

Choosing offspring: Case studies of prenatal genetic testing for thalassemia and the reproduction of a ‘saviour sibling’ in China¹

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Abstract:

This paper focuses on the current application of prenatal genetic testing and reproductive decision-making around thalassemia carriers in China. The study is based on fieldwork conducted in hospitals and research institutions, interviews with families with thalassemia-affected children, geneticists, genetic researchers and literature research during fieldwork in China from September to November 2007 and following update collections. The paper aims to provide insight into the ways in which thalassemia carriers decide to have a test for thalassemia and the choices available to prospective parents. The paper also analyses some factors affecting

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reproductive choices, and the decision to produce a 'saviour sibling', including financial implications, the state family planning policy, influential images and information conveyed through the media and propaganda, the advice and counselling from doctors, psychological pressure from the community, and social discrimination. The paper concludes with a discussion on the issues involved in the creation of 'saviour siblings', some of which are particular to China.

Key words: prenatal genetic testing, thalassemia carriers, reproductive choice, reproductive decision-making

Introduction

The development of genetic research over the late decades has rapidly broadened the range of inherited disorders that can be identified. Prenatal genetic testing can provide prospective parents with information about their chances of having a child with a specific genetic disorder or characteristic in a current pregnancy. Genetic testing combines the newest advances in genetics with intimate matters such as the reproduction of the family. In fact, prenatal genetic testing has created opportunities for parents to acquire information on the disorder they are at risk of, and make preparations for the kind of child they expect. The information includes the risk of parents passing a genetic mutation to their children and data on the genome of the fetus in the mother's womb. Such information can provide reassurance to prospective parents, or provide the basis for making important decisions: to attempt a pregnancy or not; or to continue a pregnancy or not (Genetics and Public Policy Centre 2004).

To some extent, reproduction here is not treated as a natural matter. The reproductive technology and prenatal genetic testing play an increasingly significant role in reproduction and influence the notion of reproduction and reproductive decision-making. In China, as one of the consequences of the application of the one-child policy, launched in 1979, Chinese parents have higher expectations for their offspring than previous generations. People who have a family history of a genetic disorder or live in an area with a high prevalence of a certain hereditary diseases, such as thalassemia in the south of China, have often been made aware, through campaigns, testing centres, education or the newspapers, of the availability of tests and the possibility of preventing ‘inferior offspring’. People who make use of prenatal genetic testing have a high expectancy of giving birth to an unaffected child.

Thalassemia (note 1) is widely prevalent in the south of China, especially in the provinces of Guangxi, Guangdong and Hainan. According to the Family Planning Committee of Nanning, Guangxi Province has a ratio of thalassemia gene carrier of approximately 20% (Li Jia 2006). This article is concerned with the ways in which people in the south of China decide to have a test for thalassemia and the choices available to prospective parents. Such decisions are related to the institutional facilities available to people, but also to government policies on healthcare, family planning, and to the right to procreation. However, Chinese individuals also make decisions that are not informed and preconditioned by state policies, taking matters of life and death into their own hands. Individuals, it is shown, do not simply do what policymakers tell them to do with the means available to them, but also create new paths induced by their own desires, situation and will. As will become clear, the parents of a ‘saviour sibling’ are a case in point. On the one hand, they are affected by the media propaganda directed toward good mothers loving their children and the

great feat of modern technology, which they want to hear about; on the other hand, they do not take seriously informed consent procedures, and try to ignore the cases of blood transfusion that went awry.

This study aims to give insight into the situation of thalassemia carriers and their expectation for offspring in the south of China, and is based on studies of genetic testing regarding reproductive decision-making concerning thalassemia in Nanning of Guangxi Province and Chengdu, the provincial capital of Sichuan. Apart from conducting fieldwork in hospitals and research institutions, the first author interviewed eight families with thalassemia-affected children (where both parents are thalassemia carrier), four geneticists, two genetic researchers, two haematologist and two agents of insurance companies. Based on data from archives and from the interviews, this paper focuses on the current application of prenatal genetic testing and the reproductive decision-making of thalassemia carriers, and analyses factors affecting choice in the reproduction of offspring, and the decision to produce a ‘saviour sibling’.

