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

Sui, S.

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: https://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
CHAPTER FOUR

SOCIAL, FINANCIAL AND ETHICAL ISSUES IN COMMERCIAL GENETIC TESTING

(Top line of Beijing Technology Daily: The price of genetic fortune-telling in Beijing is lower than abroad)

This chapter focuses on commercial predictive testing in China, based on interviews with company managers, regulators and clients, and literature research during fieldwork in China mainly from July to September 2006 and some data updated till 2010 March. The commercialization of genetic testing and the lack of proper formal regulation have led to bioethical problems related to dubious advertising practices, and misleading and unprofessional medical advice, of which the consequences for the users of tests are barely known. It concludes with a discussion on the social and ethical issues in the practical application of genetic testing in China.

**INTRODUCTION**

Genetic knowledge has now reached the point at which it can be used to predict future disease in individuals. These predictions can be made in the complete absence of disease symptoms (Duncan 2004). Predictive genetic testing, one of the practical applications of genetic knowledge, refers to the examination of a sample of genetic material to predict the future risk of a person to develop certain diseases. It enables the identification of individuals who are either pre-symptomatic of late-onset disease or those with an increased genetic susceptibility, conferring a predisposition to future disease symptoms (Marteau & Richards 1996).

In China the application of predictive genetic testing is becoming increasingly popular. Some hospitals and biotech companies offer genetic testing as part of their services. At present, several large hospitals, such as Beijing BeiDa Hospital, Beijing Xiehe Hospital, Nanjing Jiangshu Traditional Chinese Medicinal Hospital, and Guangzhou No1 Renmin hospital, offer predictive genetic tests as health services. These hospitals possess the qualifications authorized by the Department of Health, and usually offer prenatal genetic testing as a form of prenatal diagnosis. In addition, some biotech companies provide services for predictive genetic testing such as Shanghai GeneCore Bio-Technologies Co., Ltd,
Shanghai Fudan Bio-Technologies Co., Ltd, Beijing Anmanli health technology Co., Ltd, Nanjing Nanbo Bio-Technologies Co., Ltd, Wenzhou Huada Bio-Technologies Co., Ltd, Hangzhou Yamin Technology and Taizhou Union Center of Genetic testing. Actually, such biotech companies have been growing fast and the accurate number of such companies throughout the country is not known. This chapter focuses on predictive genetic testing offered by biotech companies and analyzes these ethical and social issues based on the introduction of the practical application of predictive genetic testing in China.

In the context of the commercialization of genetic testing in China, companies pursue commercial profits. As predictive genetic testing is not formally regulated in China, its commercialization has caused and will continue to cause social and ethical problems. Examples include the exaggerated advertisements that mislead customers and discrimination as a consequence of the misuse of genetic information. We suggest that these issues need to be addressed by the public and involve ministerial departments because genetic testing is not simply a common commercial enterprise but concerns the genetic information of individuals.

PREDICTIVE GENETIC TESTING OFFERED BY BIOTECH COMPANIES

Currently, predictive genetic testing in China is not formally regulated, legally or informally. Biotech companies planning to set up a genetic testing business have only to apply for a business license from the local Industrial and Commercial Bureau. They do not need any special medical qualification or permission from the Ministry of Health or the Ministry of Science and Technology to provide predictive genetic testing to the public; the staff who work in these companies do not need any medical qualification either.

The companies established according to ‘corporation law’ receive a business license from the Industrial and Commercial Bureau. Within the limits of the law they can freely apply for a license to commercially offer testing services. They are not limited in the way they market their testing products. Although there is no law to regulate predictive genetic testing, there is no law that prohibits such service either. So under the Chinese market economy system established in 1997, companies have the right to do as they please, as long as it is not illegal.
As a new industry, making use of advanced technologies, predictive genetic testing has the potential to yield high profits. A marketing agent of one company related that the selling price of one set of their tests services was introduced for 3,650 RMB, which is a substantial sum in a country with an average monthly income of about 1,100 RMB (in 2006). The cost price that the company declared to the Price Bureau was 1,799 RMB (Huang 2006). Such high profit margins are not unusual.

