Donation of spare embryos for stem cell research
Experiences and views of couples undergoing IVF at CITIC-Xiangya Hospital of Reproduction and Genetics, Changsha, China

Pilot study report

Anika Mitzkat, M.Sc.
Institut for History, Theory and Ethics of Medicine
University of Mainz, Germany
mitzkat@uni-mainz.de

A BIONET Student Exchange Project

Field work in China at CITIC-Xiangya Hospital of Reproduction and Genetics, Changsha, Hunan Province, P.R. China, March 10th – April 26th 2008

Project supervisor: Prof. Christoph Rehmann-Sutter, Unit for Ethics in the Biosciences, University of Basel/Switzerland
Corresponding supervisor: Prof. Erica Haimes, PEALS, Newcastle University, UK
Local reference person: Prof. LU Guangxiu, Director of CITIC-Xiangya Hospital
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1 Background and aim of the project

One of the key questions tackled in the BIONET project concerning the ethical governance of Chinese-European research collaborations is “how can vulnerable patients who are in a desperate situation (as is often the case with both ART and stem cell therapy patients) be safeguarded against risks of inducement and exploitation?” (BIONET 2008). Such a description meets many of the characteristics of the situation of IVF (in vitro fertilization) patients who are asked to donate spare embryos for embryonic stem cell research. These women, together with their partners, have to decide whether they agree to donate for research or not, and what is to be done with a spare embryo in any case. The experience and the perspective of the women concerned are of particular interest for bioethics, for evaluating the regulations that are in place, and for reviewing the practice of informed consent and decision-making.

There are a few qualitative empirical studies either still ongoing or recently completed that give evidence of the patients’ perspectives. One is being conducted by Lene Koch and Mette Nordahl Svendsen in Copenhagen (Denmark), a second by Erica Haimes and co-workers in Newcastle upon Tyne (UK), and a third one by Jackie Leach Scully, Rouven Porz and Christoph Rehmann-Sutter in Switzerland. In China, where IVF is practiced in several state-of-the-art clinics around the country in high numbers, and where several centres also do stem cell research, no systematic study of the patients’ experiences, views and ethical concerns has been conducted so far. On the basis of the studies in the UK and in Switzerland (Scully et al 2004, 2008; Haimes et al 2008), I conducted a pilot study in Changsha, one of the largest IVF centres in central China. The BIONET student exchange scheme allowed me to do field work in Changsha for this project during seven weeks, to establish the methodology and the local network that was necessary for then conducting and interpreting 5 qualitative in-depth interviews with IVF patients about their views on embryo donation for embryonic stem cell research (ES).

As regards the ethical implications of in vitro fertilisation (IVF) and embryonic stem cell research (hESC), a vast quantity of theoretical literature can be found. Compared to that, there is a lack of empirical knowledge, which could substantiate the ethical points of view in the perceptions and understandings of those involved. Data from the ongoing European studies underline that the specific situations, understandings and experiences of couples undergoing
IVF are morally significant and differ from what bioethicists find on the basis of theoretical considerations. One area of particular interest is related to the so-called “spare” embryos and to the option of stem cell donation. Starting from this perspective, the leading questions of the study whose results will be reported below, was:

*How do involved persons (clinicians, nurses, scientists and the patients and potential donors themselves) experience the impacts of IVF and the possibility of donation of embryos for research?*

*What are their perceptions and considerations concerning “spare” embryos and about decisions on what should happen to them?*

The aim of this study was to provide insight into the experience of couples undergoing IVF treatment who are directly involved in these kinds of decision-making. The short-term objective of the project was to obtain a better understanding of the individuals’ situations and the decisions of the interviewees.
2 Methods

The project can qualify as an exploratory pilot study. It follows a qualitative design with a phenomenological approach.

The interviews with Chinese interviewees challenge language and cultural differences. The most important methodological consideration was that of “open the field”. From the beginning, establishing contact with the couples undergoing IVF and building up a trustful relation for the interviews took place under recognizably difficult conditions. Prior to starting interviews with the patients, two steps were necessary to obtain familiarity with the setting. These consisted of expert interviews and participant observations. The interviews were translated by an interpreter bit by bit in both directions, audiotaped, transcribed and analysed.

2.1 Expert interviews and participant observation

During the first two weeks, I met experts from each department to familiarize myself with their work and their procedures, and also to introduce myself and build up confidence in the aim of the study. Information obtained during this period was put on record by personal notes and protocols. During the following weeks, it was possible to accompany a doctor to meetings with patients for several days at a time.

2.2 Patient interviews

Interviews with women/couples who were asked to decide whether they were ready to donate embryos for hESC were conducted after their decision had been made. The physician acted as gate-keeper to the potential interviewees.

The patients who were waiting for their appointment with the doctor were given an information sheet about the project. During the meeting with the doctor, they were asked whether they would agree to participate in our study. If they agreed, they gave their telephone number. He Chen, who later acted as translator in the interviews, gave the potential participants a call. If they still agreed in participating, a date for the interview was found. The interviews were conducted using a semi-structured questionnaire, which was adapted from the
European studies. On the one hand, semi-structured interviews allowed me to follow the study goals and, on the other hand, to find new aspects during the course of the informants’s own narratives. The interviews were accompanied by a local interpreter (He Chen) who translated in both directions, from Chinese to English and from English to Chinese. Both the original dialogue and the translations of sections of the conversation were audiotaped and transcribed. Data analysis used a phenomenological method (Giorgi/Giorgi 2003) to identify the major themes that emerged.

2.3 Ethical considerations

Couples undergoing IVF are potentially vulnerable persons, because they are a) patients and b) in a situation that might inflict mental tension upon them. The gatekeeper, i.e. the clinician responsible for the treatment of the patient under concern, was instructed to decide, after evaluation, which patients would be able to participate. In addition, an informed consent was considered an obligatory measure before the interview took place. In the information material, it was explained to the candidates that the data would be treated anonymously.

Before the recruitment process for the interviews could start, approval of the local ethics committee in the Changsha clinic has been sought.

It was an advantage for sensibly preparing and conducting this study in a complex clinical environment that I was myself trained as a nurse before becoming a qualified nursing scientist. In my previous work and during the studies, I had extensive professional training and experience in conducting qualitative research with patients and relatives in existentially demanding situations. Nevertheless, talking about intimate themes like infertility and the wish to have a baby with all the implications this wish may have is likely to cause psychological distress for the participants that could not always be anticipated. Therefore, preparations were also made for psychological support to be available on demand in the hospital.
3 Results

3.1 Features of the clinical setting

The Reproductive and Genetics hospital of CITIC (China International Trust and Investment Company) Xiangya was founded in the beginning of 2003. 15935 patients have been treated until January 2009. The average pregnancy rate is 48.17% and has raised from 40.39% in the year 2004 to 51.79% in the year 2008.