Current provision for prenatal genetic testing in China

At present, the practice of prenatal genetic diagnosis is formally regulated by the Chinese Ministry of Health (MOH). *The Measures for the Administration of Prenatal Diagnosis Technology*, which is a document promulgated by the MOH in 2003, lists the special qualifications for prenatal genetic diagnosis, and only qualified hospitals or healthcare providers can offer prenatal genetic diagnosis services. The health departments and bureaus of some provinces and municipalities directly under the central government also have promulgated detailed rules for carrying out *The*

Measures for the Administration of Prenatal Diagnosis Technology. According to this regulation, hospitals must have the necessary qualifications and get permission from the provincial health department to practise prenatal genetic diagnosis. For example, in Beijing, at present, only five hospitals have permission to offer prenatal genetic testing as a measure of prenatal genetic diagnosis: these are Xiehe Hospital, Beida Hospital, Beiyi No.1 Hospital, Beiyi No.3 Hospital and Beijing Maternity Hospital (Liu Mofei 2007). Another example is Hubei Province, where currently eight hospitals have permission to offer prenatal diagnosis (Li Changzheng & Zhou Jianyue 2005). Thus, presently in China, only a limited number of advanced hospitals and healthcare providers in comparatively large cities can offer prenatal genetic diagnosis. The range of hereditary diseases on offer for testing also varies, depending on the technology each hospital has mastered in its laboratory or can access.

Broadly speaking, a distinction can be made between groups of women who use prenatal genetic testing service: those who have already had an affected child or who have a known family history of a genetic disorder and therefore know that they are at high risk of producing another child with the same condition; and those with no family history but who are at higher than average risk of having a child with a specific condition for a particular reason, such as being of a maternal age over 35 years, getting doubtful result from the routine check-up during the pregnant period and having been exposed to noxious or radiant materials. In such cases, gynaecologists advise them to go to a genetic counselling clinic. In this study, all the interviewees would choose to undergo prenatal genetic testing for thalassemia if they knew that they were thalassemia carrier. Thalassemia carriers have no symptoms, as it is a recessive condition, and they are usually not aware that they are thalassemia carriers without taking a carrier test. Carrier testing for thalassemia is available mainly in

large cities, especially in provinces in the south of China. Some cities such as Nanning and Guangzhou had listed thalassemia carrier screening as a necessary item for premarital check-up when premarital check-ups were still compulsory. But in 2003 coercive premarital check-ups were made voluntary according to the *Rules for Marriage Registration*. After this liberalisation, the number of couples taken premarital check-ups has sharply dropped. To encourage people to take a premarital check-up, the government of Guangzhou has offered free check-up and the Nanning government, in 2006, launched a project of free carrier testing for thalassemia for a hundred thousand newly married couples in the rural area (Li Jia 2006).

Usually the hospitals that offer prenatal genetic testing have a genetic counselling clinic in a paediatric clinic and/or a gynaecologic clinic. The substance of genetic counselling in China, however, is generally limited, it has different connotation, and is not performed by professional counsellors. The American Society of Human Genetics defined genetic counselling as a communication process that deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family (Ad Hoc Committee on Genetic Counselling 1975). Peter Harper defined 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). 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 1993).

In China, the *Guidelines for Genetic Counselling*, promulgated by the MOH in 2003, regulate the application for genetic counselling, and its principles and procedures (MOH 2003). At present, the situation of genetic counselling is different from some wealthy, modern countries, such as the USA. In the United States, professionals who carry out genetic counselling must have had professional training and have a certificate from the American Board of Genetic Counselling (ABGC) [www.abgc.net]. Although in China the counsellor in the genetic counselling clinic is not a professional genetic counsellor, it has been formally regulated by MOH. According to *Guidelines for Genetic Counselling*, genetic counselling should be offered by clinicians who have a knowledge background in genetics. In practice, the counsellors in genetic counselling clinics usually are clinicians such as paediatricians and obstetricians that also have a background in genetics. Many of the clients or patients who visit the counselling clinic have previously had an affected child. In practice, the genetic counsellor advises the family to take a genetic test to confirm the thalassemia carrier condition of the parent and affected condition of the child. According to the family planning policy, parents of a seriously handicapped child are allowed to have a second child. With a certificate offered by the doctor to prove the condition of the child, and the availability of the prenatal genetic testing, the couple can apply for permission from the local government to have another child. Usually, during the counselling, the doctor will explain basic genetic knowledge about thalassemia, and introduce the procedure of prenatal genetic testing. One of the

