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The IVF-Stem Cell Interface in China: Ontologies, Value-Conceptions and Donation Practices of 'Chinese' Forms of Unborn Human Life

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Field of Interest:

Donation of embryos for hESC research; the perceptions and experiences of donors; donation procedures in the context of the IVF clinic²⁶

Guiding questions:

What value and status do IVF embryos have for potential embryo donors in China? What factors influence patients' decisions to donate?

How is the value of embryos defined in the context of the IVF clinic? How is the donation of embryos for hESC research initiated and carried out in China?

Methods:

The data presented here were gathered in February and March 2008, in five IVF clinics, and six stem cell centres in various cities in South-East and Central China. Research methods comprised the analyses of documents, semi-structured open ended interviews with 15 stem cell scientists, 15 IVF clinicians and 15 embryo donors, as well as a quantitative survey, which was conducted among 74 patients of IVF clinics, 230 students from a medical faculty and 246 students with a non-medical study background (N total = 550 participants). In the survey the underlying procedures, purposes and prospects of the use of IVF spare embryos for hESC research was explained in detail. The survey included multiple-choice and open-ended questions to which respondents could provide handwritten comments. Data analysis was carried out with the use of SPSS 14. 220 survey participants provided handwritten comments and explanations of their viewpoints. The comments were translated by professional translators in China from Chinese Mandarin to English.

²⁶ The original analytical focus of the research project on which this contribution is based was actually considerably broader than the aspects discussed here. Situated in the institutional, cultural and socio-economic contexts of Mainland China, the research formed an analysis of the transformation chains of the value, status and meanings attributed to human reproductive tissues, from their harvest to the moments of their donation, use and circulation among researchers in China and elsewhere, and as perceived from the viewpoints of donors, clinicians and scientists. A selection of topics has been made here to highlight issues that are relevant for the BIONET agenda.

1 Main-Findings 1

The embryo's value for (potential) donors and factors that influence donation decisions

In the majority of Western societies, with the UK as a major exception, hESC research has been slowed down by continuous debates on the ethical and legal permissibility of the destruction and use of human embryos. Such public and political debates seemed largely absent in the context of China, where a permissive regulatory approach was introduced within a short time, by and large following the UK example. As Chinese and other East Asian political leaders have repeatedly pointed out in this context, ethical or religiously based scruples as they have dominated debates on the usability of human embryos in the West do not exist in their societies (Sleeboom-Faulkner and Patra 2008).

In China, to some extent at least, such ideas are reflected also among philosophers and bioethicists. According to bioethicist Qiu Renzong (2000, 2007), for example, the traditional Confucian view that a person comes into being only at the moment of birth, is still valid in China. The human embryo, from this perspective, is a betwixt and between entity. It is neither a person, with corresponding moral status, nor is it inanimate matter, without any moral status. For professor Qiu, therefore, the embryo is best described as a precursory person: a form of human biological life that due to its forebearing role deserves due respect, but that can be destroyed or manipulated if there is sufficient reason, and such reason is provided amply by the strong therapeutic potential of hESC research.

A third, less philosophic, explanatory approach to the observed lenient regulatory situation of hESC research in China has been provided by Cookson, who has connected the overall support for embryo research to the one child policy (2005). The underlying assumption here is that, as a result of the high numbers of abortions carried out during the last two and a half decades in the context of the national and provincial birth politics programmes, early forms of human life are generally valued low in China, and that therefore a permissive regulatory environment would easily be accepted and introduced.

A striking feature that unites these diverging positions is that they are formulated entirely in the absence of the voices of those who in reality are confronted with the decision to donate their embryos for hESC research: women and couples undergoing IVF treatment. What value do these persons ascribe to their embryos, and what are the assumptions and concerns that influence their decisions to refuse or accept donation? These are the questions that shall be discussed in the first part of this contribution. Of interest here is that the very few empirical studies that tackle questions of the value and status of early forms of unborn human life in the context of China (Nie 2005, Cong 2007) arrive at a much more heterogeneous and complex picture, than the perspectives introduced above.