3.1.2. Results from the expert interviews and from participant observation

The first step of the observation included visits to each department of the hospital, which were guided by one of the local staff members, and it also included listening to the lectures that are regularly given for patients. Thirdly, it additionally involved walking around to acquire familiarity with the location and the people to obtain a general impression of the people’s habits and everyday behaviour etc.

The Reproductive and Genetics hospital has a clinical department, a genetics center, a reproductive center and a sperm bank. I talked to several physicians in the clinical department. However, as most of them could not speak English fluently, the possibilities of conversation were limited and it was sometimes not possible to ask questions concerning an issue in depth. The sperm bank has a capacity of 10.000 samples with a stock of 42.000 samples end of 2008. Sperm donor may give up to five samples; this is accurately document and communicated with other sperm bank centers. For an IVF treatment with donated sperms a double blind strategy is used – physicians in the IVF laboratory will know the patient’s name and the donations ID, physicians in the sperm bank know the ID and name of the donor but not the name of the couple treated. Couples who need sperm donation will choose the donor from a list that has been made anonymous using the IDs.

All of the physicians I met talked about the details of their clinical work, which basically involves examination and monitoring of the patients before or respectively during the treatment. None of the physicians performs the embryo transfer. This, they explained to me, only the professors are allowed to do. They talked about the masses of patients they have to deal with. Being asked for the reasons for the large amount of couples having infertility
problems they told me that, in most cases, there are some “tubal problems”, which might be the result of an abortion performed in the past. One physician explained to me that there are many people in China, especially in the countryside, who have only a poor sex education. Therefore, there are many teen-aged or young women who unintentionally become pregnant. In many cases, as they do not want to marry or have no possibility to do so, they have no other choice than to abort, since otherwise the baby would be born illegitimately. But abortion, one doctor told me, is also a social taboo so it will be carried out in secret and therefore mostly with a very low budget. In many cases, she told me that these abortions are badly done, often causing infections and constrictions of the tube. Another doctor told me that there is also often a problem of low quality sperms; these two factors together result in a high number of couples who hope for a baby via IVF treatment. This hope is also nourished by the fact that being childless is socially despised. All agreed to the statement that, in China, a woman ought to be married and have a baby before she is 26 years old. I here wish to mention that most of the physicians and also the other clinical staff were in their twenties and did not seem to share this opinion. But they explained to me that there is a severe social pressure and that it is not easy to break with traditions – especially if the couple is living in the countryside and has a low education.

Compared with the results from the European studies, the relation between the “need” to have a baby and the choice for IVF treatment is interesting. Most of the couples, or at least the women, had a very strong desire to have a baby and were not able to become pregnant without IVF treatment, although physically they sometimes had a 50% chance. But after having the first child through IVF treatment, many of them got pregnant naturally. To discuss this relation is outside the focus of this project, but it might be an interesting issue for further studying the psycho-social influences on pregnancy.

Another topic we were talking about was the decision-making of the patients concerning the question of embryo donation. The couples have to decide what should happen to the “bad quality embryos” (see below 3.2: “good ones – bad ones”) or, respectively, the frozen embryos after the paid period of freezing ends. This decision takes place while the couple waits for the embryo transfer and first gets the results of IVF or, respectively, ICSI (see below 3.1.4, where I will summarize my observations from the pre-embryotransfer interview). I was told that most of the patients chose to donate the embryos for research. Being asked for their reasons, the physicians told me that, in their view, the patients wanted to contribute. One of
them told me that the only reason why patients refuse to give their embryos for research is the fear that these could be used for other couples.

It would have been interesting to summarise the talks with the physicians about their attitudes towards the patients in a more detailed and systematic way, but from the available data this is not possible. What was obvious to see is that there was a lack of time to conduct longer conversations with patients, and particularly a lack of time to explain embryonic stem cell research during informed consent. This brevity was dictated by circumstances.

The other visits and talks took place in the IVF laboratory, the genetics center and the sperm bank. Since I am no expert in the field of genetics I will not expand on them. I want to mention that I had a long talk about the issue of donated embryos with one of the experts who worked in the laboratory. He was astonished that hESC research is forbidden in Germany and even more about the reasons why. Due to language restrictions (I had no translator with me) it was not possible to deepen this discussion.

The most structured interview that I could conduct was the one I had with the expert from the sperm bank. First he mentioned ethical principles: benefit, informed consent, protection of offspring, wellfare, secrecy and talked about commercial issues. I asked him how these principles are practiced and he explained each step to me using a handbook and patient information forms, which he translated as well as possible. Again, the substantive content of the conversation is not so important regarding my aim to “get into the field” than the attitude from which the expert talked to me. If I were to summarise all these interviews from a highly subjective point of view and verbalize my personal impressions, I would say: There was something identical to pride – to have so many patients, to be one of the best, to do this kind of research, to have ethical principles and so on. There was also a certain openness to talk with me, but though there was also an uncertainty as to what I might be interested in or how to say things. People spoke more openly after they had met me several times. I did not conduct the expert interviews in a formal way, following any standardized questionnaire. I left it up to them what to tell and when. With some of the experts I went out to dinner more than once and on such occasions there was also a lot of small talk. In the end, I performed participant observation without even recognising it. This is a non-scientific part of this study. It could perhaps have been utilized as data, if consequently protocolled and reflected upon.
But in order to reflect I would have needed to take up a specific point of view and in this situation and setting I was not prepared to assume a special perspective.

One comment of an expert working in the IVF laboratory is still very present in my mind. In addition to other subjects, he explained me how the eggs and sperm come to his laboratory, and what is the normal procedure for fertilization. Further, what happens to the fertilized eggs, the “good and bad embryos”, how they get to transfer, are frozen and how they handle the donated embryos “once they are given to research, they are only a number”. He was very enthusiastic telling me about his work in the IVF laboratory and I asked him: “What exactly are you doing there”. His answer was: “Creating life”. I said to him that he seemed to be very enthusiastic about this and he said: “Creating life is amazing”. I said that for me there is a conflict between “creating life” and “giving a number to research” and he answered: “Yes, but research is necessary and otherwise there would be no use for it (the embryo)’’.

