mao 1998, p. 690) is incorrect. Hence, there is no reason to require newborn screening for sickle cell disease in China (Mao 1998, table 1). Cystic fibrosis is also very rare in China. Hence, there is also no need to perform newborn screening for this disease (Mao 1998, p. 690). Population screening for defective alleles of the α-antitrypsin gene (i.e., the PiZ and PiS alleles) has revealed none in China, with the exception of one case with the genotype of M1S. Therefore, it will be meaningless to conduct genetic testing for α-antitrypsin deficiency among workers in very dirty workplaces (Mao 1998, p. 689). Actually, it will be very difficult to define "very dirty workplace." Mao also stated that "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'" (pp. 692–693). We wonder whether any knowledgeable human geneticists will believe that human genetics can decrease the population quantity. We also doubt that the number of deleterious genes—especially "recessive genes"—in the population can be readily reduced. As for the term "eugenics," one should be very careful not to equate it with "you sheng" in Chinese, which means "to give birth to a healthy baby." There are many other controversial points in Mao's article. For example, his table 4 asks whether the country should have laws to prohibit disability discrimination. The original questionnaire, however, asked whether the country has or does not have laws to prohibit disability discrimination. The percentage given in table 4 will lead readers to the conclusion that Chinese medical geneticists do not favor the enactment of such laws! This letter will be too long if we try to list all of the controversial points in Mao's article. We are fully aware that, because of differences in culture, value systems, customs, religion, and demographic and economic situations, our viewpoints on many ethical issues may be different than those of our Western colleagues. This stresses the importance of dialogues between us to promote mutual understanding. All constructive suggestions will be heartily welcome, and we will be most grateful for all of them.

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Reply to Guo and to Chen et al.

To the Editor:

Ethical, legal, and social issues in human genetics are hot—but also complicated—topics in developed countries. Since my article (Mao 1998*a*) about Chinese geneticists' views on ethical issues in genetic testing and screening was published, it has attracted attention from the international scientific community and the media. Many gave positive comments on the article (Mao 1998*b*, 1998*c*; Coghlan 1998; Knoppers 1998), but others, such as Guo (1999 [in this issue]) and Chen et al. (1999 [in this issue]), expressed different views.

Ethical, legal, and social issues in human genetics are very sensitive inside China (as well as elsewhere), and there have been few Chinese scientists, either in genetics or in the social sciences, willing to investigate these subjects. For example, Chinese geneticists were invited to take part in the first international survey on ethics and genetics, conducted in 1984, but none responded (Wertz and Fletcher 1989). The report on ethics and genetics in China presented in the September issue of the *Journal* last year (Mao 1998*a*) came from the second international survey on ethics and genetics, which was conducted in 37 nations, including China, in 1993 (Wertz and Fletcher 1993). In this survey, a total of 402 Chinese geneticists, in 30 provinces and autonomous regions, were targeted with the Chinese version of an anonymous questionnaire that included 50 questions on ethical issues. All of these geneticists were registered members of the Chinese Association of Medical Genetics, the Human and Medical Genetics Branch of the Chinese Society of Genetics, and the Chinese Society of Family Planning. In all, 255 (63%) Chinese geneticists responded. Although some of the situations described in the questionnaire might be remote from Chinese geneticists' own practices in 1993, the survey results definitely helped to define the geneticists' attitudes toward ethical, legal, and social issues in genetics at that time and provided, for the first time, a scientific basis for international discussion of ethical issues in genetics in China (Mao and Wertz 1997; Wertz 1997, 1999; Mao 1998*a*; Wertz and Fletcher 1998).

Eugenics and laws related to it are the most contentious ethical issues in the world of genetics. On the basis of the first comprehensive national survey data and the actual situation in China, my article provided well-informed evidence of the balanced opinions on eugenics and genetics ethics in China, which aimed to promote constructive dialogues between Chinese geneticists and their Western counterparts on these issues. I agree with Chen et al. (1999) in their desire for more-comprehensive scientific reporting and more unbiased international discussions on genetics ethics in China. Perhaps this is the proper approach to exploring the cross-cultural eugenics and genetic ethics in developing nations.

Guo (1999) suggests that the article supports the "eugenics" section of China's Maternal and Infant Health Care Law. As I stated in the article, my purpose was to present the survey data and to discuss the likely basis of eugenics in China (Mao 1998*a*). Accomplishing this aim does not mean I have to support or oppose the law.

