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

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CHAPTER THREE

THE PRACTICE OF GENETIC COUNSELLING – A COMPARATIVE APPROACH TO GENETIC COUNSELLING IN CHINA

(A couple is waiting in the reception of genetics clinic in a hospital in London)

Pregnant women are waiting in line for clinical session in a hospital in Beijing

A baby with his mother and grandmother are waiting for a genetic clinical session in a hospital in Beijing
Genetic counselling is an important part of genetic services. This chapter provides an empirical account of the application of genetic counselling in China based on interviews, clinical observation and literature research during field study from September 2008 to February 2009, which was carried out mainly in China and partly in the United Kingdom. Taking comparison with the situation in the UK, and from a social science perspective, this chapter narrates the situation of genetic counselling in China, like the qualification for genetic counselling providers, the model of genetic clinical services, and its governance and supervision in Chinese social contexts; and it demonstrates the comprehensions and practical
applications of some ethical issues, such as non-directiveness, informed choice and decision-making, and reflects the administrative, political and socio-economic environments in a certain society. This chapter argues that the current situation and existing issues of genetic counselling in China are mainly due to its executive governance, non-professional genetic counselling provision, economic conditions and lack of full healthcare coverage.

INTRODUCTION

The twentieth century saw the emergence of genetic practices that defined individuals in relation to their genetic constitution (Rose 2007). Among those practices, genetic counselling is an important one, and the rapid development and application of genetic testing technologies make the provision of genetic counselling increasingly important. The American Society of Human Genetics defines genetic counselling as ‘a communication process that deals with the human problems associated with the occurrence or risk of a genetic disorder in a family’ (Ad Hoc Committee on Genetic Counselling 1975). Harper defines genetic counselling as ‘the process by which patients or relatives at risk of a disorder that may be hereditary are advised of the consequences of the disorder, the probability of developing and transmitting it and of the ways in which this may be prevented or ameliorated’ (Harper 1988; Harper 2004). According to these definitions, the process of genetic counselling involves an attempt to help the individual or family to comprehend the medical facts including the diagnosis, the probable course of the disorder and the available management strategies, to appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives, to understand the alternatives for dealing with the risk of recurrence and to choose a course of action which seems to them appropriate in view of their risk and their family goals, and to act in accordance with that decision, and to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder (Tibben & Duivevoorden 1994). These concepts have been generally recognized and accepted. Accompanied by the application of genetic counselling in a particular society, its governance also has been formed under the social network. The traditional model of
technology governance leans heavily on the principle of scientific authority, and it is being replaced by the view that non-scientists can make decisions relevant to sophisticated technological applications based on their own life expertise, experience and social existence (Mavis & Brian 2003). In fact, technology is an integral part of the creation of stable socio-technical networks, and the practice of emerging technology is socially shaped to reflect the activities and interests of the groups involved in the formative process. And the process in the formation of such networks is the creation of particular expectations for how the technology might be used in practice (Martin 2001). In practice, within a certain society and under the social contexts, the governance and the issues concerning genetic counselling and the understanding of such issues have their own specialities. Aiming to better understand genetic counselling in different contexts, a field study was carried out mainly in China, partly in Hong Kong and the United Kingdom (UK) from September 2008 to February 2009. During field research, I interviewed genetic counsellors, clinical geneticists, nurses, coordinators of patient groups, the chairman and members of professional institutions, patients and their families. Clinical observation was also undertaken. This chapter is based on the findings of this fieldwork. It narrates the current situations of the practice of genetic counselling in China, including the requirements and qualifications for genetic counselling providers, the type of clinical genetic services and its governance and supervision. Additionally, this chapter offers an insight of the comprehension and practical application of some ethical issues in genetic counselling, such as non-directiveness, informed choice and decision-making. Such issues reflect the administrative, political and socio-economic environment in current Chinese social contexts.