On the websites of biotech companies or in newspapers such as Beijing Daily and Beijing Keji Daily, we can easily find commercial advertisements and advertisements disguised as academic articles introducing genetic tests, in which they also explain the merits of their products. Some biotech companies declare in their advertisements that they cooperate with a state-supported university or a research institution. But, in fact, some forms of so-called cooperation are uncommonly indirect. The company usually has only one or two technical advisers who are also researchers/professors in an academic research institute. For example, in its advertisement, Shanghai Fuda Genetic Testing Distribution Co. Limited [Shanghai Fuda Jiyin Jiance Xiaoshou Youxian Gongsi, for short: Fuda Company] advertises that it cooperates with and receives strong technological support from Fudan University. In fact, information obtained from Shanghai Industrial and Commercial Bureau by a reporter of Shanghai-Dongfang Daily shows that Fuda Company was founded on the 17 August 2005. Its registered capital was 5 million RMB, which includes 3 million RMB of investment capital from Shanghai Fudan Bio-tech Co., Ltd. Fudan Bio-tech Co., Ltd is a main company of Union Gene Technology Group [Lianhe Jiyin Keji Jituan]. The foundational registration capital of Union Gene Technology Group of 80 million RMB includes 9.55 million RMB of investment from Fudan University. The information above shows that Fuda Company does not have a direct relationship with Fudan University. Despite the complexity and the indirect nature of their relationship, Fuda Company asserts that it works in collaboration with Fudan University on ‘advertisement articles’. The proclamation of cooperation with state-supported research institutions aims to obtain the trust of the public, because people trust

---


state-supported research institutions and universities more than they do commercial enterprises. In their advertisements, the companies also publicize their genetic testing services for a wide range of multifactorial diseases. For example, Shanghai Fudan Biotech Company offers genetic tests for susceptible genes, which identify possible predispositions for diseases, or pathogenic genes for about forty-seven diseases, including tuberculosis, allergic rhinitis, psoriasis, Graves’ disease, senile dementia, leucocyt ethemia, kidney cancer, oesophageal cancer, rectal cancer and breast cancer. The company only requires several drops of blood or a few mucous membrane cells from the client to test the carrier of genes and his/her predisposition status (Lu 2005). In fact, the majority of these inherited diseases are complex and multifactorial. They are caused by a combination of multiple-gene variations and environmental factors (Frosst & Wattendor e 2006). That is, they are generated by the interaction of several genes whose expression is influenced by environmental factors. For the single-gene inherited diseases, such as Huntington’s disease and thalassaemia, companies do not even offer tests.

Some biotech companies have agents in other big cities. For instance, one biotech company in Shanghai has an office in Beijing with a special agent, who needs to remain anonymous. Potential customers in Beijing can contact the agent and need not go to the company in Shanghai. The agent arranges for her/him to be sampled in a hospital and mails the sample to the company. If she/he wishes, she/he can even receive ‘door to door’ service and be sampled at home. Seven to fifteen days later, the client receives a report with the testing results on her or his predisposition status. The results are stratified into three kinds of risk as ‘high’, ‘medium’, and ‘low’ – there is no accurate percentage available. The probability of onset is explained in terms of chance in comparison with the ‘average’ individual without predisposition. If the results show a medium-level risk of developing senile dementia, it means that the client has an increase probability of developing senile dementia of five times compared to an ‘average’ person. Additionally, the report usually provides advice on a healthy diet and lifestyle, allegedly to prevent and avoid the disease in question.

