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

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Citation for published version (APA):
In August 2004, I came to the Netherlands for an interview for the position of PhD candidate. That interview brought me a wonderful chance to attend an international research project, the Socio-genetic Marginalization in Asia Programme (SMAP), and an opportunity to do research work in Amsterdam University from 2005. This was just like opening a door for me into the social-genomic research field. Such a research field is an interdisciplinary frontier research area. From a social science perspective, to understand the social implications of genetic testing is very attractive and challenging for me. And using English as working language, and writing academic papers in English, is also a big challenge. I had put in a lot of hard work for my research. In fact, as time has passed, I have loved my work more and more, and feel my research more and more meaningful. I have gradually come to understand the application of genetic testing in China, and the difficulties faced by families affected by genetic disorder in Chinese socio-economic, culture and political contexts. During my research, I interviewed many families. I appreciated it greatly that my interviewees shared their sad stories with me, revealing to me their sorrows and bringing out grievances that lay buried deep in their heart. I know it is beyond my power to change their situations. However, my understanding and kind consolation might relieve some of their psychological pain. And I also feel gratified that my research has contributed to a better understanding of the social and ethical issues in regard to the application of genetic testing and to the situation of the vulnerable population.

The last four years have been hard but very valuable for me. Now, when I look back on it, I feel it is more precious. During this period I made progress inch by inch. I published several academic papers in international journals and gave presentations at international conferences. I know that I could not have reached such achievement without support and help from the people
around me. Here, I would like to express my earnest appreciation to my supervisors, Doctor Margaret Sleeboom-Faulkner and Professor Anita Hardon. Margaret is also SMAP Programme director. My supervisors have evaluated my research work progress on every stage, provided me with valuable advice on my study and comments on paper writing. They have been extremely helpful in their comments. Whenever I have been stuck and needed instruction, I have always received quick feedback and comments from them. And also, when I felt depressed, they encouraged me in a timely way and gave me confidence. I feel so lucky to have them as my supervisors. This is especially true of Margaret Sleeboom-Faulkner, who gave me very valuable advice on the research framework, design and thesis writing. For all of my articles, she gave instructive direction and many very valuable and constructive comments. My articles reflect her hard work and assistance. I owe much of my progress and achievement to her strong and helpful support. There is no words can fully express my appreciation.

I would like to express my special thanks to many people who kindly helped me to build connections to carry out my fieldwork. They are: Professor Qiu Renzong, Professor Zhai Xiaomei, Professor Shi Huifang, Professor Huang Shangzhi, Professor Zhang Xinhua and Doctor Meng Yan who helped me in China; Professor Nikolas Rose, Professor Angus Clarke and Dr Ayo Wahlberg who helped me in the UK; and Dr Stephen T.S. Lam and Dr Mary Tang who helped me in Hong Kong. There are simply so many persons that I do cannot list all of their names here, but I appreciate all their help. Many thanks to all the hospitals, institutions and organisations I visited in China, the UK and Hong Kong, and all my interviewees, including geneticists, genetic counsellors and patients. Their stories and personal experiences are the first-hand data of my research.

Amsterdam School of Social Science Study (ASSR) and International Institution for Asia Study (IIAS) provide a great environment for my study and research. Lots of thanks to Manon Osseweijie, Jose Komen, Michiel Baas, Hermance Mettrop, Anneke Dammers, Mrriam May, Teun Bijvoet, and all other staff in ASSR and IIAS, they make the working environment pleasing. Many thanks to all my PhD candidate colleagues in ASSR, during my study in Netherlands, I got many help and learned lots from you. I have good memory of the days I was in ASSR and IIAS. Thank you so much!

The research was financially supported by the Netherlands Organization for Scientific
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Research (NWO). The generous financial support from NWO for SMAP is the precondition for my research, which is subproject of SMAP. Also, I would like to express my sincerely thanks to my colleagues of the SMAP working group, director Margaret Sleeboom-Faulkner and team members Jyotsna Gupta, Prasanna Patra, Masae Kato and Jan-Eerik Leppanen. Their discussion, advice and comments on my work were helpful for my study. Working with them has given me so many beautiful memories. I will remember all the happy time we spent together. I also appreciate the London School of Economics and Politics (LSE). Its BIONET stipend supported my short-term study at the LSE and my fieldwork in the UK.

I would like to give my sincere thanks to Professor Stuart Blume. During my PhD study, he advised and help me a lot. He is also an excellent mentor of me. And many thanks to Professor Sjaak van der Geest. The knowledge of medical anthropology and culture anthropology I learned from his course was very helpful for my research. He encouraged me in my study of anthropology when I felt discouraged. I also thank Lee Brown and Zoe Goldstein for the English copy-editing, and thank Chip Huisman and Daan Keiman for the Dutch translation of my thesis’ summary. And warm thanks to my friends in the Netherlands, Hu Hai, Paul Guo, Zhang Benzi, Wang Yanjing, Hu Huile, Fang Yue, Lei Ray, Xia Xin, Le Yang, Margaret, Benjamin Kwansa, Jonathan Dapaah, Pride Linda and many others. Because of you, my life and study in a foreign land were more pleasant.

Additionally, here I would like to give the most heartfelt thanks to my husband Shan Guojun, my daughter Shan Yangyang, my parents and my elder sister’s family. I feel so lucky to have them and to have received their support and encouragement. My family’s support and love has been a source of my strength to continue my research. As for Yangyang, my dear little girl, I feel so sorry to have always been separated from her during her childhood from the age of 4 to 8, an age when a girl needs her mother. I am so moved that she is such an understanding girl. Special thanks to my sister’s family for helping us to take care of my daughter when I have been away in the Netherlands or on fieldwork trips. Their generous help made me concentrate on my work and my thesis. All of them have given me the support and courage to overcome all the difficulties and challenges to complete this thesis.

Finally, I would like to point out that any mistakes and shortcomings in this thesis are my own responsibility.