THE CURRENT PRACTICE OF GENETIC COUNSELLING IN CHINA

In China, there are no professional genetic counsellors and, in practice, genetic counselling services are offered by clinicians. The government has been trying to regulate the clinical application of genetic counselling. The Chinese Ministry of Health (MOH) promulgated Guidelines for Genetic Counselling in 2003. The guidelines are official government rules that regulate the application of genetic counselling, particularly as related to prenatal
diagnosis. According to the guidelines, genetic counselling should be offered by clinicians who have a background in genetics, have a certificate of qualification in maternal and infant healthcare, and whose work concerns prenatal diagnosis. The guidelines also state the common procedures and requirements for genetic counselling. For example, it states that in the genetic counselling session, the clinician who works as genetic counsellor should: collect information, draw a family pedigree, provide information of the measures for prenatal genetic diagnosis, diagnose genetic disorders and confirm the inheritance mode, estimate recurrence risk and offer advice to patients. In practice, these are the content of the genetic counselling clinic session and are all done by clinical geneticist. This basic situation of genetic counselling in China is different from that in the UK where there are professional genetic counsellors. In the UK, the clinical genetic counselling teams consist of medical geneticists and genetic counsellors. In practice, genetic counsellors and clinical geneticists work in close partnership, and parts of the counselling services they offer are joint or combined. As is shown in the figure below, ellipse A represents the practice of genetic counselling and ellipse B the practice of clinical genetics. Generally, genetic diagnosis and the determination of hereditary characteristics are done by clinical geneticist, as shown in B1; the clinical procedure of genetic testing, the explanation of the implications of the diagnosis and the help/support for the patient for decision-making, are done by genetic counsellor, as shown A1. Prenatal diagnostic counselling and pre-test and post-test counselling for predictive/carrier genetic testing, the estimation of recurrence risk, and the explanation of genetic testing results could be done by the genetic counsellor or clinical geneticist, as shown in A2/B2. Increasingly, a proportion of counselling work is counsellor led.
Currently in China, only hospitals or healthcare providers with authorization from the Provincial Health Department to practise prenatal genetic diagnosis can develop a clinic genetic counselling service. Usually, the genetic counselling service is combined with the genetic testing and the main task of the clinic is to offer testing to diagnose. As the prenatal genetic testing and diagnosis need advanced technology and equipment, not many hospitals get permission. Some big and well-known hospitals get such permission; for example, in Beijing in 2007 five hospitals got permission to offer prenatal genetic diagnosis: Xiehe Hospital, Beida Hospital, Beiyi No.1 Hospital, Beiyi No.3 Hospital and Beijing Maternity Hospital (Liu 2007). Usually, these hospitals have the genetic counselling clinic in the paediatric department and/or in the gynaecology department, which have regular sessions one or two times a week. In practice, the clinics have similar working procedures, as the flow diagram shows below.
Genetic counselling procedure

Patient visit clinic session

Initial visit → Second visit

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Inquire disease history & establish patient record

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Physical examination, other appropriate checks if needed

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Primary clinic diagnosis

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Offer available testing (chromosome or genetic test)

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Based on test result, confirm diagnosis, estimate risk, offer prenatal diagnosis if needed, discuss with patients

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Analyse result, offer information and advices for patient to refer

↓

Sort out and file patient record

(In general, the genetic counselling procedure is as the flow diagram shows. The reference information, which is in Chinese, comes from the website of Medical Genetics of Hunan Xiangya Medical College: www.cnlmg.com/cn/Item_Page [Accessed date October 2009]).
In China, there is no national medical health coverage system (*guojia gongfei yiliao tixi*). The costs for medical care are paid by patients. There is no organized referral system among the hospitals, and every hospital charges the medical care fee itself. The hospitals establish a new patient record at the first clinical visit, and only take responsibility for what they do for patients in their own hospital. It is same for the genetic counselling clinics. The patient can choose in which city and which hospital to visit clinics, depending on their own choice and the financial capability to afford all the costs, including the possibly incidental expenses such as the costs for transportation and accommodation. However, in practice, the choices for genetic counselling clinic are limited because of the limited availability of genetic counselling clinics across the whole of the country. Such a situation is different from some counties/area where there are referral system and national medical health coverage system, as in the UK, with the National Health Service, all the medical services for patients are free. For the genetic services, patients do not visit genetic counselling clinics directly, but must be referred by medical professionals in a certain hospital or local healthcare provider. The referral document for a patient is sent to the local Regional Genetics Service when the doctor/family doctor considers the patient needs to attend a genetic counselling clinic. Genetic counselling is provided by professional teams in regional genetic centres/services within the medical care system of the National Health Service (NHS).