In practice, biotech companies in their advertisements and in their public relations (PR) leaflets manipulate the public, using attractive and striking concepts, such as ‘decode the
mystery of life, predict your future health’, \(^8\) ‘genetic testing – the most fashionable healthy lifestyle in the twenty-first century’, \(^9\) ‘personal treatment, decode health’, \(^10\) and ‘create a healthy life based on genetic technology’. \(^11\) These sensationalist headings lead people to believe that genetic testing can provide predictable health and a healthy future. These images have a great power to attract the public, increasing the popularity of genetic testing in China, especially in big cities. More and more biotech companies are emerging, and the commercialization of genetic biotechnology is evident. In their attempts to attract customers, biotech companies focus on asymptotically healthy individuals and target a comparative wealthy part of society. Some companies point out that genetic tests are suitable for anyone, and encourage healthy people to purchase tests for themselves, their partner, their children, and their parents. They also encourage employers to purchase tests for theirs employees. To combat commercial competition, some of the companies offer sets of services at discount prices. In spite of the high price (500–875 Yuan for one disease, 2680 Yuan for a set, 8040 Yuan for forty-seven diseases; prices vary per company) (Lu 2005), the comparatively rich constitute a potentially huge market for genetic testing, which for the testing business translates into potentially high profits.

However, biotech companies do not offer prenatal genetic tests for pregnant women, an enormous number of potential customers. The main reason for this may be the availability of official regulation for prenatal diagnosis. The guideline entitled Measures for the Administration of Prenatal Diagnosis Technology was promulgated by the Ministry of Public Health in 2003. \(^12\) The regulation prescribes the qualifications, procedures and other stipulations for offering prenatal diagnosis, such as genetic counselling, informed consent and the duties and responsibilities of medical doctors. And according to the regulation, only qualified medical personnel and officially recognized healthcare institutions can offer prenatal genetic testing, and only in cases of medical treatment (MOH 2003).

---

\(^8\) Available at: http://www.qiji.cn/scinews/detailed/2330.html [Accessed date October 2007].
\(^9\) Available at the website of Fudan Biotechnologies Co, Ltd. http://www.fudan.com [Accessed date October 2007.]
\(^10\) From leaflet of Shanghai Gene Core Biotechnologies Co, Ltd.
\(^11\) From name card of an agent of one Bio-tech company.
THE VALUE OF PREDICTIVE GENETIC TESTING

Genetic testing is usually advertised as a powerful technological tool that enables the prediction of future health status. The basic principle of genetic testing is that it facilitates the diagnosis of a disorder in the absence of disease symptoms and can therefore be predictive. Early identification of susceptibility to such diseases would permit the detection of symptoms through regular medical check-ups and the close monitoring of the progress of the disease at an early stage. Optimal, permanent healthcare is expected to benefit the individual not only by increasing the effectiveness of therapeutic intervention but also by providing reassurance and emotional support. In this day and age, many people perceive the pace of life as fast, especially in big cities. By pointing out to people that they are always busy working and do not pay enough attention to a healthy lifestyle, testing companies play on the conscience and uncertainty of people who have little knowledge about genetics. This, of course, is not to deny the very existence of lifestyle related diseases. Through predictive genetic testing, the identification of the susceptibility status of individuals, previously unaware of their high susceptibility status, will present them with opportunities for preventive measures, related to diet, lifestyle, employment or geographical location. These are hoped to be effective, to varying degrees, and, depending on the disease in question, in delaying the time of onset and/or reducing the severity of disease symptoms (Marteau & Richards 1996). The test would alert individuals about their health condition, and also place greater responsibility on individuals for their health (Rose & Novas 2003). Nevertheless, only a minority can afford to purchase these tests.

At the same time, predictive genetic testing is hoped to benefit the quality of social healthcare. Some multigenic diseases such as heart disease and some forms of cancer have a higher incidence among certain population groups. Through predictive genetic testing, it is hoped that the predisposition to some hereditary diseases can be identified early and perhaps prevented by making people more aware of their health and lifestyle. Looking further into the future, once the genetic basis of multigenetic diseases has been identified, early diagnosis of predisposition to certain disorders will become increasingly important in an effort to increase the effectiveness of preventive health policies. Examples are heart disease and cancers, which have a high incidence
in the population and are especially burdensome on society in terms of depletion of health resources, loss of working days and cost of sick benefits (Marteau & Richards 1996).