The history of eugenics in Western society has shown that socioeconomic and cultural factors contributed considerably to the development of the movement in industrial nations (Paul 1992). Dikötter analyzed the many dimensions of the history of eugenics in China. In his book, Dikötter concluded that Chinese eugenics law reflects an articulation of Chinese knowledge of heredity and disease and demonstrates how Chinese assumptions about the relationship of the individual to the society form the core of their attitudes toward procreation and their cultural, social, and economic views of population and disability, as well as the trend of nationalism generated from late imperial China to the People's Republic (Dikötter 1998). Dikötter's studies provide evidence that sociocultural differences are most likely to give rise to a disagreement between China and the West on the ethical, legal, and social issues that surround genetics, including the issue of eugenics.

The aims of the International Survey on Ethics and Genetics were to investigate the attitudes of genetics service providers toward ethical, legal, and social issues in their practice and research. The first section of the international questionnaire collected the participants' sociodemographic data and made a particular effort to check the credentials of the survey respondents. These data have been presented elsewhere (Mao and Wertz 1997).

Guo (1999) suggests that better knowledge of genetics will alter beliefs about reducing the number of deleterious genes in the population. China has made genetic research the top priority of its basic science research program and also has made a large-scale investment in the Chinese Human Genome Project (CHGP) (Lei 1998). If Guo is correct, then Chinese beliefs about eugenics will probably disappear in the future, when China catches up to the West in genetics. Views have been expressed in the West that, if genetic knowledge is not used properly or ethically, then it is likely to do more harm than good. My article (Mao 1998*a*) showed that, in 1993, most Chinese geneticists thought that ethical guidelines were necessary to improve genetics services in China. So far, however, very few Chinese geneticists and ethicists have been interested in the ethical, legal, and social issues of CHGP, although enhancement of research in this area has been listed as a subproject of phase II of CHGP (Chen and Zhang 1998). Ethical guidelines for genetics research and practice have not been drafted, nor has there been any public debate on these issues in China. All of these facts indicate that it is imperative that the international genetics community should export advanced genetics technologies to China and should help the Chinese people learn how to use genetic knowledge ethically to avoid any potential harm. One approach to altering beliefs about eugenics depends on facilitating public debate on these issues and establishing an evidence-based policy-making system worldwide. Perhaps these will be the toughest issues in genetics in the new millennium.

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The Duty to Recontact: Benefit and Harm

To The Editor:

The survey by Fitzpatrick et al. (1999), "The Duty to Recontact: Attitudes of Genetics Services Providers," represents a significant contribution to, and an important step forward in, the resolution of a complex and troubling issue. But, in both their Introduction and their Discussion, the authors refer to statements of mine (Sharpe 1994*b*) that have been taken out of context and therefore misrepresent my position on this issue. More critically, Fitzpatrick et al. have failed to take note of medical principles and legal obligations that are fundamental to discussion about whether a duty to recontact exists within the context of medical genetics and genetic counseling.

For example, the authors wrote that I stated "a physician's duty of care toward patients is considered to include the obligation to advise them of any developments in management and treatment that would be beneficial or detrimental" (Sharpe 1994*b*). This statement, in the context in which it is presented, is incorrect. My article (Sharpe 1994*b*) focused on the psychological aspects of presymptomatic testing for Huntington disease and, in particular, on whether a geneticist would have a continuing obligation to provide psychological support after disclosure of the test results. This issue was examined within the context of a physician's traditional postoperative duties of care to a patient, including the duties to monitor a patient's condition, to provide appropriate aftercare, to refer, and not to abandon the patient. As cited in my article, such obligations have long been recognized in the various codes and principles of ethics of organizations such as the American Medical Association and the Canadian Medical Association.

With respect to Huntington disease, because of the potential for and the nature of the psychological and psychiatric responses associated with risk clarification or a clinical diagnosis, I suggested that, in the same manner in which a physician may have a duty to continue treatment until recovery is complete, a geneticist may have a continuing duty of care until appropriate psychological or psychiatric counseling has been arranged. Once such counseling has been secured, however, the geneticist's obligation would come to an end.

In the same article, with respect to phenylketonuria, I also speculated—as evidenced by my explicit use of the term "theoretically"—that, because of the necessity of maintaining a low-phenylalanine diet and the fact that the gene technically has been expressed, a geneticist might have a duty to monitor a patient's condition over