interviewees, Ms C (note 2), a mother of a thalassemia-affected child, explained that the doctor in the counselling clinic drew a simple picture to explain the heritability of thalassemia. Although she has only a primary school education, she understood the information well and drew on it during the interview. In fact, it is the doctor in the genetic counselling clinic who prescribes genetic testing for patients, and it is also the doctor in the counselling clinic who explains the test results to the patient. Ms C stated that the doctor had especially explained to her that her son's illness was unrelated to punishment for sins committed or for evil before he told her the result of test, trying to prevent the mother from blaming herself and feeling guilty. In this study, all interviewees said they would go to a genetic counselling clinic and apply for a prenatal genetic test if they were in the position to have another child. Almost all of the interviewees believed and trusted that genetic testing would help them to give birth to a healthy baby. Had no genetic testing been available, none of the interviewees would want to take a risk, and some of them expressed the desire to adopt a healthy child instead. For instance, Mrs Y said:

I would have decided not to have children if I had known I am a thalassemia carrier and if the doctor could not help me. I do not want to take risk and depend on fate [*qu maoxian he peng yunqi*]. I already have one affected child.

That is an expensive and bitter lesson! [Transl. SS]

In other words, the availability of genetic testing is crucial for couples in their decision to give birth to a child. Without the tests, the only alternative is to have no children of their own, though some would opt for the adoption of a healthy child. Others, however, use abortion to terminate the thalassemia-affected foetus. This

would also be in line with the family-planning policy, which advises doctors to suggest that the pregnant mother have an abortion in these cases. According to the *Chinese Population and Family Planning Law*, controlling the quantity and improving the quality of the population is the purpose of family planning; the national government established the premarital and pregnancy healthcare system to prevent and reduce birth defects [*chusheng quexian*] (Chinese Population and Family Planning Law 2002). The National Population and Family Planning Commission launched a national project entitled *Intervention with Birth Defects* in 2001, which encourages the application of prenatal diagnosis and consequential selective abortion to prevent birth defects (National Population and Family Planning Commission 2001). Additionally, *The Measures for the Administration of Prenatal Diagnosis Technology* also requires doctors to inform patients about the result of continuing the pregnancy and to give patients his/her opinion if the next fetus is found abnormal as well. In fact, in such cases these laws and regulations instruct doctors to counsel pregnant mothers to terminate the pregnancy. The doctor's advice or implication is very important for patients, although the final decision of keeping or terminating the pregnancy is made by patients themselves. In this respect, genetic counselling can be said to differ fundamentally from the ideal of non-directive counselling.

Reproductive decision-making and the 'saviour sibling'

The usual medical treatment for thalassemia patients is blood transfusion. If the affected children receive blood transfusion regularly, usually twice per month, the disorder can be controlled. To a great extent, the life of an affected child depends on the blood transfusion, but for many families the costs of blood transfusion is very high, approximately two times Renminbi 2.000 (c. 290 UD\$, note 3) in one month. It is

such a great economic burden for the majority of families in China, not to mention for the families in the comparatively poor rural areas which are far away from hospitals that can offer blood transfusion treatment for thalassemia patients. In fact, there are many families that discontinue treatment because they cannot afford the high costs although they know the child will die at the early age without the treatment of blood transfusion. Blood transfusion cannot cure the disorder and the prospects and life expectancy of thalassemia-affected children is not very clear.