Narratives of Life, Death and Value

My own research findings clearly confirm this complexity. It shows that the attitudes among providers of embryos are much more variegated and multifaceted, than commonly suggested in political and philosophical debates on the issue. The notion, for example, that ethical scruples regarding the use of human embryos do not exist in China, cannot be upheld in the light of the following data. While among the 550 participants of the survey the overwhelming majority (97.5%) regarded hESC research as making meaningful contributions to medicine and the sciences, only 45.7% of all survey participants indicated that they would actually agree to the donation of their embryos for hESC research, while 53.4% made it clear that they would refuse donation (0.9% remained undecided).

Among the latter group, 52.9% (28.8% of all respondents) rationalized their refusal, by supporting the statement that 'using the embryo is the same as consuming a life' – an assertion that actually echoes one of the key complaints against the use of embryos for hESC research in many Western societies. The issue was qualified in several of the survey respondents' handwritten comments²⁷:

To donate an embryo to research is equal to killing a life. I think life cannot be destroyed casually. (Student, Medicine, female, 25 years)

The embryo is the descendant of me and my wife. It is an organism and it can't be killed. (Student, Financial Engineering, male, 23 years)

It is a moral matter. The embryo is also a life and has its right to live. (Student, Medicine, male, 21 years)

An underlying reason for the widespread support of the declaration that using an embryo for hESC research is equivalent to terminating a human life, might be that, quite contrary to Confucian-based interpretations, by far the majority of the survey respondents indicated that in their view the life of a human being starts already at the initial stages of embryogenesis: 56.8% of all respondents selected in response to the question 'when do you think does the life of a human being start' the answer option 'at the moment of fertilization', and another 31.4% opted for the moment 'when a fertilized egg cell has evolved to an embryo'. Altogether, only 10.8% of all 550 respondents conceived of the starting point of the life of a human being as being situated at a later moment during gestation: 3.3% opted for 'the development of the nervous system', 3.6% argued in favor of 'the development of the organs' and solely 3.9% provided support to the perspective that 'the life of a human being starts at the moment of birth' (1.0% of the total remained undecided).

²⁷ The relative young age of these respondents can be explained by the over-proportional high number of students who participated in the survey. In fact, in some of the IVF clinics I encountered some serious bureaucratic obstacles, when asking for permission to carry out the survey. In the universities, in turn, I encountered no problems when asking for permission to carry out a survey among students.

These findings suggest that lines of ethical reasoning that depart from the Confucian-inspired idea that a person comes into existence only at the moment of birth, do not correspond to the ideas of the overwhelming majority of research participants in this study. Accordingly, debates or regulatory approaches that depart from this line of reasoning fall short in accounting for the rich plethora of meanings and actual needs of the persons confronted with the decision to donate their embryos in China. To depart from the actual values and forms of reasoning of these people should be a central matter of respect.

Assessing the emotional impact of donation

That a more donor-centered perspective is required in debates on the use of human embryos for hESC research, which accounts for the subjective, embodied and emotionally charged perspectives of the women and couples who are actually confronted with the decision to give away their embryos for research, came to the fore also in the response patterns to survey questions that addressed the (anticipated) psychological and affective impact of embryo donation. Interestingly, 31.4% of all respondents here endorsed the statement 'I expect some psychological or emotional difficulties after the donation of my embryo'. And a sub-group of 37.9% of the 293 respondents who had specified that they would refuse the donation of their embryos provided support to the statement: 'I do not donate my embryos because I am afraid of emotional or psychological consequences' (these are 20.2% of the total number of survey participants). Such fears were also reflected in several of the handwritten comments of survey participants:

It [embryo donation] may have consequences for people in a spiritual and psychological sense. Also it may bring conflicts with morals and ethics. (Student, Chinese Literature, female 23)

It may hurt the person who donates mentally. (Student, Computer Science, male, 21)

That women are likely to build up a stronger emotional bond with their embryos can be seen also from the following excerpt of an interview with an IVF patient. Just before our conversation the women had heard that she was in the first phase of pregnancy:

I want to keep these (frozen surplus) embryos for a long time. I really cannot consider giving them away now. Maybe later, when my child is four or five years old [...] but also then I would not like to give them away all. I still would like to keep some. (IVF patient, 29 years)

That this expression of affection toward super-numeral IVF embryos was not just a singular exception can be seen also in the following: 34.7% of all respondents provided support to the statement 'I have strong feelings for my embryos', while another 29.0% indicated to 'have some feelings for my embryos'. Only 19.7% indicated to 'have low or no feelings for my embryos' and 16.6% remained undecided.