**QUALIFICATIONS FOR PROVIDERS OF GENETIC COUNSELLING**

The education of counselling providers plays an important role in genetic counselling. The understanding of the significance of genetic counselling, the required standards of genetic counselling, the professional skills and codes needed, can only be well appreciated by relevant education and training. Suitable qualifications and accessibility of education/training for

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4 Government officials and employees in state-owned units can get a proportion of their medical care expenditure reimbursed from the units they work for. The healthcare insurance system is underdeveloped and the inherited diseases are excluded from insurance. Although in some parts patients share cost with the insurance companies, the majority of the population pay medical costs themselves. Presently, new healthcare reform is being tried in China, so hopefully the situation will change to some extent.
counselling providers are the prerequisites for the practice of counselling.

In China, the *Guidelines for Genetic Counselling* regulates the requirements for counsellors. Firstly, counsellors must be a clinician with a licence. In addition, they must also have either: (1) a bachelor’s degree of medical education, at least five years’ clinical experience working in an obstetric department as an obstetrician or other interrelated clinical departments, and have specific training in clinical genetics; or (2) at least ten years’ working experience in prenatal diagnosis with special knowledge of clinical genetics and technology skills. They are also required to be well educated in genetics, have ample genetics knowledge and the ability to accurately diagnose conditions, accurately analyze test results, and appropriately estimate the inherited risk and recurrence risk. At present, there is no official degree programme in genetic counselling in China. In practice, genetic counselling providers are clinicians trained as paediatricians or obstetricians. Training programmes for prenatal diagnosis are sometimes available, for example at the national prenatal diagnosis training programme hosted six times by Hunan Xiangya Hospital prenatal diagnosis centre. Usually these training sessions have a lecture for genetic counselling given by a senior geneticist (Xiangya Hospital 2008).

In fact, the professional education or/and training is necessarily required for working as a genetic counsellor in some counties/areas. For example, in the UK, clinical genetic counsellors are required to have either a background in nursing with appropriate training, or have completed a master’s degree in genetic counselling. Two master programmes in genetic counselling were developed in Manchester in 1992 and in Cardiff in 2000 in the UK, which are designed to educate students for clinical genetic counselling.

The students in such programmes are educated to be the clinical genetic counsellor. In the UK, there are two routes to enter into the genetic counsellor profession: a minimum of six years of usual training and work experience prior to entry to the profession, for the professional route, or five years for the MSc in the genetic counselling route. Registration for a professional genetic counsellor can only be undertaken after a training period of two years following entry into the profession by either of these routes. The requirement is the submission of a master’s-level portfolio of evidence of professional competencies. By registration, therefore, all prospective genetic counsellors will have completed seven to eight years of training, with many more having considerably longer.
MAIN ISSUES CONCERNED GENETIC COUNSELLING

As what described above, the basic situation of clinical counselling and counsellors, the requirements and qualifications of counsellors and the education/training of counsellors in China have its speciality. This part of this paper will focus on the understanding of the issues concerning genetic counselling in the Chinese social contexts. Here, a comparing approach is taken to shed light on such issues.