In order to cure their affected children, some families decide to use a treatment that involves having another, unaffected, child. The child that results from this attempt to create unaffected offspring with a tissue match with the affected child is called a 'saviour sibling'. The umbilical cord blood of the 'saviour sibling' is utilised to save her or his thalassemia-affected sibling. Although the ideas of creating a child for the purpose of saving another did not receive much attention among the interviewees, the high cost of umbilical cord blood transplantation, approximately RMB 200,000 (c.29,000 US\$), did. Even though, some families want to save their children through this way. For instance, Prenatal Diagnostic Center, Guangzhou Maternal and Neonatal Hospital, during 5 years from 2001 to 2006, had 52 couples who required tissue matching test when undergoing prenatal diagnosis to detect thalassemia. All these couples already had a thalassemia-affected child and opted umbilical cord blood transplantation for the affected children if the sibling baby donors were normal and had an identical tissue matching(C Liao, D Li, et al 2006). Ms S, the mother of a thalassemia affected-child, explained her feeling:

I cannot watch my child die. If there is a way, I would like to do anything to save my child. I worry about the fee for the transplantation, which is huge like

an astronomical number [*tianwen shuzi*] to us. But it is better than to worry about the death of my child, and the fee for blood transfusion is also high and cannot cure the illness. It is a bottomless hole [*wudi dong*] and we cannot see any hopes at the end. Anyway, I hope my child will be cured. [Transl. SS]

To save her son, Ms S decided to give birth to a ‘saviour sibling’. However, her family could not afford the fee for the transplantation. Ms S was so desperate to raise money that she took to begging in front of the hospital. The forcefulness of the belief with which Ms S collected money to pay for the operation requires explanation. It is well known by the doctors that there are substantial risks involved: first, it is not easy to produce an unaffected sibling; second, the child is not automatically the right match; and, third, transplantation has certain risk and the operation does not always succeed. And this does not even take into account the financial, psychological and social burdens associated with either success or failure of the treatment.

The next case of a thalassemia ‘saviour sibling’ illustrates some of these problems. The first child of Ms Y and her husband Mr Z was a thalassemia-affected girl, who died at the age of six. Their second child was intended to be a ‘saviour sibling’ for his sister. However, he also suffers from thalassemia. Because the prenatal genetic test failed to offer the accurate test result, then the ‘saviour’ attempt failed. This time, to save the boy’s life, the couple decided to try again to give birth to another ‘saviour sibling’. Ms Y terminated the third pregnancy after prenatal genetic testing showed that the fetus had a positive result for thalassemia. Attempting to create a ‘saviour sibling’ for their son, Ms Y decided to become pregnant for a fourth time. On 13 March 2007, the couple gave birth to their fourth baby as a ‘saviour sibling’ for their son. When Ms Y was asked how she felt after the three births, she said, ‘I had tried to

give a chance to my daughter, so I should also give a chance to my son' (Yang Dan & Xie Lu 2007). She added:

My son came to this world as a saviour sibling, and now he should be saved as well. Otherwise it is unfair to him. As a mother, I would like to suffer instead of my child. God blessed me in giving me a healthy and blood-matching baby. The second son is not only saviour for his brother, but also the life saviour of the whole family. We will love him more. [Transl. SS](Note 4)

In fact, there are some cases of thalassemia 'saviour sibling' that were reported by newspapers and TV programmes. Usually, the purpose of the reports is to praise the mother's love, arouse sympathy to the difficult condition of the families and appeal to the public for donations. The hospitals that can offer umbilical cord blood transplantation also introduce the treatment to the public on their websites. In the case of procreating a 'saviour sibling', there are concerns about the welfare of a child that is born to be a 'saviour sibling'. Concerns exist that once conceived as a 'saviour', it is difficult to place limits on the extent to which it is reasonable for the child to be used to benefit another person. With regards to such a situation, the US Human Genetics Commission considers that it is difficult to justify preventing parents who have a child with a life-threatening disorder that may be cured by a stem cell or bone marrow transplant from attempting to create a 'saviour sibling' (Genetics and Public Policy Centre 2004). Although there are ethical discussions about this in China, interviewees regarded giving birth to a child for the purpose of saving his/her sibling as meritorious and respectable, finding it worthy and understandable for the parents to create a 'saviour sibling'.

