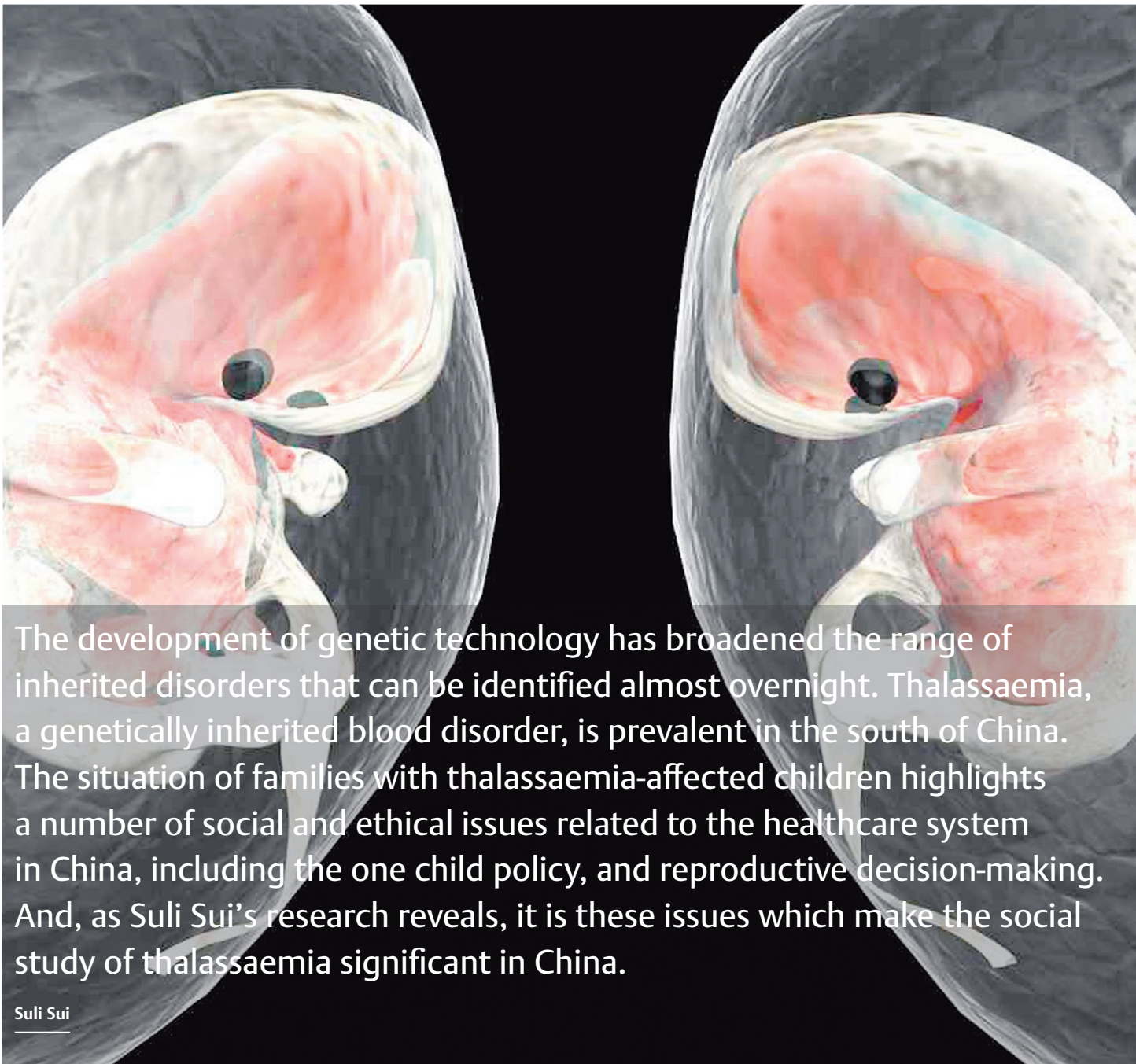


Creating a 'saviour sibling' in China



The development of genetic technology has broadened the range of inherited disorders that can be identified almost overnight. Thalassaemia, a genetically inherited blood disorder, is prevalent in the south of China. The situation of families with thalassaemia-affected children highlights a number of social and ethical issues related to the healthcare system in China, including the one child policy, and reproductive decision-making. And, as Suli Sui's research reveals, it is these issues which make the social study of thalassaemia significant in China.

Suli Sui

Should human beings be welcomed and valued just as they are or also because of what they can provide for other people?

THALASSAEMIA begins to show itself in early childhood. Children with thalassaemia cannot make enough haemoglobin in their blood. They need regular blood transfusions from infancy onward to achieve normal growth and development. If no blood transfusions are given, death at an early age is inevitable. A person who is only a carrier of thalassaemia is symptom free and appears perfectly healthy. If both parents are thalassaemia carriers, their children have a 1 in 4 chance of inheriting both their genes and developing the disorder.