Goals of practical genetic counselling

In the beginning, the essence of genetic counselling was stated as informative: its aim was to convey relevant genetic facts and reproductive options in order to enable families to plan reproductive decisions and to adjust realistically to, or cope better with, their genetic problems (Hsia 1977). Accompanying the development of genetic counselling, the goals of genetic counselling have differed over the past three decades. American researchers from the National Human Genome Research Institute of the USA pointed out that there are two prominent viewpoints of the goal of genetic counselling. One view upholds the goal of preventing birth defects and genetic disorders; the other view promotes the goal of improved psychological well-being in client adaptation to a genetic condition or risk. Both goals emphasize that clients should make their own reproductive decisions; however, the former relies on clients making decisions that will reduce the impact of genetic disorders (Biesecker 2001). In fact, the goal of genetic counselling virtually directs and dictates its practice, and hereby the counselling practices demonstrate different goals. Meanwhile, the accepted professional code of ethics, government guidelines and the genetic counselling providers’ awareness of their role and duty also express or reflect the goal of genetic counselling.

In China, according to regulations enacted by the MOH, genetic counselling is treated as one item of prenatal diagnosis technology (MOH 2003a: Article 2). The MOH states that the main purposes of enacting a guideline of prenatal diagnosis technology are ‘in order to safeguard the mother and infant health, improve the quality [su zhi] of the newborn population, to ensure the safety of the prenatal diagnosis technology’ (MOH 2003a: Article 1).
Guidelines of Genetic Counselling is an attached document of the Measures for the Administration of Prenatal Diagnosis Technology enacted by the MOH in 2003. According to this guideline for genetic counselling, genetic counselling is for patients inquiring about a genetic disorder, birth defect and reproductive decision-making (MOH 2003a: Foreword). Some well-known genetic experts working as clinical geneticists hold the opinion that genetic counselling is a type of medical guidance \([yixue zhidao]\), and consequently the application of genetic counselling will reduce birth defects, thereby improving family welfare and social harmony \([cujin jiating xingfu he shehui anding]\) and enhancing the population quality of the nation \([tigao minzu sushi]\) (Xia & Wu 2003). Currently in China, clinical genetic counselling is combined with genetic testing. The main reason patients resort to the genetic counselling clinic is to undertake a genetic test. For pregnant women who know they are at high risk, the purpose of counselling is to avoid giving birth to an affected baby. One of my interviewees, a pregnant woman who has a son with Duchenne muscular dystrophy (DMD), expressed her view:

I heard from the doctor in local hospital in my hometown that this hospital has a genetic counselling clinic and can offer prenatal genetic testing. Then I come here to take the test. I hope I will have an unaffected child. Otherwise, why would I to spend so much money coming here and to pay for the test.

[Trans: S. Sui]

Another interviewee has a nine-year-old son with DMD and a daughter who is 21 and has reached the legal age to marry. She described how the doctor in the clinical genetic counselling session told her that the test result of the boy, confirming DMD, would enable her daughter to be aware of the high risk. The doctor explained to her that when her daughter got pregnant she could resort to a genetic counselling clinic to take a test, to avoid giving birth of a child affected by DMD. The doctor emphasized this would be an important and significant action to prevent a ‘tragedy’ happening again \([beiju chongyan]\) to her daughter, and she also agreed.

In the UK, the Association of Genetic Nurses and Counsellors (AGNC), founded in 1980, is the professional organization which represents genetic counsellors and genetic nurses
in the United Kingdom. The AGNC approbates the definition of genetic counselling defined by the American Society of Human Genetics in 1975. As the professional organization of the genetic counsellor, the AGNC represents the view of the profession and prescribes standards of clinical practice in genetic counselling. Also, the AGNC attempts to clarify and guide the conduct of genetic counsellors. It states that all genetic counsellors must be aware of the ethical implications of their professional role, and adhere to the principles and guidelines in the code developed by the AGNC (AGNC 2008a). The AGNC also states the aims of genetic counselling are to help the individual or family understand the information about the genetic condition, appreciate the inheritance pattern and risk of recurrence, understand the options available, make decisions appropriate to their personal and family situation, and make the best possible adjustment to the disorder or risk (AGNC 2008b). A counsellor interviewed in the UK also expressed such a view as below:

We understand that the patients are under pressure. They are full of worries when they encounter genetic problems. It is not very difficult for the patient to understand the genetic information and available options when we explain them in a proper way, but it is difficult for them to make a decision. We help our patients to reduce their psychological distress, reduce self-blame and relieve their worries. That is what we are here for.