In practice, pre-implantation genetic diagnosis (PGD) is also a possibility to reproduce thalassemia-free children, even a 'saviour sibling'. In China, in 2003 the first thalassemia-free child was born after PGD, and some studies have confirmed the technological success of PGD in China (Jiao Zexu et al. 2003; Deng Jie et al. 2006). At present, in China there are eighteen hospitals/ reproductive research centres that have official permission to clinically apply assisted reproductive technology (ART). Among them, only seven have permission to apply PGD (MOH, 2006). The average price of PGD (excluding a tissue matching test) is around fifty thousands Renminbi (c. 7.260 US\$, note 5), which the majority of thalassemia carriers cannot afford. Although it is possible in China to use PGD to avoid a thalassemia-affected child, and although the reduced need for an abortion of an affected foetus is welcomed, thalassemia carriers seldom chose it. In this study, no interviewee could afford to try PGD and the doctors in genetic counselling clinics do not advice PGD. For example, Doctor Shi, a geneticist working in a genetic counselling clinic, advised thalassemia carriers that if they were fertile, it is better to get pregnant naturally [*ziran huaiyun*]. A main consideration, however, for thalassemia families, is the forbiddingly high cost of PGD. Other considerations are that PGD combined with IVF (in-vitro fertilization), a technology for the treatment of infertility, has a successful pregnancy rate of approximately 25% to 30 % in clinic practice. This rate is not considered sufficiently high compared to the fortune spent on the treatment in the light of the possibility of abortion. Moreover, the doctors and informed patients are aware that PGD still requires prenatal genetic testing to confirm the thalassemia-free nature of the pregnancy.

Social issues involved

This section discusses some of the issues involved in the creation of ‘saviour siblings’, some of which are particular to China. These issues involve community pressure, the media, policy of family planning, views on abortion and motherhood and discrimination. A combination of choice-constraining factors, it is shown, does not necessarily suppress the initiative and agency of prospective parents.

The termination of possible ‘saviour siblings’

The primary purpose of prenatal genetic testing for thalassemia is to avoid having an affected child. The harsh social conditions and poor facilities make it undesirable for parents to carry a handicapped fetus to full term (Yang Huanming 2002). If the result of the prenatal genetic test is positive, terminating the pregnancy is the usual choice. One pregnant woman said before undertaking a prenatal genetic test:

Of course, I will have an abortion in such a condition. I would prefer to have no baby rather than an affected one. If not, why would I pay money to take the prenatal genetic test? If I still continue with the pregnancy knowing that this fetus is affected with thalassemia, anyone will think I am crazy. [Transl. SS]

In fact, it is socially acceptable and advisable to abort a fetus with a life-threatening disorder such as thalassemia. But in the case of using prenatal genetic testing to find out whether a fetus will be a good match to donate blood or tissue, namely be born as a ‘saviour sibling’, the pregnancy will be terminated if the test result shows that the fetus is not a good match. This fact is also related to the one-

child policy, which only allows the birth of one more child if the first one is disabled. Allowing the birth of a child that is not a blood match for the diseased child means there will be no other chance to create a 'saviour sibling'. In practice, prenatal diagnosis requires amniocentesis, a procedure associated with risk for the pregnancy, which often takes place at the beginning of mid-term of pregnancy. Currently, the earliest amniocentesis can be done at 15 weeks of pregnancy, and in clinical practice sometimes occurs at around 20 weeks. Thus, a healthy 15-week or older fetus is terminated only because the expected baby is not a good match for the sibling. This poses questions about the meaning of human life in relation to the expectations harboured about the value of offspring. It is not easy for the mother to make the painful decision of aborting a healthy fetus. Although abortion is accepted as a way to stop an unwanted/unplanned pregnancy in China, it is a grievous experience for the mother; it frequently results not only in physical but also in psychological suffering. One interviewee expressed her feelings of ambivalence:

I decided to conceive again in order to save the life of my poor son. As a mother I try to give a chance to my child to live... A nearly five-month-old fetus already has a 'person shape' [renxing] ... To my son, I am a kind mother, but I feel I am also like a murderer. I cannot try to save a person and at the same time to kill the other one. [Transl. SS]