3.1.3. Lectures

Every Monday, a 45-minute lecture is given to potential patients and their relatives. About 80 people attend each week. This lecture is not mandatory and most of the patients who already know the details of IVF treatment (for whatever reason) do not attend this lecture. It is held on the second floor of the clinic by a nurse, using a powerpoint presentation. It gives a short introduction to the hospital including the work of Prof. Lu in particular and an introduction to the concept of IVF treatment in general. There it is said that the research center and reproductive hospital exists since 1980 and has been certificated by the Ministry of Public Health of P.R. China. It shows the history of IVF babys (first birth 1978 in the UK, first birth in China 1988) and provides statistical data that in Xianga hospital, until 2006, 3363 babies have been born. <<Check meaning of the number: probably IVF including ICSI >> It shows pictures of the Professor together with a number of babies as well as with other famous clinicians working in the field of IVF. Reasons for infertility and the process of IVF treatment are visualized, using anatomical pictures. Also the circumstances of a natural pregnancy are explained. Pictures of embryos in the laboratory were also included in the show. The lecture ends by providing information on the time flow and the cost of IVF treatment, and on some statistical data about the increase of the success rates of IVF treatment during the last years.
While this lecture is not mandatory, there is another lecture for patients who already have decided to undergo IFV treatment, which must be attended by each patient. It is given every day. After this lecture, the patients receive a questionnaire that will be used by the physicians for the informed consent interview. The procedure of IVF treatment is explained in more detail, starting from the process of obtaining the eggs and sperm, and it is also explained how eggs and sperms are joined in IVF or ICSI (intracytoplasmatic sperm injection), respectively. The couples are familiarized with the fact that they will have to stay in Changsha for at least 20 days for monitoring the outcome of the treatment. The next part of the lecture is about the medication during the whole process. For the treatment after the embryo transplantation, patients will have to choose between the internationally used FSH (follicle-stimulating hormone) that will cost 400 RMB (Renminbi or Chinese Yuan) per treatment and the Chinese derivative that will costs 40 RMB per treatment. The effects and also side effects of the hormones are explained. The patients are told what kind of examination will be performed during the treatment and what expenses they have to expect depending on their decisions and on the clinical development. This will amout to a sum between 25000 and 35000 RMB for one cycle. (The average monthly income in the region is about 3000 RMB). The last two parts of the lecture are about possible complications in IVF treatment (such as extrauterine pregnancy) and the indications for an abortion (such as multiple pregnancy without a chance of a fetus reduction) and finally about frequently asked questions. These concern the patients’ behaviour after the embryo transfer and deal with practical questions such as having sex, going to work, and using the shower or the toilet.

All in all, this lecture provides the patients with a whole lot of information. The questionnaire, which the patients have to fill out afterwards, asked for information about their recent physical condition and medication, as well as what they understood or not. The patients are told that the physician will later talk to them on the basis of this questionnaire.

In addition to the lectures, more information for patients could be found on the web page from the hospital (www.hn-ivf.cn). These include an introduction to the hospital and to the medical staff, as well as practical tips concerning health, pregnancy and sterility.
3.1.4. Participant observation of physician-patient-interviews

After a first introductory period of my study, there was an interruption due to the BIONET conference, which absorbed the time of He Chen, who made all contacts in the clinic for me, as well as myself. During more than two weeks, He Chen could not make any arrangements for me.

But in the last two weeks of my stay in Changsha I accompanied several physicians to their patient interviews whenever it was possible. That was in total six times. In these patient-doctor-meetings the results of the IVF or ICSI treatment were explained. They were held soon before the transfer of the embryos. There are two consulting rooms for this purpose, each with two tables and four chairs, and a waiting room for about 20 patients. Each day, there were about 30 couples who waited for the results and also for the last step of IVF to become possible: the transfer of the embryo. Most of the women were dressed down. Sometimes, there were two doctors in but most of the time only one was available. There was always a nurse and a doctor in the consulting room. The nurse was preparing the patient documentation and the physician was talking to the couple. During my observations, I sat between both at one side of the table, the couple took seats in front of the physician. It was interesting that the doctor, in the majority of cases, did introduce me to the patient and the patients seemed not even to notice that I was there. In some of the observation sessions, the doctor asked the couples if they are interested in participating in my study. Then I was briefly introduced as a researcher and the doctor gave me their telephone number for later contact.

Several forms were given to the couple:

a) the results from the laboratory, including a consent form;
b) the contract on freezing not needed embryos;
c) the informed consent to discard the “bad quality” embryos or to give them to research;
d) the informed consent to discard the frozen embryos or to give them to research, or to continue freezing them once the contract of freezing will run out.

The procedure took place in this sequence:

- The couple sits down.
- The physician explains a): x eggs have been extracted, y eggs could be fertilized, z of the fertilized eggs are good embryos, q of the fertilized eggs are bad quality embryos, r embryos will be transfered, s embryos are “spare.”
Most of the time, the couple looks at this sheet.

The doctor asks them what to do with the “bad ones” and tells them, where to mark it on the form to discard them or to donate them (see (c) above).

The physician continues: The good ones, which the couple will not need now, could be frozen for later use. He gives them another form, explains it and shows where to sign (b).

When the time of the freezing contract runs out, the doctor explains, they could either discard the frozen embryos, leave them frozen or donate them to research (d).

The next step takes place in silence. The couple looks at the forms that are lying in triplicate in front of them.

Sometimes they talk to each other or ask questions to the physician.

Signing: the couple is asked to sign the documents. After signing, they have to give their fingerprints with red ink. There is an ink-pad and some toilet paper on the table – mostly the doctor gives a piece of toilet paper to the patients after they have used the red ink.

The couple then goes upstairs to the surgery.

During my observation of this setting most of the couples who had their first cycle were irritated about having their fingerprints taken. But nobody asked. They decided to donate or not without posing any further questions. The average duration of one patient interview was five minutes.

3.2 Patient interviews

3.2.1. Sample

Due to the restricted time of my stay in Changsha but also because of difficulties to establish full contact with patients, it was only possible to talk to a small number of patients. Five women gave their consent to the study and were interviewed.

The first two interviews took place in an apartment close to the clinic which four women rented for the time of their treatment and shared together. In the living room, four beds were placed close together. All the women were still lying in bed when the translator and I arrived
at 9:30 in the morning. Both, Hui\(^1\) with whom I talked first as well as Mai stayed in bed during the interview. The other women could overhear our conversation but they seemed neither to be interested nor did the interviewees seem to feel uncomfortable with the situation.