The embryo as part of the family and kinship group

A final aspect that should be highlighted addresses assumptions about the entwinement of IVF embryos in the web of social, bodily and emotional relations of the family and wider kinship group. To whom the embryo belongs is actually an ambiguous matter and among a certain segment of potential embryo donors in China the opinions of family members seem to play an important role in decision making processes:

Such a decision [to donate the embryo] must be discussed with the family as a whole and the opinions of the others must be respected. If there is a member who disagrees, I will think about this. But it really depends on the attitude of this person. If his or her opinion is very strong, that means, opposes donation very strongly, I would not donate. I do not want to hurt the relationship between family members just because of donation. (Female IVF patient, 32 years)

Such patterns of inter-familial respect and obligations appear to be closely intertwined with culturally mediated conceptions of the human body and notions of physical interrelatedness between the generations. As one of the researchers I interviewed explained it to me:

You know, in Chinese cultural tradition people regard their bodies as coming from their parents, and it is seen as very precious, so we have to take good care of our bodies, we cannot give any part of it to others. So in the Chinese tradition it is forbidden to give away... to donate your tissues or organs to others, including your cells, your gametes, which include oocytes and sperm. Therefore, [many] people cannot agree, if their embryos shall be used for research.

I: What would happen if someone believes in these ideas but would still donate?

This would be an activity that means that you do not respect your parents. Your parents gave you your hair, your body, your organs, this..., the whole of you. The parents gave this to you and you did not take good care of it, you gave parts of it to others. So you don't respect your parents.

From this perspective, donation of embryos without prior consent of the donors' parents forms an obvious violation of culturally mediated social norms and represents a serious act of disrespect and disloyalty. This way of thinking is reflected also in a larger number of handwritten comments of survey-respondents:

From a Chinese traditional point of view 'we get our bodies from our parents', so we can't give it away casually, not to mention a new life. (Student, Medicine, female, 25)

The traditional concepts (sayings) tell us it is unsuitable to donate the embryo. I'll give up the donation for the principle of filial piety. (Student, Accountancy, male, 24)

The aged ones tend to pay more attention to life. As to Chinese people, parents and grandparents care always much about their children and usually will not agree to donate the embryo, which possibly can be a child. The traditional and conservative thoughts are a critical reason for their disapproval. I'll respect their opinion. (Student, Human Resources, male 22)

Discussion Part I

Taken together, these findings suggest that attitudes and perceptions of the value and of the permissibility to donate and use human embryos for hESC research are much more varied and complex in China than is commonly suggested. Claims that ethical concerns regarding the donation and use of embryos for hESC research were something typical for Western societies, but absent in China, can not be upheld on the basis of the data presented above. The decision making process for the contribution of super-numeral IVF embryos to research seems, at least among a larger proportion of individuals in China, to be characterized by careful reflections on the nature and value of these human biological resources, and on an introspective assessment of the psychological and emotional consequences of the act of donation, as well as of its permissibility in the light of inter-generational patterns of respect and obligations. Accordingly, lines of ethical reasoning that depart from the Confucian-inspired dogma that the life of a human being starts only at the moment of birth seem to fundamentally mismatch with the ideas and perceptions of the majority of the population of potential donors in China. They fall short in accounting for the rich plethora of meanings and needs put forward exemplarily by the participants of this study. Equally flawed, however, appears the assumption that the value of early forms of human life, as a result of the high number of abortions that have been carried out in the context of the one child policy, is generally regarded low in China. Instead, as the above introduced data suggest, forms of embryonic life in China, are entangled in a rich web of overlapping and sometimes contradictory layers of meaning, value, values, emotions and social relations, that analysts, policy makers, researchers and clinical staff should well be aware of (*cf.* Cong 2007; Dikötter 1998; Nie 2005; Greenhalgh and Winckler 2005). In the next section, I shall continue with the exposition of findings that provide some insights into the manifestations of clinical practice through which the donation of embryos is initiated and carried out.