In some hospitals in Guangxi and Guangdong, chorionic villus sampling (CVS) is performed together with genetic screening to determine chromosomal or genetic disorders in the fetus. This can be done during early pregnancy, usually from days 25-65 of the pregnancy. To make sure that the fetus is thalassemia-free, some doctors suggest pregnant women take both CVS and amniocentesis. Currently, there is hope that the number of 'saviour siblings' created could be decreased by using cord blood

from the Umbilical Cord Blood Banks that have been set up in China recently. In China, the MOH enacted *The Measures for the Management of Umbilical Cord Blood Banking* in 1995, which was the original impetus for the creation of Umbilical Cord Blood Banks. Presently, six Umbilical Cord Blood Banks in China have permission from MOH to establish facilities (He Xin 2008). According to statistics released by the MOH, the number of blood samples in stock is approximately twenty-five thousand, and among them 400 samples have been used in the clinical transplantation for leukaemia patients (Wei Mingyan 2008). However, there is still no successful case of matching samples in the Umbilical Cord Blood Banks for the use in transplantation for thalassemia patients. This situation continues the situation in which prospective parents try to give birth to another child as a ‘saviour sibling’.

Potential harm possibly caused by the test and the exaggerated expectation of creating a ‘saviour sibling’

Amniocentesis is commonly used as a measure to collect samples for prenatal diagnosis. In prenatal genetic testing, fetal cells obtained through amniocentesis are genetically tested. Amniocentesis is performed at approximate 15 to 20 weeks’ gestation in current clinical applications in China. Although the exact risk associated with amniocentesis is controversial, it is not a completely innocuous procedure and can result in a spontaneous abortion. Amniocentesis can also result in future reproductive complications (Wapner 2005). Nevertheless, most of the patients put great trust in the technology and believe the technology could help and benefit them. Also, they trust their doctor and are inclined to obey the doctor’s advice. Before taking a test, the patient usually signs the informed consent form to confirm that they understand the medical procedure and the potential risk associated with it. But, in fact,

not many patients take the informed consent form very seriously, because they know they have to sign the forms to obtain the test. In such conditions, the potential harm of the test does not receive as much attention as it deserves. At the same time, exaggerated expectations of umbilical cord blood stem cell transplantation can lead to disappointment. And the realisation by the parents that they are worse off than before the procedure.

The high expectations of the treatment of the thalassemia child involves extraordinary risks in the case of Chinese parents, who feel they have to abort the ‘saviour sibling’ when it turns out not to be a good match. Both the motivation and feelings of the parents are formed under strong social pressures which limit their choice. To some extent, the reports and presentations about the cases of ‘saviour siblings’ in the media, with their high praise of the love of the mother for the affected child, strongly influence the thalassemia-carrier parents’ decision to create a ‘saviour sibling’. These pressures easily lead the parents to ignore the mental and financial costs, the medical risks of the procedure and the risk of cord blood transplantation and the bone marrow transplantation. According to Professor Z, a haematologist, in addition to the high price for the transplantation and the difficulty of obtaining a blood match, the stem cell research involved is a comparatively new field. In fact, there is still much room for improvement regarding the curative effect of umbilical cord blood stem cell transplantation.

Social discrimination and financial pressure

People with a family history of genetic disorders, as in the case of thalassemia, may not have to deal with just the heavy financial burden, but also with feelings of social inaptitude and psychological pressure of their fate. Currently, in China, insurance

companies do not offer medical insurance for serious genetic diseases such as thalassemia. This narrows the options even for the families that are relatively well off. Only some can afford to pay for cord blood transplantation, but most families have to take recourse to the two-monthly blood transfusion and pay a high bill. The families that cannot afford the treatment cost and that have no access to help have to forego treatment for the affected children, which means that such children die before the age of five.

But even if the family can afford to pay for umbilical cord blood transplantation, it is not always easy to find a match and there is no guarantee that the transplantation will succeed. Furthermore, genetic technology cannot guarantee that the testing results are always 100 percent correct. Thus, some children are born with thalassemia because the test failed to provide accurate results. Their birth is usually regarded as an ‘unlucky birth’ and the beginning of a tragedy. In a newspaper report, these children were called ‘thalassemia children that should not have been born’ (Zhu Hongjun 2006). Sometimes the purpose of such reports is to pay attention to the abominable situation of the affected child, but such a pronouncement also implies that the children are not welcome in society. In some cases publicity arouses sympathy. Ms Y’s case, for instance, was reported in the newspapers and on TV programmes, after which she received donations meant for cord blood transplantation.