**OPINIONS FROM MEDICAL EXPERTS AND THE CHINESE MINISTRY OF HEALTH**

Some medical experts and officials in the Chinese Ministry of Health, such as Profession Zhu Ping, director of the Clinical Gene Center, Beijing University No.1 Hospital, Liang Qianjin, professor of Beijing Normal University, and Wu Chaoqiu, professor of Fudan University’s Bioscience and Genetics Institute, recommend the public use predictive genetic tests with caution. Professor Wu reasons that the genetic tests the companies provide all belong to the realm of clinical diagnosis, and should not be performed by commercial companies (Zhou 2006). According to Professor Zhu, predictive genetic testing has some value but not as much as companies claim them to have in their ‘advertisements’. Professor Zhu Ping considers the pathogenesis of many kinds of diseases as too complex to predict (Beijing Daily 2006). Many other, environmental, factors can also affect the development of disease, while test results cannot resolve health problems. Even if an individual is genetically susceptible to a certain multifactorial disease, it does not mean with certainty that the person will suffer from such a disease. Besides, an unwelcome result may cause heavy psychological pressure. For example, if a girl is identified as a carrier of a susceptible gene for breast cancer, she may become very nervous about the probability of developing cancer in the future, and may live under great pressure. However, if she is identified as having no susceptible gene for breast cancer, it is not guaranteed that she will never develop breast cancer. It may even cause her to delay or ignore other chances to have health check-ups and timely treatment.

According to the Chinese Ministry of Health (MOH), the technology used for genetic testing in many cases is still in a research stage, and it is too early to put it into clinical practice. The MOH has authorized some scientific research institutions to do genetic research with experimental genetic tests, but these are not part of the public services (Lu 2005). Because services offered by the biotech companies are not authorized by the MOH, and because there are no special laws or statutes to regulate them, these services are not intended
as medical care or treatment, but in general function only as commercial businesses. Over the past decade, more and more biotech companies have emerged. We can find advertisements on the Internet in which biotech companies try to recruit new agents and to attract investors in predictive genetic tests for susceptible genes.\(^\text{13}\) In short, biotech companies pay more attention to their own financial profits than to public health and the benefits for the individual.

**SYSTEM OF BUSINESS OPERATION AND AGENT RECRUITMENT**

In order to boost business volume, some biotech companies try to recruit sales agents. As a commercial business, a company has the right to organize its business operations as it sees fit within the boundaries of the law. In general, then, agent recruitment is a legal commercial method. However, the system of agent recruitment used by several biotech companies has been proven dubious and problematic. For example, Shanghai Fuda Genetic Testing Distribution Co., Limited (Fuda Company) recruits agents throughout the country and, according to the investigation by a reporter of the *Shanghai Dongfang-Zaobao* (Eastern Morning Post), is suspected of the practice of so-called multilevel marketing [*chuan xiao*], which is illegal in China. It works as follows. Firstly, a primary-level agent of Fuda is required to pay a company 35,200 RMB to become qualified as an agent. The money is used to run fourteen units [*14 bi ye wu*] for selling of genetic tests where the agent should take on three units herself/himself. Secondly, the agent has to recruit three other agents as his/her daughter agents [*xia xian*]. And each of these three newly recruited agents also pays 35,200 RMB to the company for her/his agent qualification and takes on three units, which result in nine units. Finally, two units will be left for the agent to sell to customers. The income of the agent constitutes a percentage of the company’s profit, which increases with the number of agents they recruit. According to the new revision of ‘Corporation Law’, which was enacted on 1 January 2006, ordinary persons can apply for a ‘One-Person Company’.\(^\text{14}\) Fuda Company now requires its agents to register as a company. Therefore, Fuda Company

---

\(^\text{13}\) Available at: http://www.cinet.cn. [Accessed date October 2007].