2 Main-Findings Part 2

Clinical Practices: The value of embryos as defined in the IVF clinic and the ways in which donation is initiated and carried out

For persons who undergo infertility treatment the in vitro fertilized embryos signify a profound source of hope and value. After the diagnosis and experience of infertility the creation of these embryos constitutes an important source of 'reproductive capital' that embody the promise to re-render the long cherished but recurrently discouraged dream to have one's own child, back into the realm of the possible.²⁸

Whatever the initial outlook of infertility patients on their embryos may have been, however, in the course of the IVF treatment these ideas and feelings are subjected to considerable changes. Exposed to new forms of expertise and explanations and to the rigorous testing of their embryos' quality and reproductive viability, these persons learn to conceive of the characteristics, properties and value of their potential offspring in previously unheard and unimagined ways; a process that forms a considerable cultural challenge for many lay-people. These restructuring processes of attitudes, mental pictures and ideas about their embryos, do clearly facilitate the attempts of clinicians or stem cell researchers to motivate IVF patients to donate their spare-embryos for research. This is so, not only because created IVF embryos get evaluated and categorized along parameters of reproductive potentiality, but also because they allow for the overcoming of alternative understandings of life, value, ethics and sociality, such as defined by common sense, tradition or religion. While I cannot discuss these points here in detail, I shall provide a number of examples that offer insights into the concrete ways through which the donation process of embryonic tissues is initiated and carried out in the context of the IVF clinics I visited.

Exploring clinical practices

The ways and routines through which the donation of embryos was carried out in the visited clinics varied considerably, across but also within different institutes. Overall, especially among senior IVF clinicians (who in many instances are also stem cell researchers), a highly developed consciousness of responsibility for the needs and concerns of patients was expressed. The requirement to stick to ethical principles such as informed consent and the right for a voluntary and autonomous decision were unanimously endorsed in this group:

They [the patients] have the right ... their behavior is totally voluntary not under any pressure from the researchers or the doctors and [...] no matter

²⁸ It should be noted at this point that the desire for a child is, in comparison with other societies, likely to be even more pronounced in the context of China, where infertility is often stigmatized, and the moral and filial duties of children play a vital social function in intergenerational patterns of reciprocity, in which children shoulder the responsibility to provide moral and financial support for their aging parents (and grandparents).

how they will decide, their clinical treatment will not be influenced at all. (Senior IVF clinician 7)

We have to explain to them, we have to offer different options, and then the patients make a decision by themselves. (Senior researcher 4)

We have to protect the rights of the patients, so that they receive all the embryos they need for a successful pregnancy. Then we have to give information to donors about our research [...]. We have to inform patients, also if we want their low quality embryos. (Senior researcher 3)

Many more examples could have been provided here. However, it should be noted that the overwhelming majority of these statements were from clinicians (or clinicians/researchers) in highly organizational functions, who would only sporadically deal with the practical sides of donation procedures in person.

Not too surprisingly, at the immediate level of clinical practice a more varied picture emerges. The sense of responsibility displayed in the quotations above was reflected at this level in a clearly less consistent way. While a large number of the clinicians and researcher who were involved in the facilitation of informed consent (IC) procedures, seemed really to do their uttermost best in informing patients, in answering their questions patiently, in offering time and the opportunity to discuss things with friends or family, so that a genuinely independent and voluntary decision can be derived at, others would carry out IC procedures in less mindful and patient-friendly ways.

As the following example shows, ideas such as 'the right to be informed' were sometimes handled in superficial and rather unsatisfactory ways:

I: When you ask patients to donate their low quality embryos for hESC research, what information do you provide to them?

R: Information? (Laughs)... Not much information. Just these words written down on this paper here, not much more information.

[She points to a multiple-purpose informed consent form that lies on the table in front of her, which has to be filled in and signed before the onset of the treatment; most of the issues that were covered here refer to the risks and procedures of the infertility treatment itself; the donation of low quality embryos for hESC research was only one issue among many, and dealt with in two sentences. It is specified that the donated embryos shall be used for research and that they will be destroyed in the process and can not be reclaimed.]