**Hui** is a 24 year old woman who has been together with her husband for six years, of which they have been married for three. In spite of their not using any contraception, she never became pregnant. They knew from friends that there is “some technology to solve fertility problems” and went to a hospital where they diagnosed some “tubal” problems” and “problems with sperm motivation”. They started the first cycle with ICSI in autumn 2007, which was not successful. The day of our talk was the fourth day after the transfer of the two embryos that had been frozen from the first cycle. She had decided against donating spare “bad quality” embryos for research.

**Mai** is 28 years old and she had the embryos from her first cycle transferred three days ago. She had been together with her husband for eight years without pregnancy occurring, although they never used any contraceptives. They married two years ago and after marriage they tried very hard to get a baby. She says that “in China, they think that if a woman cannot get pregnant, it must be the woman’s problem”, so she went to the hospital for examination “but there was no problem and then [my] husband went to hospital and they found out that there is some problem with him”. They knew from friends that there is something like IVF and started an internet research to find a hospital, using “test tube baby” as keyword. She had still plenty of “good quality” embryos frozen and would be positive to donating spare embryos to research.

The third interview was with **Ling**, a 31 year old woman who six week ago gave birth to her daughter whom she had from her first IVF cycle. She and He Chen, the translator, knew each other from earlier in their lives. Therefore, the visit had a semi-private character and took place in her parents’ apartment. Two other friends joined us to visit her and there was some small talk previous to the interview. Afterwards we went for dinner together. For the interview we separated from the others and went to the parents’ bedroom. Ling and her husband live in the countryside but during the week she and the baby live with her parents. They care for the baby while Ling is working. Ling and her husband had been married for several years before they started trying to obtain a pregnancy. After an ectopic pregnancy in

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\(^1\) All patients’ names have been changed.
2000, the doctors had to excise one of the fallopian tubes, and told her that she still has a 50% chance of incurring a natural pregnancy. But from 2000 to 2007, her husband had to work far away, and they had no chance of being together very often. During this time, Ling already began to think about some form of treatment and went to the hospital, underwent some hormone treatment and gathered informations about IVF. They were quite well informed about the whole process when they started IVF treatment. She decided against donating spare embryos to research.

The fourth and the fifth interviews took place at the inpatient ward of the hospital. In both women, pregnancy with triplets occurred, and they had to stay in the hospital for observation after the IVF treatment.

Chen is 29 years old and in her eighth week of pregnancy after the second IVF cycle. Before, she was already married for four years, without getting pregnant. She reported for superficial examination, and it was found that she had an obstruction of the Fallopian tubes. She had several treatments in other hospitals, though she is not sure about what was exactly done there. Finally her sister in law, who herself had fertility problems, told her about IVF treatment and recommended her to go to the hospital for genetics and reproduction. She and her husband live in the countryside, her husband is working as a taxi driver. Chen donated “bad quality” embryos to research.

The interview with Xiaomeng was special because on the day of the interview she just had been admitted to the hospital for symptoms of miscarriage. The doctor told her that she was still pregnant, but it was still unclear if she could hold the triplets. The situation was more emotional than the others, and being asked about her story, Xiaomeng started to cry softly. She had married 7 years ago but was unable to become pregnant because of tubal problems, which were diagnosed in 2002. After the diagnosis she went to many hospitals for treatment without any result and a friend finally told her about IVF treatment in some kind of hospital. “When she went there, the doctors asked her to give extra money for the treatment and she didn’t have much money, so she had to quit the treatment. Later, she met a woman who is working at our hospital and lives in the same street and so she finally received treatment at our hospital” He Chen, the interpreter, explains. “She was already under much pressure from family members, from her parents and also from other friends, discussing about them and talking about this. So she feels a lot of pressure and she also says that, if she can’t get
pregnant, she will obtain a divorce.” In addition, for Xiaomeng it was her second cycle with fresh embryos. She agreed to donate spare embryos to scientific research.

3.2.2. Themes

There are evident limitations in what can be extracted from such a small sample of five interviews. We decided to consider all interviews essentially as individual cases, which prove to be similar in some respects, different in others, and we thus abstain from drawing generalized conclusions. But since this investigation has the character of a pilot study, the experiences and concerns that these five women authentically and sincerely expressed might, however, be relevant. They can guide the preparation of more extensive studies, where the topics that came up here will be studied in greater depth and based on a larger sample.

There is another restriction: Not all the themes that emerged in the interviews can be described in sufficient detail. In order to do this, the sample should also have to be larger, so that it would be possible to meaningfully contrast one experience with another. Some details that might be relevant were probably lost due to the bi-directional translation. The interpreter, He Cheng, did the best one can do under these circumstances and both her language skills and her understanding for the medical as well as the ethical sides of the issues are excellent. But summarizing all questions and answers in another language necessarily led to a certain loss of detail and accuracy.

Bearing this in mind as well as the purpose of the study, which was to learn about the patients’ views on embryo donation, the views of the women themselves on the embryo shall be described in the following, as well as their considerations as to deciding on whether to donate embryos for research or not. The interviewees did not talk about their experiences in depth. It seemed to me that they just felt that it is “not a big thing”, rather than feeling uncomfortable with the interview situation. In addition to the background of the women (outlined above) it should be stated that all were very conscious about how many eggs they had and in which cycle, how many had been fertilized and how many were of a good or, respectively, bad quality. For all couples, it was clear that they wanted to have those embryos that were not transferred frozen for a later cycle. All of the women expressed a strong feeling of community with other patients, once they started treatment at the hospital. They exchanged experiences with other patients right from the beginning. After a successful treatment, the
women I talked with had an attitude of wanting to help other women with fertility problems. Ling, for example, said (in the words of the translator): “like if they have friends, or [if] people in the same working place … have the same problem, they will also communicate and exchange their experiences. And then she suggests them to do this.”

Before looking at the participants’ views on embryos and embryo donation, I wish to summarize the experiences they narrated to me concerning their desire to have a baby and the pressure involved during the period before our interview took place.

(i) From the desire and the pressure to have a baby to IVF treatment

All women had a long-standing history of efforts to become pregnant. In four cases, they never used any contraceptives but, as soon as they married, they started examinations and treatments at several hospitals. IVF treatment seems to be the last step on a ladder that each of them had to climb – sometimes more or less alone, sometimes with support from their husbands and parents. They were informed about IVF treatment by friends who had been in the same situation. Hence, IVF treatment signifies their hope to finally have a baby. Xiaomeng’s statement was translated as: “even if she fails this time, she says she would do it again because she knows that for her, this is the only way to get pregnant.” IVF is “the technology that can solve fertility problems” (Hui).