This statement shows that genetic counselling in the UK not only offers information about the genetic problems but also considers the psychological issues that counselees face in such conditions.

**Non-directiveness and decision-making in practical genetic counselling**
Genetic counselling is one practice in which individuals are encouraged to reflect upon their inherited constitution, with the explicit aim of affecting their conduct (Rose 2007: 113). Thus, the directive or non-directive way in which counselling attempts to affect the individuals’ conduct, especially for reproductive decisions, is significant. Non-directiveness, also known as client-centred therapy, which was established by Carl Rogers in 1940s and 1950s (Rogers 1951:
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means that the counsellor leaves all decisions about future reproduction up to the family, and does not provide any recommendation for treatment or intervention. Non-directiveness is one of the guiding principles of genetic counselling. For the individual genetic counsellor, it has provided practical and ethical guidance in the complex tasks of presenting technical information, giving emotional support, and assisting in the process of decision-making. At the professional level, it has served as a basis for developing ethical standards, counselling techniques, and professional identity (Weil 2003). Non-directiveness is based on the desire to uphold the personal nature of reproductive decision-making and a reluctance to pass judgement on the worthiness of the life of a person affected with a genetic condition (Murray 1996). This concept has been influential in the way of working with counselees. In practice, the understanding of non-directiveness and of how to achieve non-directiveness is very important.

In China, offering advice is one of the duties of clinician working as a genetic counsellor. According to the Guideline of Genetic Counselling, clinicians working as genetic counsellors should offer advice on marriage, reproduction, or some general consultation. It regulates that clinicians should try best to avoid expressing their own opinion during counselling. A medical expert I interviewed pointed out that currently few clinicians pay more attention to psychological aspects when they offer genetic counselling. In fact, for most patients, the feasible options are limited because of their economic situation, the healthcare system and family-plan policy. One genetic counsellor’s words demonstrate this:

In most conditions, I need not say more and the patients know clearly what they can choose. They resort to the genetic counselling clinic with the clear wish to have a healthy, unaffected baby. I think I need not or cannot say keeping an affected fetus is an option. The patients already thought this is not option for them. Imagine, when I say she also had the option to keep the affected fetus, that the patients asked me where they can get money to treat their baby. I would be dumbfounded [sha yan] and could not say anything. [Trans: S. Sui]
One clinical geneticist also expressed a personal opinion of non-directiveness:

I think nowadays we are trying to be non-directive in counselling. We require the patients to sign an informed consent form before they take a genetic test, which is a necessary procedure now. We cannot promise the test results are always 100 per cent accurate. We need to make sure that the patients voluntarily take the test and voluntarily take the risk. This is also a way to avoid potential dissension. We do not write ‘clinician suggestion’ on the test report and we do not advise patients to terminate or keep a pregnancy. We explain the test result to patients. Usually the patients have already thought over their choices, which depend on the test result. In fact, when the patients understand the test result, they know what they will do. [Trans: S. Sui]

One genetic counsellor shared her experience and her opinion about non-directiveness and informed decision:

Usually, if the pregnant women already know the fetus is affected, they will terminate the pregnancy. For this, they hardly need any advice. They regard the test as a way to avoid having an affected baby and understand well it is so hard to have an affected child. Actually, I have only come across one case that a pregnant mother still kept her pregnancy when she knew the test result was ‘bad’, which was years ago. She already had one affected child and I explained to her that her fetus would have the same condition as the affected one. She did not believe it, because she resorted to the fortune teller, and the fortune teller told her this fetus was perfect and would bring amazing good luck to her family. I think I had told her what I should have done. After the fetus was born with a disorder, she came to the clinic again for diagnosis with great regret. But it was too late for regret [houhui moji]. Judging on the basis of this case, I think sometimes we still need to ‘direct’ the patient. [Trans: S. Sui]
In the UK, non-directiveness is treated significantly in counselling concerned with reproductive decision-making. In my fieldwork, all the genetic counsellors I interviewed in the UK insisted strongly that the genetic counselling should be non-directive, and they considered their clinical practice of genetic counselling to be non-directive. Such opinions are shown by their own words:

During the counselling session, we tell the clients their genetic condition. As for the decision-making, especially for the reproductive decision-making, we do not tell the patient what they should do. We offer options to patients but no suggestions. We help and support any decision the patient make without our judgement. Certainly, I have my own opinion. But, I try to avoid my opinion influencing my patient’s decision-making. We do not lead or hint to our patients to make their decision. Actually, I think it is patients who ‘lead’ us. During our counselling, from what the patients tell us, we can feel their worries then help their relief. Sometimes we can feel they have already made their decision but they are hesitant because they need support psychologically, then we support them.

I think we are always trying to help our patients reach the ‘good’ decision from their personal view. We let the patients understand there is no right or wrong, only a suitable decision. The important thing is they understand well their choice and what will happen if they take this choice. We do not guide them to any decision, as to test or not to test, to terminate a pregnancy or to keep it. We never say ‘maybe it is better to do …’

If a patient asks me what I would do if I were him, I will tell him everyone is different. We are different and something I think what is good for me may not be good for you. I do not regard non-directive counselling as irresponsible. I will do my best to help a patient to make their personal decision, but not lead or direct.
In practice, non-directiveness and informed decision-making in genetic counselling are commonly known as ethical principles. The counselling providers interviewed in this study all regard their counselling a non-directive, or believe they are doing their best to keep it non-directive, but their understanding of non-directiveness and the extent of its application are different. Comparatively to say, non-directiveness has gained more virtual currency in the UK than in China. One Chinese geneticist I interviewed regarded current ‘non-directiveness’ in China as a ‘skin deep’ [biaomian shang de] non-directiveness.

DISCUSSION

Based on the introduction and comparing of the different situations of genetic counselling in China and UK, this section will examine and analyse factors that have contributed to genetic counselling in China.

Non-professional counsellor in China

Usually, in medical treatment for the patient’s welfare, to some extent, a doctor’s job is more likely inclined to be directive. In China, for the clinician working as genetic counsellor, they were educated as a clinician but not a professional genetic counsellor. Currently, there is no institution to certificate counsellors and specifically govern the group of counsellors. A geneticist I interviewed said the counsellors have no ‘niang jia’ (‘niang jia’ literally translates as mother’s home of a married woman, which metaphorically means a union for a special group). Also, he expressed his own view on the clinician geneticist working as a genetic counsellor:

I think there is no problem that the doctors can offer genetic information to patients, but to some extent this situation is wasting the ‘resource of the doctor’ [yisheng ziyuan], where supply already falls short of demand. In practice, with many patients waiting outside the door, doctors do not have enough time and energy to consider more about psychological issues. Maybe
they are also not aware of such issues. Without special and suitable training, I do not think a genetic clinician, even an expert, can make a good genetic counsellor. In practice, because ‘genetic counsellor’ is not a formally official profession, so there is no professional title for ‘genetic counsellor’. You know, a professional title is so important in a person’s professional career. I think that ‘Genetic Counselling’ has not been paid more attention by authorities. This is also a reason that many young genetic clinicians do not have enough passion or impetus to learn genetic counselling themselves and would not like working as a genetic counsellor. [Trans: S. Sui]

In fact, the qualifications for the genetic clinician who offers genetic counselling in China emphasize medical knowledge and technology. The essential professional responsibility of clinicians is to heal the wounded and rescue the dying [jiu si fu shang]. In practice, doctors try to reduce illness and eliminate human suffering from illness. For example, in the condition of prenatal diagnosis, the clinical obstetrician’s initial motive in performing prenatal genetic testing may be to detect and then reduce abnormalities. As for genetic counselling, this is seen more as psychological support for patients’ decision-making, and even this is opposite to the clinician’s initial motive. As a communication process with the patients, counselling providers need to adopt better communication skills than common clinicians, such as promoting shared language and using silence and listening skills (Baker et al. 1998: 65–70), to help counselees to overcome their emotional problems, and counsellors should avoid using scientific terminology and jargon in their explanations. Practising these communication skills requires proper education/training, which is at present lacking in China.