I: But the woman [an IVF patient] we spoke to this morning, she didn't know anything about stem cell research. Don't you have to explain it to her?

R: It is just a brief, a brief explanation. It doesn't have many details.

I: But does that happen often that a woman is asked to sign a form and she does not really know what for, I mean, for what kind of research the embryos are given away?

R: But they... most of the patients do not care about what research we are doing. They just focus on... if they can get successfully pregnant (laughs).

[...] You know, most of them just don't have any questions about it. They just go over it. They agree or disagree and then talk about other things. They don't focus on this... this is not their focus. (Junior IVF clinician 5)

Especially younger clinical staff members appear to carry out informed consent procedures in careless and sometimes highly irresponsible ways. Occasionally, the conversations that accompanied the IC process appear to be characterized by the calculated handling of silence, that is, the facilitation of 'choice' through strategic games of information concealment and disclosure. In some cases the conversations with patients also included elements of overt deception and the making of untenable promises:

I: How many percent of patients want to provide their embryos after you have talked to them?

Dr 1: Mm, maybe 75%.

I: Oh, that is a lot!

Dr 2: Yes but that is because we encourage (□□/ guli) them, we persuade (□□/ shuofu) them.

I: How do you do this?

Dr 2 (laughs and points to Dr 1): She is good at this (laughs again). She is doing this very well, to persuade patients.

Dr 1: I tell them that it is useful for scientists and useful for mankind, in the future, probably... And, ok, I will make sure that the donated embryos will not be given to other people, so that they know they will not have another baby.

I: And what else do you tell. How do you try to persuade a patient so that she really...

Dr 1: If patients come to our hospital their purpose is to have a baby, they do not care too much about the remaining embryos. [...] I tell them that the stem cells [derived from their donated embryo] can maybe be used for their children, in case they have a disease that can be cured in the future.

Dr 2: If their child has leukemia for example, maybe our research would help to cure these diseases. Maybe the patients if they hear this they think it is better for their child [if they donate], so many times they will agree.

(Junior IVF clinicians 1 and 3)

Similar tactics of leading patients to believe that stem cells derived from their donated embryos might directly benefit the future health of the donors or the donor's child could also be observed in another clinic. As a clinician in a senior position told me, occasionally he would tell patients the following:

If in the coming days, there will be the necessity that you use the stem cell line [established from your embryo] for medical purposes, we will check whether your embryos have become a cell line, what and where the cell line is today, and whether it is possible to use this line for you. If in the future there is a technique you are the first to use this technique. You have the privilege to use the stem cells. (Senior IVF clinician 2)

Discussion Part II

While I do not want to preclude that such promises may – at least partly – be based on good intentions, or at least on a genuinely optimistic attitude towards the medical potential of stem cell research, it is clear that these conversations with patients contain elements of deception and manipulation. In addition to that, from a legal perspective, such claims remain entirely unsupported. In the consent forms that patients sign, it is unmistakably specified that with the act of donation the donor gives up all future rights on the embryo, including all claims to get access to future therapies or economic gains derived from research for which donated embryos have been used.

3. Summary and Take-home Lessons

Summary

In this contribution I have highlighted two different aspects related to the donation and use of human embryos for hESC research in the context of China: perceptions of the value of donated embryos among real and potential donors (1), and an exploration of the ways through which the donation of embryos is initiated and carried out at the level of clinical practice (2).

Research findings to the first of these two thematic clusters have suggested that attitudes and ideas on the value and the permissibility to donate and use human embryos for hESC research are much more complex and diverse in China than is commonly suggested. Claims that the donation and use of embryos in China goes without any form of ethically based concerns or scruples could not be maintained. Also speculations that, as a result of the high abortion rate related to the one child policy, the value of early forms of unborn human life is generally low among Chinese people could not be confirmed.

But also assumptions that Confucian-inspired ideas on the starting point of human life are still valid in China were not supported by the participants of this study. Almost 90% of all survey respondents had indicated that in their view the starting point of the life of a human being is located at the earliest stages of the gestation period. While it may be, that on an intuitive level Confucian-based ideas on the starting point of the life of a human being, find a higher level of support among people in China, than was expressed in this survey, it seems to me, that the specific procedures of the IVF treatment, through which patients are confronted with new ideas, insights and images of their embryos, clearly favor perceptions in which the starting point of the life of human beings is seen to be located at much earlier points during pregnancy.