Managing thalassaemia

Thalassaemia is prevalent in the south of China, especially in the provinces of Guangxi, Guangdong and Sichuan. According to the Family Planning Committee of Nanning, approximately 20% of the population of Guangxi Province carries the thalassaemia gene (Li Jie 2006). The usual medical treatment for thalassaemia patients is blood transfusion. If the affected children receive blood transfusion regularly, usually twice per month, the condition can be controlled. To a great extent, the life of an affected child depends on the blood transfusion. As a mother of a boy with thalassaemia said, 'My child is so cute. He is like a beautiful flower, but we have to water him with blood.' According to the Haematology Department of 303 Hospital in Nanning City, capital of Guangxi province, the costs of the twice monthly blood transfusions are approximately RMB 2,000 (US\$290). This is prohibitive for most families, and there is no national medical health coverage system (*guojia gongfei viliao tixi*) in China. Generally, costs for medical care must be paid by patients, and in the case of thalassaemia, treatment costs will increase as the children grow up and more blood is needed. For the average Chinese family such an economic burden would be hard to bear, but for families in the comparatively poor rural areas, which are far away from the hospitals that can offer blood transfusion for thalassaemia patients, it is especially difficult.

During my fieldwork, conducted from April to August 2007 in China, I met a 10-month-old boy who was having a blood transfusion in 303 Hospital in Nanning. His parents told me that this was the second, and also the last, time that he would undergo a blood transfusion. They simply could not afford the ongoing costs of long-term treatment and other expenses, such as long-distance travel and accommodation.

A child is like a flower watered by blood

Thalassaemia is a lifelong condition. While blood transfusion can control the disorder it cannot cure it. In the search for a cure for their affected children, some families decide to use a treatment that involves having another unaffected child. The child is genetically matched to provide life-saving umbilical cord blood, which can be transplanted into a sick brother or sister. Such a child is called a 'saviour sibling'. Prenatal genetic testing and subsequent selective abortion can help the families avoid giving birth to another thalassaemia-affected child. Currently, the cost of umbilical cord blood transplantation in China is very high, approximately RMB 200,000 (US\$29,000), which is far beyond what most Chinese families can afford. Nevertheless, some families choose to save their children in this way. For instance, Prenatal Diagnostic Center, Guangzhou Maternal and Neonatal Hospital, in the course of five years from 2001 to 2006, treated 52 couples requiring a tissue-matching test during prenatal diagnosis to detect thalassaemia. All of these couples had already given birth to a child with thalassaemia and opted for umbilical cord blood transplantation for the affected children, if the sibling baby donors were normal and had an identical tissue match (Li Dongzhi et al. 2006). Ms Shi, the mother of a child with thalassaemia, explained her decision:

"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. The fee for blood transfusion is also high and cannot cure the illness, which is like a bottomless hole [wudi dong] and we cannot see any hope at the end. Anyway, I hope my child will be cured".

However, her family could not afford the fee for the transplantation. She was so desperate to raise money that she took to begging in front of the hospital.

Another case of a thalassaemia 'saviour sibling' had dramatic consequences. The first child of Ms Yin and her husband Mr Zeng was a girl with thalassaemia who died at the age of six. Their second child, a boy, was intended as a 'saviour sibling' for his elder sister. However, he also suffers from thalassaemia. Because the prenatal genetic test had failed to offer an accurate test result, the 'saviour' attempt failed. To save the boy's life, the couple then decided to try to give birth to another

'saviour sibling'. Ms Yin terminated the third pregnancy after prenatal genetic testing showed that the foetus had a positive result for thalassaemia. Ms Yin decided to become pregnant for a fourth time. On 13 March 2007, the couple gave birth to a 'saviour sibling' for their son. When Ms Yin 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'. 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".

The younger brother not only donated umbilical cord blood but also bone marrow to his older brother. On 19 August 2008, the operation to draw bone marrow from the young brother, who was about one and half years old, took place in Nanfang Hospital in Guangzhou. On the same day, the elder brother received the umbilical cord blood and bone marrow transplantation. The total cost for the transplantation was approximately RMB 300,000 (US\$43,600). Although this family was lucky to have donors, nearly half of the expenditure was borrowed. The mother said that the family would be in debt for the rest of her life, but she was happy to have two healthy sons. I contacted the family in June 2009 and was pleased to learn that both boys are healthy.

Some cases of thalassaemia 'saviour siblings' have been reported in the media. Usually, the purpose of the reports is to praise the mother's love, arouse sympathy for the difficult condition of the families, and appeal to the public for donations. However, to some extent, the reports and presentations about the cases of 'saviour siblings', which emphasise the love of the mother for the affected child, may influence thalassaemia-carrier parents' decisions about giving birth to a 'saviour sibling'.

The doctors I interviewed during my fieldwork currently regard blood transfusion as a better choice of treatment. Receiving regular blood transfusion, a thalassaemia-affected person can lead a relatively normal life. In the UK, one thalassaemia-affected person has already reached the age of 51, has a family and children, and is in good health. Moreover, aside from the high price for the transplantation and the difficulty of obtaining a blood-matched child as a 'saviour sibling', transplantation carries certain risks and the operation does not always succeed.

Born as a child or as medicine?

There are concerns about the welfare of a child born as a 'saviour sibling'. The phenomenon raises issues about the meaning of human life and expectations regarding offspring. Should human beings be welcomed and valued just as they are or also because of what they can provide for other people? In the case of creating a 'saviour sibling', what is the real expectation for the offspring, a child or a child as medicine? 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 for the benefit of another person. The judgement of the US Human Genetics Commission is 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 in my research regarded giving birth to a child for the purpose of saving its sibling as meritorious and respectable, finding it worthy and understandable for the parents to procreate a 'saviour sibling'.

Suli Sui

IIAS Fellow

Amsterdam School of Social Science Research,

Amsterdam University

suisuli@hotmail.com

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