A model of genetic counselling
Since the concept ‘genetic counselling’ was coined in 1955 (Reed 1955), there have been four models proposed: the eugenic model, the medical preventive model, the decision-making model, and the psychotherapeutic model (Baker et al. 1998: 2–4).

The eugenic model aims at counselling families with a history of ‘defective’ offspring not to reproduce. The medical preventive model and decision-making model emerged from the
1950s to the early 1970s. They attempt to give families information and offer the option to avoid recurrence of a particular genetic disorder. Their aim is the optimization of population health, mostly through the prevention of birth defects (Fine 1993). The decision-making model allowed a more interactive type of counselling so that individuals were not only educated about the risks but also were helped with decision-making on further testing and reproductive concerns. And the counselling provider believed that those who were at risk of having defective children, once given accurate knowledge, would make ‘responsible’ use of that knowledge and make their own prudent decisions concerning reproduction (Rose 2007: 115). In the psychotherapeutic model, which became dominant during the 1970s, the genetic counsellor not only provides the individual with the necessary information but also helps the individual through any psychological and emotional difficulties. And increasingly they were addressed as autonomous individuals making informed and responsible choices for their own futures (Dice 1952; Herndon 1955; Rose 2007: 115). This research shows that current genetic counselling in the UK has adopted this model. In China, current genetic counselling is more like the medical preventive model or the decision-making model. In the latter, clinical counselling offers mainly genetic diagnosis, the determination of hereditary characteristics, the estimation of recurrence risk, the explanation of genetic testing results, availability of treatment, content of treatment and feasible measures to prevent the condition. This model emphasizes the genetic disorder itself and the associated medical problems. The psychological and emotional aspects are left to the clients and to an extent are even ignored. In fact, currently, the patients who resort to genetic counselling clinics do not expect more psychological therapy or consolation, although they hope the clinician will understand they are in difficulty. One of my interviewees, who has a son affected with DMD, explained her view, and many clients interviewed in China have a similar opinion:

I do not come here for psychological therapy. The doctor here is not psychologist. Certainly, I hope the doctor is kind, patient, warm-heart and understanding. For the psychological and emotional pain, I think I try to, and have, overcome it. If needed, possibly I will turn to my family or friend.

[Trans: S. Sui]
All clinical geneticists and counsellors interviewed in this research prefer the psychotherapeutic model and agree this model cares more about the patient’s psychological difficulties and it is better for the patient’s well-being. The counsellors interviewed in the UK consider the current model in the UK very good. The Chinese geneticists interviewed think it is much more difficult for clinical geneticists to carry out such model in the current Chinese context and considering that the current genetic counselling in China is realistic.

**Limited choice and decision-making**

In China, illness has a close correlation with poverty, especially in rural areas. The cost of medical services has not only been shown to be a major factor influencing hospital utilization by the poor, but also medical costs contribute to families falling into poverty (Kaufman & Fang 2002). Nowadays, Chinese parents have greater expectations for their offspring under the one-child population policy, and at least a healthy baby is the wish for prospective parents. For the absolute majority of Chinese families, the ensuing financial burden of medical treatment for a child born with a serious genetic disorder, for example thalassaemia, is so oppressive that it is hard to afford. Additionally, the deficient public welfare, shortage of social support/help for the disabled, and the potential social stigma and discrimination make prospective parents worry more. These limit the feasible options concerning reproductive decision-making. Genetic counselling, which is combined with genetic testing, plays a major role in preventing birth defects. In practice, for patients/families who resort to the genetic counselling clinic, the main purpose is to take a genetic test in order to avoid having an affected child. For them, the financial stress outweighs psychological pressure, which also might be caused or sharpened by financial stress. Compared with China, the UK and Hong Kong are wealthy and have public healthcare systems and comparatively better public welfare. For the parents in the United Kingdom, to a certain extent, the cost of abortion in terms of remorse and guilt may outweigh the financial burden of rearing a handicapped child (Clarke 1991). Additionally, the inference of culture or/and the religious opinion of the moral position of embryo and the status of fetus also plays a certain role in the reproductive decision-making. Anyway, without worrying about medical treatment expenses, it might be the more feasible options for reproductive decisions, although, to some extent, balancing the possible options sometimes is hard.
Non-directiveness and non-judgement