All women started searching for the reason why they could not become pregnant with themselves. Mai’s statement was translated as “in China they think that, if a woman cannot get pregnant, it must be the woman’s problem, so she goes to the hospital for examination.” She was talking about “a lot of pressure during all the treatment and the waiting time.” Being asked about this pressure, she made a more concrete statement to the effect that “she was not sure whether she could get pregnant or not because, although they were having premarital sex without contraception, no pregnancy had happened up to then; this meant that, once married, she was afraid of her husband discovering she was not fertile, resulting in arguments and problems resulting in divorce or something like that. So, in her opinion, as they were still not married at the time, the pressure does not come from her family or society but is actually from herself. (“...and she was afraid because they didn’t had any contraception and she was afraid that maybe after she’ll get married and then her husband finds out that she can’t get
pregnant and there will be some argument and some problem and they will get divorced or something like that so she thinks the pressure is not from the family or the society because at that time they were not married but from herself.”) But Xiomeng on the other hand “was already under a lot of pressure from her family members, from her parents, and also from other friends discussing about them and talking about this. So she feels a great deal of pressure, and she also says that if she can’t get pregnant she will be divorced.”

Beneath this strongly emotional desire and/or the high social pressure to have a baby, for many couples IVF treatment was a matter of money. Hui and her husband saved 100,000 RMB over a period of several years and they spent nearly everything on the treatment. If they are not successful this time, they will have to borrow money from their parents. Chen and her husband had to borrow money from relatives. In the first cycle, they were told that none of the embryo is good enough to be transferred, but Bai Chen insisted on the transfer in hope it would work anyway. It did not, and they had to borrow more money for the second cycle and they decided to undergo ICSI in order to get more embryos so they could freeze some for later use. A third cycle would not be possible for them to pay. Xiaomeng was in a similar situation. Her statement was translated as: “her mother-in-law gave her 30,000 RMB for the treatment and if she succeeds it will be okay, but if she fails, it will not.” For her, the situation is even worse. Now she is pregnant with triplets with a high risk of losing all the babies and is worrying enormously about her family’s future. On the other hand, if she does have triplets, it will be difficult for her and her husband to earn a living. One exception to this difficult financial situation was Ling and her husband. Both were working, with her husband in a profitable business. They even both stayed at home for one year because “they decided to have a baby [...] they had saved enough money and they wanted to be successful in having a baby.”

But although IVF treatment is a financial problem for many couples, all participants in the interviews agree that it is worthwhile. Hui pointed out “that every woman also wants to be a mom and it is also very important for the family”.

None of the women talked much about the time after the examinations and IVF treatments started. Ling said that “they came to the hospital and also they had very good cooperation with the doctors, and then they just wanted to do this.” Xiaomeng left it up to the hospital to do what was necessary: He Chen translates: “There is a lot of trust between her and the
doctors, although maybe she doesn’t understand what is embryo and she says the only way for her to get pregnant is to cooperate with the doctors so she can get pregnant. And in the first cycle she doesn’t know all those things and procedures. The doctors have told her but she doesn’t understand everything in IVT treatment.”

There seemed to be no strikingly important step between the day they decided to undergo IVF until the day they obtained the results from fertilization, and have the embryos transferred. Mai was the only woman who had this experience for the first time and still very present. “She says she feels fine and she is waiting”. Being asked what she thought of the embryo in her womb, she replied: “yes, she thinks of it as a baby.” Hui, who had her second IVF cycle, said that she also thought of the baby in the first cycle and that her wish to be pregnant arising immediately after embryo transfer in the first cycle had ended in a disappointment. Now, in the second cycle, she “tries to think about this in a common way and, no matter if she is successfull or if she fails, she just waits for the result.”

Ling told us that she stayed in bed right from the day of the transfer. “It was not that she felt uncomfortable or sick, but she felt that doing heavy work, running or being active in some way will, maybe, cause her to suffer a loss.” Actually she was talking about the embryo just transferred as if it was a baby that she could have. She did a pregnancy test every day because she wanted to have this confirmed, but for her, she was pregnant with a baby even 14 days before the test gave a positive result. This leads to the question as to how the women considered an ‘embryo’ as being an entity.

(ii) The image and definition of the embryo

What is an embryo? When is an embryo a baby? These questions are descriptive in character but they also demand an ontological assessment. Therefore, it is important to ask the women involved if we want to discuss the ethical status of the embryo. The biological consideration of an embryo as being a developing multicellular entity might be easier to explain. Results from interviews with couples undergoing IVF about their experiences in the UK and Switzerland (Haimes et al. 2008, Scully et al., in press) have demonstrated that the definition of what an embryo ‘is’ or ‘means’ depends on the situation in the course of the IVF process and therefore the question of what ‘the’ embryo is for patients, is not expected to have a
simple or general answer. In the view of those persons involved, the ethical definition seems to be multiple and more dynamic than static.

In this small sample taken in Changsha, there were at least two distinctions that seem to have been important for the women and appeared in all the interviews. The first one is that between the “good ones” and the “bad ones” (embryos), the second is that between the transferred and the frozen embryos.

“Good ones” – “bad ones”
To distinguish between embryos with good quality and embryos with bad quality is customary in the clinical praxis in the Changsha clinic. All the women I talked with told me how many “good ones” and “bad ones” they had. I asked them about the difference between both. “The doctors explained to them in a simple way about the good quality and the bad quality embryo. A so-called good one means that it develops in culture, but a bad one develops very slowly or stops developing, hence their difference from the good ones. And, when talking about a four-cell-embryo and an eight-cell-embryo. [...] She thinks [that for] the bad ones there is no use” (Hui). Mai only had “good ones” and “the doctors didn’t talk so much about the embryos, they only said the embryos are good.” Chen thinks that “embryos are very important for her and the quality of the embryo has a very close relation to the success. [...] In her opinion, when a doctor talks about a good or a bad one, only a good one can be transferred.” When Wang Xiaomeng was given the results of her first cycle, which implied that there were no good embryos, she started to ask the doctor a lot of questions, i.e. why her embryos are not good, and what is a good one and what is a bad one. The doctor explained it to her with pictures, “for the good embryo has eight circles around it and that is the good one which can make her pregnant.”

