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SPECIAL SYMPOSIUM

Predictive Genetic Testing in Asia: Social Science Perspectives on the Bioethics of Choice

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Introduction

For some time now bioethics has been dominated by legal and philosophical perspectives and this has limited our understanding of the issues involved in the application of newly developed biomedical technologies. Our approach emphasises the need for empirical research, theory and method from the social sciences when dealing with bioethical issues. This special symposium introduces and provides examples of social-science approaches to practices of predictive genetic testing in Asia. It aims to show that without adequate insight into the unintended socio-economic consequences of government policies and regulation, and without awareness of socio-political inequalities across national borders, even the most superior bioethical policies are of no avail to lives of the genetically unfortunate, in any cultural context.

It is now possible to conduct predictive testing for a range of monogenetic disorders such as Down's syndrome and Huntington's chorea. As a result of ongoing developments in genetic testing, large human groups will in future have access to information about a variety of multifactorial genetic disorders. This information will have a much higher margin of uncertainty, however. This is because susceptibility screening for disease such as cancer, cardiovascular and neuropsychiatric diseases will require analysis of multiple genes as well as environmental factors, such as life style and living conditions. A high margin of uncertainty will create bioethical dilemmas for potentially 'pre-symptomatic' groups of people, and may lead to anxieties and difficulties regarding the long-term decisions people make in life.

The decision even to take a genetic test may be a dramatic one where no cures or therapies are available, where people do not have the financial means to pay for healthcare, or where the financial and social consequences of a positive test outcome are an overwhelming burden. To some, a genetic test may bring benefits, either by indicating the *possibility* of a disease-free life or providing the 'certainty' of knowing what will come. To others, genetic test results may be potentially disastrous for the meanings they have attached to life so far. In the case of a late-onset disorder such as Huntington's chorea, for which there is no cure, a disease foretold may annihilate the meaning of life itself. Prenatal testing may lead to difficult decisions about abortion. The ways in which

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people deal with such ‘choices’ can only be understood in the light of the experience people have with disease and their ways of dealing with it. This complex of considerations is referred to here as the *ramifications of choice*.

Predictive Testing and Asian Societies

Different cultural, economic and political conditions lead to different testing practices, different ramifications of choice, and therefore different approaches to bioethics. In this special symposium, it will become clear that Asian countries are diverse in terms of population policies, forms of family organisation and the ways in which gender distinctions are drawn. They also contain a multitude of views about the value of the embryo and human life, the provision of health services, and regulatory policies in the field of reproductive medicine.

To complicate a straightforward understanding of predictive genetic testing, the ramifications of bioethical choice in Asian societies, as in other societies, are couched in terms of cultural categories at the same time as they are conditioned by these categories. For instance, various cultural and religious norms may be used to encourage or discourage prospective parents to terminate a pregnancy. Thus, depending on the environment and circumstances, questions that physicians and nurses ask may culturally condition a pregnant woman’s choice. ‘Don’t you want the best for your child?’ ‘Do you want to become a burden to society?’ ‘Do you believe God would want you to respect the life you are carrying?’ To understand how cultural factors are related to choice, we need to understand the meaning and implications of the use of cultural categories of ‘abnormality’. Furthermore, we need to know how these cultural and religious categories relate to other ‘hidden’ personal motivations for choosing to undergo particular tests.

Crucial to an understanding of the ramifications of choice, we need insight into how motivations are related to the material/social circumstances in which people consider the possible outcomes of predictive genetic tests. How does the unfolding of a foretold disorder affect the life, work and ambitions of individuals and families in Asian cultures? How does it affect family relations? What sense do people make of the probable futures revealed by genetic tests? What choices do prospective parents have in the light of their perception of the anticipated outcome of the prediction? How and why do they couch their views in ethical terms?

Social Science Approaches to Predictive and Genetic Technologies in Asia

The articles selected for this special symposium reveal the variety of issues that arise from the application of similar biomedical technologies in different conditions found in various Asian societies. The introductory essay [1] provides an overview of the various predictive genetic tests that the biomedical sciences have made available, and argues that social-science approaches are indispensable when it comes to exploring difficult bioethical and social issues in economically and culturally diverging societies.

The second article [2] examines prenatal diagnostics in Sri Lanka, and shows that an abstract discussion about the moral choices involved in genetic testing takes for granted social-economic and cultural factors crucial to the question of whether it is ethical to use the test in the first place. This is because in Sri Lanka, as in other societies, once a disease is diagnosed, the possibilities for acting upon it may be limited. This so-called ‘therapeutic gap’ is discussed in the light of the economic, cultural and political factors linked to the decision to undergo testing, the availability and access to therapy and the ethical and cultural aspects of the termination of pregnancy. The article draws on surveys of doctors and medical students conducted between 1986 and 2006, and interviews with parents of children who have Down Syndrome conducted between 2002 and 2003.

The third article [3] examines the health care needs and interests of specific population groups with regard to genetic testing, and how these are reflected in state healthcare policies. This article clearly shows the crucial influence of the availability of healthcare and the cultural politics of gender and human perfection on the potential successful application of genetic testing. Recently the Indian government has introduced a newborn screening programme in which all newborn babies at certain selected centres will be tested for three conditions: congenital hypothyroidism, congenital adrenal hyperplasia, and G6PD. The author discusses the wisdom of this for a resourcepoor country such as India, and the consequences of testing for specific social groups in light of the fear of socio-genetic marginalization, and the access to healthcare and counselling.

The fourth and final article [4] concerns the genetic testing services of biotech companies in the People's Republic of China (PRC). The authors provide an overview of the various forms of genetic testing currently available in the PRC. Even though some hospitals offer prenatal genetic testing as a form of prenatal diagnosis, biotech companies increasingly offer genetic testing on a commercial basis. Lack of regulation of genetic testing and widespread unawareness of the significance of genetic testing among the public combine to yield a potentially lucrative market for commercial testers. This article thus focuses on the ways in which biotech companies market predictive genetic tests, and some of the social, ethical and financial problems related to this practice.

When it comes to understanding the difficulties and advantages associated with predictive genetic testing in Asian countries, knowledge of the law is not sufficient, and nor is knowledge of the various cultures and religious traditions. The policy choices that are made about making predictive genetic testing available, and the individual choices people make about whether to undergo these tests, are intimately related to a constellation of commercial, political, cultural and historical factors. This social context forms the focus of the articles presented in this symposium.

References

1. Sleeboom-Faulkner, M. (2007). Social-science perspectives on bioethics: Predictive Genetic Testing (PGT) in Asia. *Journal of Bioethical Inquiry, 4*, DOI 10.1007/s11673-007-9064-3 (this issue).
2. Simpson, R. (2007). Negotiating the therapeutic gap: Prenatal diagnostics and termination in Sri Lanka. *Journal of Bioethical Inquiry, 4*, DOI 10.1007/s11673-007-9070-5 (this issue).
3. Gupta, J. A. (2007). Private and public eugenics: Genetic testing and screening in India. *Journal of Bioethical Inquiry, 4*, DOI 10.1007/s11673-007-9059-0 (this issue).
4. Sui, S., & Sleeboom-Faulkner, M. (2007). Commercial genetic testing in mainland China: Social, financial and ethical issues. *Journal of Bioethical Inquiry, 4*, DOI 10.1007/s11673-007-9062-5 (this issue).