The counsellors I interviewed insist that genetically at-risk individuals must govern themselves and their lives, and the counsellors regard what they are doing in practice as non-directive, but non-directive counselling is difficult to attain. For non-directiveness, it is essential that the counsellor/clinician be non-judgmental. In practice, the counsellor’s motives, conscious or unconscious, are relevant during counselling, and it is the counsellors who decide what kind of information should be given to the patients, which involves a value judgement. In fact, it is not easy for counsellors to avoid their personal value judgements. It had been suggested that ‘non-directive’ counselling is an abdication of professional responsibility and that it is impossible to maintain a sincerely non-directive approach to counselling about a genetic disorder while simultaneously aiming to prevent that disorder (Clarke 1991). The counsellors I interviewed consider that there is still scope for improvement for the ideal non-directiveness, even though some of them regard their current counselling mode as very good or perfect. However, most of them do not agree that non-directiveness is irresponsible. As the same time, they do not deny that sometimes, to a certain extent, directive counselling is supportive and understanding for the patient. In China, one of the main aims of current genetic counselling is prevention of genetic disorders, and the guidelines/regulations require clinicians to offer advice to patients. Also, from the aforementioned Chinese interviewee’s words, current genetic counselling in China can be said to differ from non-directive counselling, although the clinical geneticists consider it to be non-directive. Nowadays, with the development of medical ethics in China, the recognized principle of non-directiveness is becoming well known. It is understandable that counsellors wish their work to be in accordance with the ethical principles. Also, in practice, claims that counselling is non-directive, and that no directive advice is offered to aid patients’ decision-making, perhaps helps the counsellors to avoid potential dispute or litigation. Frankly, in practice, ideal non-directiveness and non-judgement in genetic counselling is hard to achieve. Although non-directiveness connects with free autonomy of decision-making, in fact, more understanding and psychological support for patients are needed. Sometimes, in certain conditions, even for a very personal decision such as reproductive decision-making,
directive and feasible advice from experienced clinicians/counsellors is also very helpful.

CONCLUSION

This chapter aimed to show the practices of genetic counselling in China and different practices of genetic counselling in the UK. In China, genetic counselling service is offered by clinical geneticists, and the clinical genetic counselling related to prenatal diagnosis is under governance of official guidelines with the goal of reducing birth defects. These are the features of practice of genetic counselling in China. In the UK, there are professional counselling services of the psycho-therapeutic model counselling and non-directive counselling style. In fact, the social contexts make genetic counselling distinctive in individual societies. Generally, this chapter argues that the economic conditions, the non-professional status of the genetic counselling provider, lack of full coverage of the healthcare system and national population policy are the formative factors of the current version of Chinese genetic counselling. Compared with in the UK, where individual well-being and autonomous reproductive choice are more respected, patients in China have fewer feasible options concerning reproductive decisions. Such situations contribute to the practice of genetic counselling and its governance in China, and, to some extent, limit proper communication and applicability of non-directiveness in genetic counselling in China. Considering the clinical genetic testing and counselling are combined in China, from what is described and discussed in this chapter, we can basically understand the situation and the main issues concerned in clinic genetic service. Chapters Five and Six respectively of this thesis take thalassemia and Duchenne muscular dystrophy as case study targets to discuss the genetic testing practice and involved issues in Chinese contexts. The case studies will offer an insight to well understand the problems and the impacts that the families with a genetic disorder may encounter in the application of genetic technology under the Chinese social factors.