From my observations I also had the impression that the couples did not pay attention to the distinction between “good” and “bad” embryos in the same way. Instead, they had a rather pragmatic perspective and focussed on the embryos that can either be transferred or frozen. A bad quality embryo implies that it can be an embryo which is less useful for pregnancy.

Embryo - Baby
Most explicitly, the idea that the embryo was a baby was narrated by Ling and Xiaomeng. Ling, as we have seen before, was pregnant immediately following her embryo transfer. She
recounted – in the words of the interpreter – that “they were talking about embryos as babies and taking care of them” (Ling). Xiaomeng told us that “she already sees the embryo as baby now, and right from the day they were transferred, she touched her tummy and said: Grow up and don’t leave me, and no matter if there are three of you, just stay! And from the day of the transfer, she also put up a picture, and talked to it every day. And she also gave names to the three embryos.“ Hui “knows that they (the transferred embryos) have the possibility of failing in their development at every step [...] but still feels them to be similar to babies.” Chen saw it more gradually. She said “that if the embryo is in her body and then day by day it grows and becomes a baby. [...] From the day she had the pregnancy test – then, from that day it was not embryo it was baby.”

Despite the fact that the women in the interviews talked of their transferred embryos as babies, they did not use the image of a child when they were talking about it. “Because the doctor already told them that the embryo is like one fourth of a drop of water, this meant that they could never imagine what it would look like in their bodies, and so they never connected with anything tangibly imaginable. It was not really material.” (Hui) Xiaomeng talked about the picture of the eight-cell-embryos but she petted her “babies” through her tummy.

Ling gave a very clear statement about when, in the course of IVF, the embryo becomes a baby. She saw the frozen embryos as “possibility to become a baby”, but “when it is transferred into the womb, then she thinks it is a baby.” I summarized this in the interview: “So, in a more abstract way, an embryo is a baby when it has a mother? And an embryo in the fridge has no mother only somebody who gave eggs and sperms.” Ling approved this summary: “Yes, it is like that.”

Frozen Embryos

Being able to afford more embryos than those that will be transferred from one IVF cycle is a highly important factor for most couples, simply for cost reasons. Hui “is worried that if she does not get pregnant this time, she does not have any frozens left.“ And this would mean paying for another cycle. Although she knows that her chances of becoming pregnant with frozen embryos are statistically reduced, it is interesting that she thinks the “frozen ones are better, because the frozen ones stayed there for half a year and still survive. So being able to survive makes them stronger.” The frozen embryo is “like a positive expectation for her and her husband, because they failed the first time and so they still have the frozen embryos,
which gives them a greater hope for having a baby.” Ling gives a similar account. Her husband told her “not to worry about whether they didn’t succeed, they still have six other embryos in hospital and they still can do this. They still can get pregnant.” (Ling) Ling thinks that “the frozen embryos have the possibility of becoming babies, but only the embryo inside her body is a baby.” For Mai, the frozen embryos are like babies but “she does not think about the frozen ones, because she thinks the hospital will take good care of the babies and she will take care of these two (the transferred embryos) by herself.”

(iii) Donating embryos for scientific research

All the women who participated in this study were asked to donate embryos for scientific research. Mai, Chen and Xiaomeng decided to give the “bad quality” embryos for scientific research, and to give away the frozen ones in case they became pregnant and didn’t need them any longer. But none of the participants was really clear about the nature of the research they were asked to donate for. “She just thinks it’s medical research she doesn’t know about embryonic stem cell research” (Chen). Mai even intended to donate spare “good quality” embryos to scientific research. But she was not clear that it would be hESC research. Her idea of “scientific research” was that it would “maybe advance the technology and knowledge about IVF treatment.” This coincides with Chen’s view based on her ignorance about the nature of scientific research, as she thought “it is just some medical research for the IVF treatment.”

Not knowing what kind of research might be performed with the donated embryos was the reason for Hui and Ling not to donate embryos, neither the bad quality nor the frozen embryos. The interpreter summarizes Hui’s justification for her decision not to donate: “Because they don’t know the meaning or what purpose of that scientific research so they didn’t think about this. They just choose to destroy. There is no use for us, so destroy.” In the words of the interpreter, Ling explained that “it is because they don’t know much about scientific research, they are not clear about it. (...) She doesn’t really know what kind is scientific research and she thinks that it is maybe some kind of research using her embryo for other women. She doesn’t want to do this. And she didn’t choose. But if she knew about embryonic stem cell research and it was good for human health and implied solidarity with other women, then she definitely would do this.”
Two important issues emerge from this last statement: The first issue is the fear that donated embryos could be used for other women. This reason for not donating embryos was also often mentioned by the doctors I spoke with. They told me that sometimes, when the doctor in a particular case promises that the embryos will not be used for other women, the patients change their minds and give their informed consent without asking any more questions. “They are just afraid that the hospital is using these embryos for others.” (Ling) – The second issue is the attitude of contribution to others. Right at the beginning of the interview, when I explained the purpose of my research, Xiaoameng said, she would “donate eggs or embryos or anything for research because she wants to help others.” She does not really know what this research is about but she trusts the doctors and hopes it will help other women. “She says that she hopes that Prof. Lu could do more research so that the success ratio can be higher and then other patients can also have better treatment.” (Xiaomeng)
4 Conclusions

The necessity for translation in both directions between Chinese and English brings several limitations to the interpretation of the interviews. Through the period of observation and getting in contact in the run-up phase to the interviews, a trustful relationship between He Chen, who translated, and myself was developed. This climate of confidence had a positive effect on the interview situation, as it seemed to me. Nevertheless it is important to keep in mind that He Chen is the secretary of the director of the clinic, Prof. Lu, and that most of the patients know this. It is unclear how much importance or meaning should be attached to this when interpreting sentences like “She feels good in our hospital because the doctors and nurses are good to her and also everything goes smoothly, she is quite satisfied with the service.” (Hui) Translation by a staff member is a factor to keep in mind when interpreting such statements, but there is also a factor of social desirability that could influence how patients talked about uncommon themes such as IVF treatment. The fact that no woman spoke about why she had medical problems might be related to this, particularly as no woman ever specified having had an abortion in the past; and this - as many experts in the clinic suggested to me - was a very frequent reason for their infertility.