\(^\text{14}\) Article 59, 60 of Chinese Corporation Law (Gongsi Fa 59, 60 tiao, 公司法第 59, 60 条).
declares that its agents are not natural persons (‘nature person’ is a legal terminology, which is ziran ren in Chinese) but corporations, and that the relationship between agents is a business relationship between companies. However, in fact, these so-called companies are only ‘bag companies’ [pibao gongsi]. Pibao Gongsii means a company runs its business with only a company name, an official business stamp and only one or a few members of personnel without an office and business staff. They are called ‘bag companies’ because everything of the company can be easily gathered and moved to an unknown place at any time. The practice resembles ‘post-box number companies’ in English. At the same time, the agents are mainly interested in how to develop new agencies, encouraging their friends and relatives to take part in the business and induce them to become their new agents (Zhou 2006).

POTENTIAL SOCIAL AND ETHICAL ISSUES OF COMMERCIAL PREDICTIVE TESTING

Predictive genetic testing involves many ethical and social issues. Examples are informed consent, confidentiality of personal genetic information, genetic discrimination, personal autonomy, the legal relationship between parties, and the relationship between interested parties and society. As a commercial business, predictive genetic practices in China may be comparatively problematic for various social and economic reasons.

a. Social issues of commercial predictive testing

Minimizing business risk

In order to minimize their business risk, biotech companies only offer tests for multiple-gene inherited diseases and not for single-gene inherited diseases. After all, the test result for the latter should be defined as either positive or negative. The companies therefore have to concentrate on tests whose outcome are usually indefinite and open to interpretation, for obvious mistakes could easily lead to conflict and could be followed by a lawsuit and demand for compensation. If companies only offer tests for multifactorial inherited diseases, then no matter whether the person who took the test develops the disease or not, the company is never
entirely wrong. After all, there are also other factors, such as lifestyle and the environment, involved in the onset of the disease.

**Exaggerated advertisements**

Advertising on the Internet is very difficult to regulate. In the USA, advertising for genetic tests is regulated by the Federal Trade Commission (FTC). The FTC may take formal actions against the creators of fraudulent advertisements. However, the enormity of the Internet makes advertisements difficult to regulate (Frosst & Wattendorf 2006). The situation is similar in China, where the Internet is also widely used. Usually, biotech companies have their own websites and publish their advertisements there. For them, it is an efficient way of spreading information, but for the state it is difficult to regulate, especially as there is no formal regulatory mechanism for advertising in the area of healthcare. The messages in advertisements are very tempting and often greatly exaggerated. Many advertisements are misleading, as their appearance looks reliable. For instance, they appear as scholarly articles, small essays, news reports, interview reports, introductions of genetic knowledge and surveys. According to a technical newspaper *Beijing Technology*, genetic testing was called ‘genetic fortune-telling’ (Tong 2005). In this parlance, the scientific technology is treated as divination (Lock 2005; Konrad 2003). Some companies encourage people to take a test in order to attract more customers by unethical means. For instance, in an article, ‘Genetic testing – precaution of serious diseases’, a biotech company advises parents to buy predictive genetic tests for their newborn baby and to design a healthy lifestyle for their baby according to the test result. They also advise young people to obtain genetic information of their boyfriend (or girlfriend) before deciding to get married. These kinds of advice may create problems and increase existing social and ethical tensions.

In China, as elsewhere in the world, many people do not understand what genetic testing is about. When faced with the advice from so-called genetic experts, senior physicians and other professionals, many people are tempted by the promises of advanced scientific technologies and are easily led to believe them. People with little critical reserve and education may be especially vulnerable to the promises of misleading advertisements for predictive genetic testing.
Public need or ‘luxury’ for the wealthy

The price of genetic tests is high for most people with an average income living in cities, not to mention the average inhabitants of small cities and the countryside – the average monthly income of people in cities is about 1,533 RMB.\textsuperscript{15} Although predictive genetic testing is not only developed for people with a family history of a genetic disorder, it will be especially significant for them rather than for others. Often, the people with a family history of a genetic disorder are among the financially disadvantaged and cannot afford to undergo testing. Those with a higher income, however, may be attracted by the advertisements and take the tests for fun. An agent of a biotech company said that the company targets white-collar workers, whose higher-than-average income makes them potential customers. The application of genetic testing technology in China to some extent therefore does not benefit the people who really need it and tends to become a luxury for a wealthy minority. However, such luxury does not always bring benefit for the wealthy either, as unwelcome test results may form an unnecessary psychological burden for them.

