Vulnerable populations and genetic disorders: a socio-science approach to the application of genetic technology in China

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SUMMARY

This research is a subproject of an international research project, the Socio-genetic Marginalization in Asia Programme (SMAP). SMAP explores cultural, social and economic aspects of the role of genetic technologies played in the area of state organisation, population policies, healthcare systems and research regulation in China, India and Japan. The research is experiential and it sheds light on the applications of modern genetic technologies in China. It takes the application of genetic testing in China as the point of departure to explore links in relation to Chinese society, with consideration of social economics, national population policy, national healthcare system and traditional/local culture in China. To develop this study, fieldwork was mainly conducted in China during a three-year period from 2006 to 2009. Based on the fieldwork, the study discusses social and ethical issues involved in Chinese contexts. Through the discussion, the study explores the identity and vulnerability of populations with regard to the practice of genetic services in China and delineates the socio-economic and socio-political factors that influence, shape and sharpen their vulnerability.

In China, genetic counselling services are offered by clinical geneticists, and the clinical genetic counselling related to prenatal diagnosis is under the governance of official guidelines, with the goal of reducing birth defects. In order to better understand the situation of genetic counselling and its related issues, the research compares with the similarities and differences in the practice of genetic counselling in China to that of the United Kingdom and Hong Kong. In the UK, there are professional counselling services following the psychotherapeutic model and non-directive style. In Hong Kong,

the practice of genetic counselling is offered by non-professional counsellors with some professional training and a non-directive style. In practice, non-directiveness in genetic counselling is harder to achieve in China, and current genetic counselling is more like the medical preventive model. It is the social context that makes genetic counselling distinctive in individual societies. In China, the economic conditions, non-professional genetic counselling providers, lack of full coverage of the healthcare system, and the aim of counselling services and national population policy are the main factors that form the practice of genetic counselling and its governance, and, to some extent, limit proper communication and applicability of non-directiveness in genetic counselling in China.

Accompanying the development of genetic technology is the economic benefit of its application. Currently, there is no law or regulation of the application of predictive genetic testing, such as susceptibility (or predisposition) tests. In the pursuit of profit, some biotech companies have acquired business licences and have been carrying out predictive genetic testing as a technical business. In practice, a lack of proper formal regulation and the commercialisation of genetic testing have led to bioethical problems related to dubious advertising practices and misleading and unprofessional medical advice. At the same time, the emergence and development of commercial genetic testing may have resulted in genetic discrimination in employment and in insurance for the ‘potential patients’. In fact, when considering the ‘potential patients’, there is no doubt that the patients with genetic disease and their families are more vulnerable. The research carried out a case study of the practice of genetic testing, mainly of prenatal genetic testing, to better understand the situation of those families with a genetically affected child.

Prenatal genetic testing is an important part of clinical genetic services. At present, prenatal genetic testing is regulated by official regulations promulgated by the Ministry of Health, and qualifications are required to clinically develop a testing service. For the case study, the research chose thalassaemia, an autosomal recessive inheritance disorder, and Duchenne muscular dystrophy (DMD), an X-linked recessive inheritance disorder, as two research targets for case study. Through shedding light on special cases of the

clinical prenatal testing on thalassaemia and DMD, the research delineates the clinical practice of genetic testing, and discusses the finance difficult, heavy psychological pressure, social stigma and discrimination, and the limited reproductive choices of families with an affected child in Chinese contexts. The expense of treatment for a child with thalassaemia is so high that many families cannot afford it. In practice, some families try to intentionally procreate a child, a so-called 'saviour sibling', as a cord blood donor to 'save' the affected child. Such cases are not common but do exist. The intention of choosing to have an offspring as a 'saviour sibling' may lead us to consider more about the social and ethical implications of intending the birth and existence of a human being. For DMD, as a lethal disorder without effective treatment, the chronic muscular atrophy results in serious walking, then moving disability, and then death, and makes the boys with DMD and their families vulnerable in the society. The hereditary character of DMD, which is passed down to a son by a carrier mother, impacts the position of females, who are already are weak and vulnerable, in society and family. Meanwhile, explanations of pathogenesis based on religion and superstition sometimes are used to stigmatise families with severe handicaps. In Chinese contexts, such implications, and links with the traditional preference for a boy, sharpen the social stigma and discrimination against families with a son with DMD, and also sharpen their vulnerability.

In practice, besides social, economic and cultural factors, political implications, such as the national population policy, the social healthcare system and the social welfare system, also play an important part in the forming of the practice of genetic testing/counselling and of the condition of the families affected by genetic disorders. Along with the implementation of the family planning policy, population quality and superior birth have been highlighted along with the effort to reduce population quantity. Prevention and reduction of birth defects is a definite goal of all levels of the official genetic service nationally, especially with regard to prenatal genetic diagnosis. A eugenic approach was once adopted as a legal way approach the highly desired goal of to reducing birth defects. These considerations led to the development of opinions that people born with birth defects are a burden to both society and family, and people with

mental retardation have no reproductive value. Such opinions, in fact, exacerbate genetic discrimination and social stigma and worsen the vulnerability of the individuals and families affected by genetic disorders. In the post-genome era, the rapid development of genetic technology and its application have strongly impacted society. During such times, the living conditions of vulnerable populations do not get the attention they deserve. This research offers an insight to understand the vulnerable population with genetic disorders in the Chinese social contexts and from a social science perspective.