But it was primarily the small number of women that I could talk with that made it difficult to draw conclusions from the results of the pilot study at this point in time. At best, it is possible to adumbrate the themes that came up in the individual interviews, as we have done, and perhaps to compare the results with some aspects from European studies. There are certainly a number of differences and similarities to be mentioned:

a) The number of couples affected by infertility might be different in Europe and China, and the reasons for infertility may also differ. A factor that certainly influences this type of study is the differing attitude to childlessness in European and Chinese societies.

b) Definitions and ontological determinations of the embryo of the Chinese women were very similar to those European studies (Haines et al. 2008, Scully et al. in press): In both contexts they seem to change during the process of IVF and vary between the individuals. Similar categories have appeared. But one striking difference was that, in the Changsha interviews, after the establishment of a successful pregnancy, a frozen embryo looses its importance for the couple. We could hypothesize that, for Chinese
couples, the embryo is more like a medicine that you consume when you are ill. The woman hopes to become healthy again, which is equivalent to becoming pregnant. The medication needs to be taken as long as necessary. When your condition is still pathological, the medication (both the pills you have just swallowed and those pills that still are in the pack) remain enormously important. Once you are healed (i.e. have a baby), the drug has no significance any longer.

c) The basic tendency in Chinese interviews was also that women considered their embryos to be „babies“; however, this less represents a doctrine that embryos are „persons“ so frequent in European contexts, as for example in Swiss interviews, where the term „Eskimo“ was frequently used for frozen embryos. Perhaps it can be said that the women in Changsha saw all embryos together (!) as the baby, not each embryo individually as a potential baby.

d) The number of Embryos that could potentially be donated to research differs due to the one-child policy in China. Basically, after pregnancy, a frozen embryos becomes useless.

e) Awareness as to the kind of scientific research donated embryos should be used for was slight. However, also in Swiss studies (Scully et al. in press), perhaps in contrast to those in the UK, the awareness of the kind of scientific research was correspondingly slight, and most women think that this research will benefit other couples in IVF. The decision to donate was taken more or less without information. In part, this ignorance led to a rejection of the request to donate. For other women, this ignorance led to a motivation to contribute, by donating embryos, to an improvement of IVF treatment for other couples affected by similar problems, and therefore to help these others with a gesture of solidarity.

f) Another factor that might differ (but was not studied here) ist the effect of the public awareness of genetics and hESC research as ethically problematic in the Europoean and American contexts (Streiffer 2008), but less so in the Chinese context.

f) Trust and informed consent has a different meaning in Changsha than in the UK and Switzerland, due to the different nature of the physician/patient relationship. Autonomy, in the sense of individualistic self-determination is a less determinant value in the decision-making process in the context of Chinese culture. This means that in the practice of IVF, the patient assumes the doctor to act in her interest. For her it is not necessary to know everything or to question anything. This however should not be judged morally. The responsibility of the doctor, in this relational setting, is not
reduced but in the contrary perhaps even more intense than in Western countries: In Western settings, the doctor’s responsibility is mainly (while not exclusively) based on the actual information and understanding of the patient, whereas in the Chinese context, responsibility is mainly (as well not exclusively) based on the confidence, which the patient offers to her doctor. The process of decision-making and finally also the provision of informed consent to donating embryos needs to be seen within a relation of autonomy and care.

h) There was a strong wish to help other couples, to provide some helpful contribution. This was also seen in UK/CH interviews: there is a need to talk about the experiences and to help other couples who are in a similar situation. There was a strong sense of identification with the group of people with infertility problems that also made an impact on the patients’ deliberations about embryo donation.

If the results prove to be reliable, they will help us to understand the processes of ethical decision-making about donation of embryos for hESC in both Chinese and European (or other) contexts from different participants’ perspectives. A more comprehensive study could also be helpful for those working on the physician/patient communication in Chinese and European centres. It would be significant for deepening our understanding of the bioethical questions around hESC research in general, particularly the clinical situations they involve or generate. It would be interesting to plan a larger study, based on these experiences in the Changsha pilot study, and apply for extra funding. Such a study could contribute to the discussion about emerging structures of ethical governance.
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Appendix

A Interview Aide-Memoire (Participants from IVF clinic, English-Chinese version)

I. Introduction

Introduction to the Project
Do you have any questions? 你对我的研究项目有任何问题吗?

Confidentiality and Anonymity 有关数据
Do you have any questions?
If there is anything that you feel would identify you could you please ‘flag’ that for me.

II. Personal Background

- Age 年龄
- Education 教育水平
- Employment 职业
- Family situation 家庭情况

Could you please tell me your story about your desire to have a child? When and how did you decided to undergo IVF treatment? 请问您想要孩子多长时间了？什么时候开始决定进行辅助生殖治疗？

Have there been any persons or happening and experiences been important for you? Did anything influences you in the whole period of IVF treatment? 是否有人向您介绍过辅助生殖的知识，您才决定进行这项治疗？在治疗中，是否有什么事情对您有影响？

III. “The” Embryo

During IVF-treatment: how have you been talking about the embryo? Did you have an image of the embryo? 您觉得胚胎对于您来说意味着什么？（胚胎是什么？）

What was your conception of the embryo?

Did the image or the conception of the embryo change during the IVF treatment? 在辅助生殖治疗中，您是否对胚胎的定义有改变？（治疗前—治疗中—治疗后（怀孕，未受孕））

IV. Being Asked to donate embryos

Were you asked to donate eggs or embryos for use in embryo research? If so, when and by whom?
是否有人和您谈过捐献卵子或胚胎用于胚胎研究？

Do you remember when the possibility of donating eggs or embryos to research was first mentioned?
什么时候是您第一次和医生谈捐献卵子或胚胎的可能性？

Who mentioned it and in what context (information session, first meeting with doctor or nurse, during the treatment cycle…)?
(e.g. Were you ever asked about whether you would be interested in being approached about embryo research?)
谁跟您谈的捐献事宜？以什么样的形式谈？您是否有兴趣对胚胎研究做一些自己能做的事情？

Were you asked to donate embryos or eggs to a particular research project or projects?
Do you recall what these projects were about?
您知道捐胚用于什么样的研究项目吗？

Were you asked to donate any other cells for embryo research purposes?
(e.g. unfertilised eggs, sperm, abnormally fertilised eggs, poor quality embryos (unsuitable for freezing), and embryos which [patients] do not want to be frozen)
您是否被问捐献除胚胎以外的任何其他细胞用于研究目的？（未受精卵子、精子、异常受精卵、质量不好的胚胎（不适合冻存）、您自己不愿冻存的胚胎）

What else could be done with eggs or embryos if not transferred or donated for research?
(Were there other options to consider or that you have heard about?)
未移植的或未捐献的胚胎您将如何处置？（除了移植或捐献外，您是否还有其他的方法处理胚胎？）

V. Decision-Making

How did you decide whether or not to consent to donate eggs or embryos for the research projects?
您怎么样决定是否捐献卵子或胚胎用于研究项目？

Did you consent to donate eggs or embryos to research?
是否同意捐献卵子或胚胎用于研究？

Have you made the same or different decisions during different cycles?
在不同的周期是否有相同或不同的决定？

How did you come to your decision? What influenced your decision?
您怎么样做得决定？什么影响了您的决定？（媒体、父母、其他病人等等）

Was there anyone else who played a significant role in your decision? (family, friends)
什么时候决定的？
Did anything that happened in the course of the treatment influence your decision or how you felt about your decision? (Did it matter to you how many follicles you had? How many eggs fertilised? What grading the embryos received?)