Reliability of test result and advice

In the test report, the test results are expressed as a ‘high’, ‘medium’, and ‘low’ susceptibility, indicating the chances of developing a certain genetic disorder. Several samples of the test reports available on websites and on PR leaflets in most cases are similarly vague. Because predictive genetic testing is not formally regulated, there is still no universal standard for describing genetic risk. It is said that the test report criteria are based on the recent publication of academic papers in the fields of medicine, genetics, biology and epidemiology.\textsuperscript{16} But it is not clear at all whether the standards used by these companies are reliable. For as yet regulatory bodies have not decided which institution should have the authority to approve such criteria. It is not surprising then that individuals who take the tests do not understand the criteria and risk evaluations. And, as indicated above, the indication of the probability in the test results may be subject to bias due to environmental and lifestyle factors, for there are many factors that are taken into account in the tests results, such as

\textsuperscript{15} Information from government bulletin of National Statistic Bureau on 27 March 2006. Available at: http://www.xuelang.net/webInfo/xuelang/work/Netmemhot/09242452372.htm. [Accessed date October 2007].

\textsuperscript{16} Available at: http://www.rjgene.com. [Accessed date October 2007].
radiation, drugs use, and chemical pollution. In fact, the positive result of a test may have a negative effect on the behaviour of the person concerned. For instance, Mr Chen, a Beijing citizen in his forties, now feels free to smoke after taking a predictive test that did not detect any gene that predisposes him to developing lung cancer (Zhou 2006).

In fact, several biotech companies ask their clients to answer a questionnaire about their everyday lifestyle. For instance, Shanghai Rongjian Bio-Technologies Co., Ltd tell their clients that precision and honesty in answering such questionnaires will help the company to confirm the relationship between the client’s genetic heredity and his/her lifestyle. It would also help the company to check whether his/her habits and lifestyle are in accordance with regular public health. The company also asks for reports on recent check-ups and declares that these would facilitate the company in providing the client with a suitable health report on health advice.17

The advice in the reports of genetic test results contain both a section on the actual predictive result of the test and a section on prophylactic measures, a feeble attempt to enhance the significance of the outcome. The advice usually concerns the lifestyle, diet, and intake of vitamins and minerals. For example, to prevent senile dementia the Beijing Huada Gene Research Center, in a sample report of the genetic test result, gives the following lifestyle advice: ‘take physical exercise for half an hour each day; do mental exercises at least for two hours a day, by for instance playing chess, playing cards and reading; do not smoke; eat five pieces of fresh fruit and vegetables every day; drink eight cups of water a day; take enough rest and sleep’.18 These pieces of advice belong to the realm of general knowledge of health, though they are certainly helpful for leading a healthy lifestyle. However, one need not take a genetic test to obtain such knowledge and, as one geneticist pointed out, there are insufficient experimental data to prove the efficacy of the intake of vitamins and mineral substances as a prophylactic measure for developing senile dementia.

**No genetic counselling available**

According to Article 11 of the *International Declaration of Human Genetic Data*, it is