Taken together, these insights highlight how important it is, actually, to depart from the situated, embodied and emotionally charged perspectives of potential embryo donors. Only then can the impact of the process of embryo donation for hESC research be understood in a really nuanced way, so that culturally or socio-economically determined complexities can be accounted for, and clinical and governance procedures can be developed that correspond to the needs of potential donors in a convincing way.

In the second part of this contribution I provided a range of insights into the contexts and communication processes through which the donation of embryos is facilitated in IVF clinics in China. A highly varied picture emerged here that offered insights into a wide range of practices that unfolded between the poles of a strong commitment to professional care and responsibility on the one hand, and forms of occasional deception / manipulation of patients on the other. Variance could be shown to exist not only across different clinics, but also within particular institutions. On average, and with notable exceptions, strong differences in attitudes and practices could be noted between clinicians and researchers in lower and higher professional positions. These gaps between promoted principles of good practice at the top level and *actual practice* indicate a lack of adequate ethical training of clinical staff or researchers. Or, as might be the case in some clinics, they refer to the absence of a true interest for responsible donation procedures, so that bioethical principles get reduced to officially proclaimed lip service, with a layer of ignorance and malpractice underneath.

Take Home Lessons

- 1) Approaches of ethical governance of stem cell research need to depart from the situated, embodied and emotionally charged perspectives of the individuals or collectives who are actually confronted with the decisions and dilemmas brought about by these new technologies, be it in the context of tissue supply, or with regard to forms of patient recruitment and treatment in emerging forms of stem cell based clinical trials and commercialized experimental stem cell therapies.
- 2) Independent social science research, especially qualitative research, or a combination of qualitative and quantitative research methods, as in the presented study, is best equipped for such an analysis, so as to derive situated, practice oriented and cross-culturally informed insights through which ethical debates, regulations and governance approaches can be informed.
- 3) Statements of politicians or government officials, who claim to speak on behalf of the ethical attitudes and values of whole nations or continents, should be met with caution. These declarations emerge in relation to wider geopolitical interests, strategies and identity politics and are likely to lack insights of the variegated and concrete perspectives and needs of those who are actually confronted with the decisions and dilemmas brought about by new technologies.
- 4) This objection applies also to purely philosophically based lines of ethical reasoning, or to sweeping forms of theorization that discount the assumed effects of major biopolitical projects such as China's birth politics. The validity of such speculations should first of all be treated with sober skepticism; at least as long there is no solid empirical evidence that supports these ideas.
- 5) With regard to the issue of the donation of reproductive human tissues for stem cell research, studies that might provide such evidence have to account for the rich web of overlapping and sometimes contradictory layers of meanings, value, values, emotions and social relations in which these tissues are embedded in, in the context of China, as elsewhere.

- 6) In the final two points I shall comment upon the facilitation of informed consent procedures as encountered in some of the visited IVF clinics. While a cross-culturally informed type of bioethics recognizes that there are variations in the ways in which social phenomena and processes are categorized and problematized, my understanding is that some of the practices I encountered, did clearly transgress the (admittedly difficult to define) borderlands of mutual respect and the positive recognition of difference. The observed ways in which patients were misled, by some clinicians, are intolerable, according to Chinese as well as international standards. (While such cases of malpractice might also happen in the UK, it is clear that controls and rule transgressions are handled there in a more consistent and strict fashion.)
- 7) Collaborating partners in China and Europe should be well aware of these problems, as well as of the possibility that conscious compliance to these conditions might backfire in the future. On the other hand, continued and more collaborations, in tandem with the ongoing efforts to improve the situation, by scientists, bioethicists and the media in China, as well as by the Chinese government, seem a promising way to work toward a better future, by promoting more and better forms of ethical training of medical staff, as well as more consistent forms of ethical governance that includes the introduction of more reliable regulatory structures and of a legal and institutional infrastructure that is able to control, monitor and sanction transgressions of valid rules and standards.

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