在治疗中或什么事情影响了您的决定或者您觉得您捐献的决定做得怎么样？（有多少卵泡？有多少受精卵？胚胎的级别怎么样？）

Did you change your mind about consenting to participate in any particular project at any time during the treatment cycle? E.g. before or after egg collection or embryo transfer.

是否改变捐献的决定？（取卵、胚胎移植之前或之后）

Did any of the information provided to you during the course of treatment influence either your decision to donate embryos or your ideas about the decision you made?

医院是否在治疗过程中提供一些关于捐献胚胎信息给您，所以您才决定捐胚？

IV. Consent forms 知情同意书

We’re also very interested in your views about the actual information and consent forms.

您对知情同意书的想法？

Can you tell me which consent form you received?

您收到了哪些知情同意书？

How many times have you received an information and consent form package?

收到几次？

Was the information provided understandable? Was it easy or difficult to understand?

知情同意书上的内容是否容易理解？

Did anyone at the clinic help you to understand the information or in participate in the process of making your decisions? Did you ask for further information? Who did you get this help or information from? Was this during a regular clinic appointment or was it a specific appointment?

医院有谁帮助您一起理解知情同意书吗？您有没有提问？是否在医院一般的就诊时间还是需要特别预约？

Do you have any thoughts on the format of the information and consent form?

您对知情同意的形式有其他看法吗？

Did you return the form? If so, who did you return it to and when? Were you asked about the consent form and whether or not you planned to return it?

是否归还知情同意的表格？什么时间交给谁？有没有人与您谈过？

V. ES Cell Research 干细胞研究

How would you describe Embryonic Stem Cell Research?

您觉得什么是干细胞研究？
Had you heard about any of this research before receiving the information and consent forms? What do you think of this research? What is it for? 在得到知情同意前是否听说过这项研究？您对干细胞研究的想法？研究用处？

Do you know what kind of research will be done with the embryos you donated? 您是否知道您捐献的胚胎是做什么样的研究？

Would you like to know about the results of the research? 您是否想知道研究的结果？

VI. **What are Embryos? 什么是胚胎？**

You’ve been through (a) cycle of treatment. Did going through IVF have an impact on what you think an embryo is? 您已经进行了一次治疗周期，是否在接受辅助生殖治疗让您对胚胎的想法有影响？

Were your embryos discussed with you during your treatment? How? When? 是否在治疗中与谁讨论过胚胎？怎么讨论？什么时候讨论？

Did you have an embryo or embryos transferred? (How many?) Were you shown an image of the embryos which were transferred during your treatment? What was your response to this image? 您看到胚胎相片的反应是什么？

Did you have any embryos other than those that were transferred? (How many?) Do you know what happened to them? (Were they discarded? Taken home? Not considered embryos? Donated to research? Which project?) 在移植后是否还有其他胚胎？（几个） 您知道这些胚胎是怎么样被处置的吗？（丢弃？带回家？不被看作胚胎？捐献于研究？什么项目？）

Do you think there are any differences between the embryos which were transferred and those that weren’t? If so, can you describe these differences? 您觉得那些移植的胚胎与未移植的有什么区别吗？您能说出他们之间的不同吗？

What is an embryo to you? 对您来说，什么是胚胎？

When is an embryo an embryo? When do you think an embryo becomes an embryo? (Do you think of abnormally fertilised eggs as embryos?) 什么时候您觉得才是真正的胚胎？什么时候变成胚胎？（您觉得异常受精的卵子也是胚胎吗？）

Now that you’ve completed the cycle, have your ideas about your decision to donate embryos or not changed at all? If so, what has influenced these changes? Do you have any concerns about the decision you made? 现在您已经完成了治疗周期，您是否仍然同意捐献胚胎还是改变了主意？如果改变了，是什么影响的？您的决定主要关注那个方面？
VII. **Further Ideas?**

We’ve talked about a lot of different issues. Do you have anything else, ideas or stories, that you haven’t shared that you would like to tell?

您是否还有什么需要说的吗？您的感觉怎么样？
Dear Sir or Madam,

thank you for taking some minutes to read this paper while you are waiting to see the doctor.

My name is Anika Mitzkat and I am a nursing scientist from Germany. I am here in Changsha for a student exchange project. The topic I am interested in is how involved people experience IVF treatment and what they consider concerning embryo donation. Why?

BIONET is a ‘Coordination Action’ funded under the Sixth Framework Programme to research the ethical governance of biological and biomedical research in China. Ethical questions that might arise from genetic and reproductive practice are discussed here. But discussing these questions is rather theoretical because we don’t know much about what people that have made experience themselves think about all the issues. Therefore my aim is to get in contact with you and talk about this issues.

What does that mean? The doctor will ask you if you feel okay to talk with. If so, you should give your name and telephone number. I will contact you via the secretary of Prof. Lu Guangxiu, He Ginny, to make an appointment with you that is comfortable for you. A talk might take about one hour, maybe shorter or longer, it depends on you – you decide, what you want to tell me. Our talk would be translated by a neutral person. Everything you tell me will be kept anonymously. Your name and personal data won’t appear on any papers.

Most important for you: whether you decide to talk with me or not, and also, what ever you will tell me, it will not influence your treatment in the hospital.

Before we talk, you will have the possibility to ask any questions that you have about the project. Giving me your name and telephone number right now does not mean that you are obliged to participate in my project. But if you do so, I would be very thankful!

With best regards,

Anika Mitzkat (nursing scientist, junior researcher in BIONET student exchange project)
University of Witten-Herdecke, Germany (benikam@yahoo.de)

Local reference person:
Prof. LU Guangxiu
He Ginny

Project supervisor:
Prof. Christoph Rehmann-Sutter, University of Basel/Switzerland
(Christoph.rehmann-sutter@unibas.ch)