---

ethically imperative that when genetic testing that may have significant implications for a person’s health is being considered, genetic counselling should be made available in an appropriate manner. Genetic counselling should be non-directive, culturally adapted and consistent with the interest of the person (UNESCO 2003). Once a genetic disorder is discovered, the question arises who should counsel the patient and/or family, and how the patient and/or family should be counselled (Fulda 2006). Although biotech companies in China offer predictive genetic testing, they do not provide professional genetic counselling. Some companies claim in their advertisements that they offer counselling and welcome people for consultations. By phoning several companies, the author discovered that the so-called counselling session is actually used to introduce the price of the test, the test procedure and the benefits of the tests they offer, and also to encourage people to buy the tests. In fact, as the prevalence of genetic testing increases, a growing number of primary-care physicians serve as genetic counsellors (Fulda 2006). However, even though the primary-care physicians are generally knowledgeable about healthcare matters, they are not trained as genetic counsellors. Furthermore, there are no control mechanisms available to check on their behaviour as professional counsellors. In a survey among physicians about attitudes toward genetic testing in Britain, most of the physicians who responded felt that it was the physician’s responsibility to counsel patients. However, the results of the survey showed that their knowledge of genetics and genetic testing was either average or poor (Kent et al. 2000). The situation is similar in China. The perceived risk of developing a hereditary disease, especially those for which there are no cures or for those that are severe, is usually accompanied by considerable psychological distress (Friedrich 2002). Without support from professional genetic counsellors, dodgy test results remain undetected and no responsible provisions can be made for the potential patient.

b. Ethical issues involved in predictive genetic testing

It is clear from the above that genetic testing companies strive to minimize the business risk of dispute, conflict, and dissension. The diseases that they offer tests for are all multigenic diseases, and the test results they provide are indefinite, while most of the advice they give comes down to general knowledge about health. It is a common business practice, in which
the company earns money and the individual obtains some genetic information. Looking further into the future, we cannot ignore the potential ethical issues related to these tests.

**Personal autonomy**

Personal autonomy is regarded by many as a basic ethical principle, and refers to the individual's capacity for self-determination. For instance, in relation to the decision whether to take a genetic test, people would have a right to make the decision themselves, independent from the views of others. The situation in relation to children is more complex. To some extent, the parents’ opinion cannot fully replace that of a child, and sometimes the decision parents make for the child does not entirely benefit the child. If a child’s adverse test result is received at a very early age, the child may have to live for a long period with the prospect of a later onset of the disease in question. In some cases, they regret knowing about the diagnosis, the consequences of which continually worry them. To some, not knowing may mean a less worrisome life.

It is necessary to take into consideration cultural factors that influence the relationship between children and parents, and men and women, for a similar situation will occur when adult children buy tests for their parents and when a husband buys a test for his wife or visa versa. These issues must be taken into account and should be part of any attempt to regulate genetic testing, especially because it is in the nature of genetic test companies to attract potential buyers. For example, one company offers a special set of tests for elderly people, named ‘filial piety’ [xiào xiàn].\(^\text{19}\) It encourages people to buy their set of tests as a gift to express their filial piety to their parents.

Although predictive genetic testing is rapidly becoming more popular, it is still a relatively new field, and thus problems in relation to autonomous decision-making have not occurred on a large scale. Nevertheless, the main concern for the biotech companies is to attract more customers. Some young people take seriously the advice they receive about obtaining genetic information about their partner before formal marriage, and some employers and insurance companies consider arranging genetic tests for their employees.

\(^{19}\) Information from leaflet of Shanghai Gene Core Biotechnologies Co, Ltd.
when the tests become more reliable. In the long run, if more and more employers and insurance companies ask for genetic information, or when they turn to genetic tests as a requirement for employment and insurance, the problem of how to protect personal autonomy will become more important, and very discrimination will probably occur as a consequence. In countries like China, with a large labour market of labour resource, weak public healthcare and a high demand for employees, these are issues with far-reaching implications.