In China, the current government encourages thalassemia carriers to undertake prenatal genetic testing, which is treated as a measure to control and prevent birth defects and improve the quality of the population. In fact, the widespread use of selective abortion to reduce the number of people born with disabilities sends a message to children and adults with disabilities, especially people who have genetic or prenatal disabilities, that ‘we do not want any more like you’ (Shakespeare 1995).

Most of the families interviewed for this study try to keep secret the fact that their children are affected by thalassemia. The information is disclosed only to a very limited circle such as relatives and very close friends. They even keep the information secret from the children's teacher in kindergarten or in school. They really hope that their children will be treated the same as other children.

Conclusion

Although the research population in this study was not large enough to make generalisations about the reproductive behaviour of prospective parents who have a high chance of conceiving a thalassemia-affected child, this study made observations about the difficulties faced by such parents and the social dilemmas they encounter. The use of prenatal genetic testing for thalassemia in China shares similar difficulties to those of other developing countries where have limited access to healthcare and are restrained by financial resources. But Chinese parents also encounter problems that are particular to China, occurring as a result of its family planning policies and the cultural values attached to healthy offspring.

The current application of prenatal genetic testing for thalassemia not only offers a way to prevent the birth of affected children, but it also makes it possible for prospective parents to create a 'saviour sibling' by providing a tissue typing test during the middle of pregnancy. Many factors constrain and limit the choices of prospective parents, including financial difficulties, the family planning policy, the media and propaganda, the advice and counselling from doctors, psychological pressure from the community, and social discrimination. The restriction of choice in some cases leads parents to take initiatives that may have far-reaching consequences,

such as when they decide to have a 'saviour sibling'. In the cases observed in this study, such initiatives were accompanied by ignoring the potential risk of failing technology and failing to take seriously the process of informed consent when undergoing invasive interference during pregnancy. Undoubtedly, with the development of advanced genetic technology such as pre-implantation genetic diagnosis (PGD) and the progress of its reliability, there will be more choices for people suffering genetic disorders, though at present the majority of the population is not in a position to access such advanced treatment.

Notes:

1. Beta-thalassemia is a genetic blood disorder. It is inherited in an autosomal recessive pattern. In beta-thalassemia major (BTM) haemoglobin production is reduced such that normal growth, development and quality of life can only be achieved by regular red cell transfusions from infancy onward. Death at an early age is inevitable if no blood transfusions are given. Where the term 'thalassemia' is used without qualification, it usually refers to thalassemia major. A person who carries the beta-thalassemia gene can appear perfectly healthy. Person's whose parents both carry the gene have a 1 in 4 chance of inheriting both their genes and develop beta-thalassemia major (UKTS 2008). The term 'thalassemia' used in this paper refers to beta-thalassemia.
2. To protect the privacy of the interviewees, all the names of the interviewees in this paper are anonymous.
3. Renminbi (RMB) is the name of the Chinese currency. According to the current exchange rate, 2.000 RMB is about 290 UD\$ (the currency exchange rate of

Chinese Yuan convert into UD dollar is 0.1452 on 4 December 2008). The price information of blood transfusion came from the Haematology Department of 303 Hospital 2007. 303 Hospital is located in Nanning city, Guangxi province and it is well known for its blood transfusion treatment for thalassemia.

4. The younger brother not only donated umbilical cord blood but also bone marrow to his older brother. On 19 August 2008, the operation of drawing bone marrow from the young brother, about one and half years old, took place in Nanfang Hospital at Guangzhou, the capital city of Guangdong province. On the same day, the elder brother had the umbilical cord blood transplantation and the bone marrow transplantation. The total cost for the transplantation was approximately 300 thousands RMB. Although this family was lucky to have a donor, nearly half of the expenditure was borrowed. The mother said that the family would be in debt during the rest of her life. The condition of the brothers is fine (23 November, 2008).
5. The information on the costs of PGD came from the Reproductive Technology Centre of Beiyi No3 Hospital, Beijing. The currency exchange rate of Chinese Yuan convert into UD dollar is 0.1452 on 4 December 2008.

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