**Genetic discrimination**

Genetic discrimination has moral and ethical implications (Fulda 2006). A potential drawback of genetic testing is the perception that individuals with predisposition to syndromes can be unjustly discriminated against in employment and in applications for health and life insurance (Harris et al. 2005). Genetic discrimination arises when individuals with no symptoms or signs receive less favourable or adverse treatment because of their genotype (Knoppers & Godard 2003). Here, I would like to give an example of a case of genetic discrimination which happened very recently and was called ‘the first genetic discrimination lawsuit case in China’ [zhongguo jiyin qishi diyi an]. Mr Xie, 22 years old, participated in civil service examinations in April 2009 in Foshan city, Guangdong Province. He passed the written examination and job interview against very stiff competition, and prepared to work in an official department of Foshan government that he applied for. In June, in the required routine medical examination, he was told that he needed to be checked by genetic testing on blood. The genetic testing result showed him to be a thalassaemia gene carrier. Subsequently, he was refused the job because of this reason. He said that he is perfectly healthy, he had donated blood before and there should be a positive acceptance of his blood. Even the physical check for entrance to the army did not require thalassaemia carrier genetic testing. Why could he not have a job for civil service? He felt he was unfairly treated simply because of his genes. There were several other people who had much the same experience. Three of them, including Mr Xie, brought a lawsuit on genetic discrimination on 29 November 2009.

---

20 Thalassaemia is a blood genetic disorder. The carriers of thalassaemia have 20% possibility of having a child with thalassaemia, but they are physical and mental as healthy as unaffected persons. More information of inherited character of thalassaemia and its distribution in China can be found in Chapter Five.
In China, this is the first lawsuit case with genetic discrimination as the cause of action. On 2 January 2010, the court session for this case was held in local People’s Court of Chancheng District in Fushan city. This case was reported by media, and was called ‘the first genetic discrimination case in China’, and many experts in law, ethics and sociology also appealed for non-discrimination on genetic information. Although this case was called ‘the first’, in fact, before this case received social attention and became known to the public, there already existed some similar situations in the south of China, where there is a high incidence of thalassaemia. Because this case received public attention, the stories of other people who encountered similar experiences also became known to public. From this case, we can see that accompanying indiscriminate application of genetic testing, genetic discrimination had emerged but it did not get the attention it deserved.

In China, the development of genetic testing has the potential to lead to genetic discrimination because the genetic information could be used in a way that harms the individual’s privacy, especially that offered by biotech companies, which have not been officially regulated. In this case, the genetic testing on carrier state and the disclosed of their carrier state resulted in the people, who are carriers, missing a chance to get the job that they actually qualified for. In practice, if employers organize predictive genetic testing for employees (referred to as jiinyin tijian in Chinese advertising), they will obtain information on the genetic make-up of their employees. For instance, individuals with a genetic predisposition for developing cancer will most probably lose the chance to find employment. This possibility is especially important in China where there is a huge labour market. Additionally, there are no laws that protect individuals against genetic discrimination.

**Privacy and confidentiality**

Privacy refers to the right of the individual to maintain control over personal information. Privacy also implies that an individual has control over the access of others to his/her
personal information, or is able to control their use of it (Marteau & Richards 1996). Genetic information is different from other personal information because it concerns the privacy of family members who usually share the same or similar genetic information. In this context, the confidentiality of genetic information is of great importance. Both the rights of the individual who undertake tests and the rights of those affected by the information of the test results deserve to be respected. The failure to protect privacy and confidentiality could, in practice, lead to genetic discrimination. As biotech companies have access to the genetic information on their clients and their families, it should be their duty to protect it and not sell it on. Such information also affects the interest of others, such as employers, insurance, and even national agencies, including those of the government. Apart from the most exceptional circumstances, the privacy of the individual should be regarded as more important than the interests of third parties and those of the public.

As an application of genetic technology, the service of predictive genetic testing offered by biotech companies has emerged and developed rapidly in China. As a commercial business, the main purpose of companies is to pursue profit. Partly because predictive genetic testing is not regulated, there are some potential social and ethical issues involved in genetic testing in China. This study of predictive genetic testing companies in China indicated problems related to misleading advertisement practices, the suitability of the groups targeted for potential customers, the reliability of test results and the usefulness of their advice, the lack of medical qualifications and the unavailability of genetic counselling to client. It also disclosed that the wide application of genetic testing brought about many ethical issues, such as genetic discrimination and the confidentiality of genetic information. But, as the following chapters will make clear, these problems do not exist only in commercial genetic testing.